The Cost of Survival: An Exploration of Colorectal Cancer Survivors' Quality of Life and Experiences of Healthcare

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Declaration

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Abstract

The Cost of Survival: An Exploration of Colorectal Cancer Survivors' Quality of Life and Experiences of Healthcare - Amanda Drury

Background and Aim: Following cancer treatment, colorectal cancer survivors may continue to experience a multitude of physical, psychological and social effects. Follow-up care is an integral part of cancer survivorship, yet less frequent contact with healthcare professionals after treatment may affect survivors' perceptions of their care and access to formal support. In addition, the emphasis placed on monitoring for recurrence during follow-up may lead to unmet supportive care and informational needs. There is limited research to determine the impact of healthcare experiences upon cancer survivors' quality of life. Therefore, this study seeks to understand colorectal cancer survivors' quality of life, symptom experience and the healthcare factors which may influence their quality of life.

Methodology: A pragmatic mixed methods sequential explanatory approach.

Methods: A purposive sample of adult colorectal cancer survivors (*n*=304) were recruited from three public and private hospitals and 21 cancer support centres in Ireland. The sample, who were between six and 60 months post-diagnosis completed a questionnaire including the Functional Assessment of Therapy–Colorectal Cancer Survey and the Patient Continuity of Care Questionnaire. A subsample of 22 survey participants took part in semi-structured interviews to elicit information about experiences relating to their quality of life, healthcare and unmet needs.

Findings: On average, colorectal cancer survivors evaluated their quality of life positively. However, more than half were dissatisfied with their quality of life; more than three-quarters reported at least one negative consequence of their treatment. Survivors appeared to mediate dissatisfaction with their quality of life through a process of reframing their illness experience, including social comparison and use of optimistic coping strategies.

Colorectal cancer survivors' quality of life was associated with a selection of socio-ecological (insurance status, social difficulties), medical (tumour status), and healthcare (continuity of care, use of cancer support) variables. Although two-thirds of survivors were satisfied with their continuity of care, an undercurrent of positive and negative healthcare events were evident, influenced by behaviours or actions at individual, organisational and political levels. Negative care events diminished survivors' autonomy, dignity and confidence in their self-management skills, and created an array of unmet information and supportive care needs. In response to these unmet needs, survivors developed a network of support beyond the healthcare system encompassing family members, social networks, local advocacy services and virtual communities. However, engagement with these networks was dependent upon the cultural context in which the individual resided and received healthcare and barriers to accessing support, such as awareness, local availability, perceived need, trustworthiness and stigma relating to discussion of symptoms.

Discussion and Conclusion: The results of this mixed methods study demonstrate the importance of continuity of care and dissemination of cancer-related information in promoting more positive quality of life among colorectal cancer survivors. Given the relationship between poorer quality of life, greater social difficulty and participation in cancer support, strategies to address cancer survivors' psychosocial needs are necessary. The study has implications for the recommendations of the 2017 National Cancer Strategy, particularly the development of cancer survivorship models of care; the implementation of cancer survivorship care plans, treatment summaries; and provision of psychosocial support. Most critically, given the finding that colorectal cancer survivors feel under-prepared for quality of life issues following treatment, there is a need for interventions to support the delivery of cancer survivorship information and assist survivors to develop self-management strategies. Recommendations are made for future research, healthcare delivery, and oncology policy, practice, and cancer support and advocacy services to begin to ameliorate the challenges and unmet needs associated with colorectal cancer survivorship.

Summary

Background: The modern evolution of cancer treatments and strategies to enhance earlier detection of cancer have led to significant improvements in colorectal cancer survival rates over the past 20 years. When combined with rising incidence rates, these advances mean colorectal cancer survivors are one of the most rapidly growing groups of cancer survivors. Although colorectal cancer survivors may report reasonable quality of life in the long-term, they live with an array of physical, psychological and social disabilities, including bowel dysfunction, fear of recurrence and financial difficulties. Survivors are enrolled in a programme of follow-up care after the completion of treatment. However, evidence suggests that monitoring for recurrence may be prioritised over supportive care activities during this period. The reduced frequency of consultations with healthcare professionals between treatment and follow-up may lead to survivors feeling less supported and experiencing psychological distress. There is a paucity of literature which examines how healthcare experiences may influence cancer survivors' quality of life.

Aims: This study was designed to examine the impact of healthcare experiences upon colorectal cancer survivors' quality of life up to five years following diagnosis in Ireland. Secondary objectives of the study were to establish the nature and prevalence of adverse physical, psychological and social consequences, and to understand the personal and organisational structures employed by colorectal cancer survivors to address unmet needs in survivorship.

Methodology and Methods: A pragmatic, mixed methods sequential explanatory design was considered the most suitable approach to address the research objectives, as it provides the opportunity to gain a comprehensive understanding of the magnitude and context of quality of life issues experienced by colorectal cancer survivors. In the first phase of the study, 304 colorectal cancer survivors were recruited from three public and private hospitals and 21 cancer support centres in Ireland. Participants of the survey phase provided information about their quality of life, symptom experience, continuity of care, and their level of access to, and support from, healthcare professionals, healthcare services and advocacy organisations. In the second, qualitative phase of the study, a subsample of 22 survey participants took part in semi-structured interviews to gain further understanding of physical and psychosocial treatment effects, healthcare experiences and unmet needs described in the survey phase.

Findings: The integrated results of this mixed methods study demonstrate that Irish colorectal cancer survivors evaluate their quality of life positively. However, more than half of survivors were dissatisfied with their quality of life (54%), and more than three-quarters experienced one or more physical, psychological or social difficulties. Survivors appeared to engage in activities to reframe their experience of disease and functional limitations. Reframing activities included the adoption of optimistic coping strategies or social comparison with peers in the oncology unit who are perceived to have a more toxic treatment regimen or a more life-threatening form of the disease.

Sixty-four percent of colorectal cancer survivors described satisfaction with their continuity of care, particularly regarding their relationships with healthcare professionals (84%) and the management of their follow-up care (78%). Ninety-five percent of the sample had access to a named doctor, nurse or other healthcare professional to discuss cancer-related worries or survivorship issues. Support in the period of survivorship was primarily derived from the hospital in which care was received (95%). Primary care services, particularly general practitioners, were underutilised resources due to inadequate communication from oncology specialists, and cancer survivors' personal preferences to receive care in nurse-led or physician-led models of oncology care. However, primary care practitioners appeared to be a valuable resource for the management of psychosocial issues during and after treatment.

Although survivors' evaluations of care were mostly positive, it was evident care occurred within a continuum of positive and negative healthcare events which did not necessarily influence overall perceptions of care. An array of individual, organisational, and political failures seemed to contribute to the inadequate management of survivorship issues, including a failure to recognise survivors' self-management expertise and perceptions of staffing levels. Colorectal cancer survivors experienced a range of chronic treatment-related effects and unmet information and supportive care needs. Where negative events of care aligned, survivors were left unprepared for the lasting consequences of colorectal cancer and were deprived of appropriate guidance in the development of self-management strategies. The contrast between positive and negative events within therapeutic relationships demonstrate how such events may act to foster or hinder survivors' autonomy, dignity and confidence in the aftermath of treatment, and negatively influence their quality of life.

A number of socio-demographic and cancer-related factors influenced colorectal cancer survivors' quality of life. Multivariate analysis suggests colorectal cancer survivors' quality of life may be explained by a selection of socio-ecological (insurance status, social difficulties), medical (tumour status), and healthcare (continuity of care, use of cancer support) variables (all $p \leq 0.05$). The unmet needs which may arise from inadequate continuity of care and supportive care meant colorectal cancer survivors had to develop a network of support beyond the healthcare system to manage ongoing quality of life concerns. Survivor's networks of support comprised of family members, social networks, local advocacy services and virtual communities. However, engagement of these networks was dependent upon the cultural context in which the individual resided and received healthcare, and barriers which may impede the quality of such support, including awareness, local availability, perceived need, trustworthiness and stigma relating to discussion of symptoms.

Conclusion and Recommendations: The findings demonstrate a variety of cultural, socio-ecological, cancer-related and healthcare-related factors which are pertinent to colorectal cancer survivors' quality of life in the five years following treatment. Continuity of care and dissemination of cancer-related information are important in promoting more positive quality of life among colorectal cancer survivors. These findings have implications for oncology healthcare policy and delivery of care in Ireland, particularly the current supplementary role played by cancer advocacy services as providers of psychosocial care in the Irish oncology healthcare system. Given the relationship between poorer quality of life, greater social difficulty and participation in cancer support, strategies to address cancer survivors' unmet supportive care and informational needs are necessary. This may be achieved through collaborative interventions between oncology healthcare services and cancer advocacy organisations. The findings also have further implications for the planned development of cancer survivorship models of care, cancer surveillance, psychosocial support in cancer follow-up and the implementation of cancer survivorship care plans and treatment summaries recommended by the 2017 National Cancer Strategy. In light of the findings suggesting colorectal cancer survivors are unprepared for physical, psychological and social survivorship issues, there is a need to develop interventions to support the delivery of appropriate information about cancer survivorship which support survivors to develop appropriate self-management strategies.

Publications and Presentations Relating to this Thesis

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Oral Presentations

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Drury A., Payne S. & Brady A.M. (2016) *The Cost of Survival: Colorectal Cancer Survivors Experience of Pain.* The European Cancer Rehabilitation & Survivorship Symposium, Tivoli Hotel & Congress Centre, Copenhagen, Denmark, 19/09/2016.

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Glossary

ANOVA	Analysis of Variance
BMI	Body Mass Index
CC-18	Patient Continuity of Care Questionnaire Total Score
CCS	Colorectal Cancer Specific concerns
CEA	Carcinoembryonic Antigen
CI	Confidence Interval
CT	Computed Tomography
DoH	Department of Health
EDL	Everyday Living
EORTC QLQ-C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 module
EORTC QLQ-CR29/38	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Colorectal Cancer module
ESMO	European Society for Medical Oncology
EWB	Emotional Well-Being
FACT-C	Functional Assessment of Cancer Therapy – Colorectal Cancer
FACT-G	Functional Assessment of Cancer Therapy – General
FWB	Functional Well-Being
HADS	Hospital Anxiety and Depression Scale
HSE	Health Service Executive
$\bar{x}$	Mean
$\tilde{x}$	Median
IARC	International Agency for Research on Cancer
ICS	Irish Cancer Society
IoM	Institute of Medicine
MM	Money Matters
MOS SF-36	Medical Outcomes Study Short Form 36
N	Total Sample
NCCP	National Cancer Control Programme
NCRI	National Cancer Registry of Ireland
OECD	Organisation for Economic Co-operation and Development
OR	Odds Ratio
PCCQ	Patient Continuity of Care Questionnaire
PEOS	Participant, Exposure, Outcomes and Study criteria
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROFILES	Patient Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship
PROM	Patient-Reported Outcome Measure
PWB	Physical Well-Being
SD	Standard Deviation
SD-16	Social Difficulties Inventory Total Score
SDI	Social Difficulties Inventory
SO	Self and Others
SPSS	Statistical Package for Social Science
SWB	Social Well-Being
VAS	Visual Analogue Scale
WHO	World Health Organisation

Chapter One - Introduction

1.1 Introduction

This thesis explores colorectal cancer survivors' quality of life and seeks to understand how experiences of healthcare may influence the quality of life of colorectal cancer survivors receiving follow-up care in tertiary oncology settings up to five years following diagnosis. This study will provide evidence to inform the development of supportive care interventions for colorectal cancer survivors which address their unmet needs and support recovery of physical, psychological and social well-being. The current chapter presents the background to the study, opening with a personal reflection upon the motivations for this study (Section 1.2). The public health impact of colorectal cancer (Section 1.3) and the oncology policies which operated in Ireland at the time of this study (Section 1.4) are presented. Thereafter, the healthcare structures (Section 1.5) and advocacy services (Section 1.6) responsible for the health and psychosocial care of colorectal cancer survivors in Ireland are explained. The chapter concludes with an outline of the thesis structure (Section 1.7).

1.2 Reflecting Upon the Selection of the Research Topic

Prior to undertaking this PhD programme, I spent several years working as an oncology nurse, practising in radiation and medical oncology settings specialising in head and neck, breast, prostate, gynaecological and gastrointestinal cancers. Several factors in my career prompted the study described in this thesis.

In my role as a chemotherapy day ward nurse, I frequently encountered patients returning for post-treatment surveillance; many living with chronic physical, psychological and social consequences as a result of cancer treatment. Later, as an oncology liaison nurse, I was struck by the oversight of chronic toxicities during follow-up consultations with cancer survivors. In my experience, programmes of follow-up were largely surveillance-orientated. Cancer survivors appeared to be complicit in this preoccupation with the results of surveillance due to their fears of possible recurrence. Where survivors did raise concerns about treatment side-effects, they were advised to return to the speciality which administered the treatment responsible for the specific side-effect. Fragmentation of care created a significant barrier to the investigation and management of post-treatment side-effects. Often survivors were attending two or more hospitals for surgical, medical oncology and radiation oncology follow-up. In many cases, patients returned for follow-up six months later with continued symptom-related difficulties, dissatisfied with the care provided to manage these symptoms.

My professional knowledge prompted an interest in colorectal cancer survivors' quality of life and symptom experiences. A preliminary literature review identified limited research in the field from an Irish context. The review highlighted that although colorectal cancer survivors' quality of life may improve over time, survivors experience a range of physical and psychosocial symptoms, which depended on the stage of disease at diagnosis and the treatment modalities used. The chronic effects reported in the literature included constipation, diarrhoea, faecal incontinence, urinary incontinence, peripheral neuropathy, pain, sexual dysfunction, fatigue, fear of recurrence, poor body image, depression and anxiety (Caravati-Jouvenceaux *et al.* 2011, Jansen *et al.* 2011a, Jansen *et al.* 2011c, Chambers *et al.* 2012b, Glaser *et al.* 2013). Only a single study considered the relationship between continuity of care and quality of life in a primary care setting (Sisler *et al.* 2012b).

The second motivation for this study arose from the political climate in which I practised as an oncology nurse. Following the 2006 National Cancer Strategy, the centralisation of oncology services into eight centres of excellence provided an opportunity to reduce the fragmentation of care experienced by oncology patients (Department of Health [DoH] Ireland 2006). However, the Strategy failed to make provisions for the care of cancer survivors (Warde *et al.* 2014). Rising cancer incidence rates and improving rates of survivorship presented challenges for the emerging model of oncology care. The 2008 economic recession placed significant restrictions upon recruitment of public sector staff with implications for an oncology workforce which had been struggling with recruitment and retention of nurses and senior physicians for over a decade (DeZeeuw & Hanan 2001, Warde *et al.* 2014). I believed that interventions would be required to facilitate the delivery of survivorship care to the growing population of survivors. However, there was a need to understand cancer survivors' experiences of care and how the current services may influence their quality of life, so that future supportive care interventions for cancer survivors in Ireland would be underpinned by evidence provided by cancer survivors themselves.

1.3 The Public Health Impact of Colorectal Cancer in Ireland and Internationally

Each year, colorectal cancer accounts for 3.5 million new cancer diagnoses worldwide (International Agency for Research on Cancer [IARC] 2014). Evolving treatment modalities, national cancer screening initiatives and public awareness campaigns driving earlier diagnosis have resulted in substantial improvements in cancer survivorship rates in the developed world (Organisation for Economic Co-operation and Development [OECD] 2015). In Ireland, colorectal cancer is the most common invasive cancer affecting males and females, with an average of 2,460 cases recorded annually (National Cancer Registry of Ireland [NCRI] 2015). The rate of survival after colorectal cancer has improved significantly in Ireland between the periods 1994-1998 and 2004-2008, in line with OECD25 averages, and currently stands at 61% (NCRI 2013b, 2015, OECD 2015). These positive changes are due to health promotion strategies supporting earlier diagnosis, the rollout of the national colorectal cancer screening programme in 2013 and improved treatment options. However, NCRI (2014b) predict that the incidence of colon and rectal cancer will increase by between 77% and 156% in the period between 2010 and 2040. Collectively, these statistics translate to a rapidly growing population of colorectal cancer survivors. As cancer survivorship has become more prevalent and more sophisticated treatment modalities emerge, the chronic toxicities and psychosocial effects of cancer are increasingly apparent. As a result, the growing population of colorectal cancer survivors and their ongoing healthcare needs will have significant implications for the health and advocacy services which are responsible for their care and the National Cancer Strategy which guides them.

1.4 The Political Landscape of Cancer Survivorship in Ireland

Ireland's first National Cancer Strategy was published in 1996, and set out two major goals within its lifetime: 1) to reduce the rates of cancer illness and death, and 2) to ensure effective care and treatment to enhance cancer patients' quality of life (DoH Ireland 1996). These objectives were realised within the lifetime of the 1996 Strategy, achieving a reduction in cancer mortality, improvements in the coordination of cancer services, increased recruitment and retention of cancer care professionals and greater use of chemotherapy, radiotherapy and surgery (Deloitte 2003). These key achievements set the scene for the second National Cancer Strategy, which focused on further improvements in the delivery of cancer care and reduced incidence and mortality (DoH Ireland 2006). The 2006 Strategy resulted in the roll-out of several national screening services, including BowelScreen and the development of eight designated centres of excellence in cancer care. Further achievements of the Strategy include rapid access clinics for suspected prostate and lung cancers, improvements in radiation and medical oncology staffing and facilities, and the development of community oncology and family risk programmes (National Cancer Control Programme [NCCP] 2015).

The publication of *From Cancer Patient to Cancer Survivor: Lost in Transition* (Institute of Medicine [IoM] 2006) marked a pivotal moment for cancer survivorship. The report recognised the inherent physical and psychosocial challenges of survivorship and acknowledged the exacerbating influence of unmet information and healthcare needs. The IoM sought to improve awareness of the consequences of cancer and its treatment, enhance quality of life, and define quality care for cancer survivors. The report made several recommendations to achieve these aims, including the implementation of cancer survivorship care plans, evaluation of models of healthcare delivery for cancer survivors, development of clinical practice guidelines in survivorship care and access to adequate and affordable health insurance. The IoM also advocated for awareness of cancer survivorship as a phase in the cancer trajectory and delivery of appropriate care by cancer care professionals in this period. In Ireland, the National Cancer Strategy (2006) recognised cancer survivorship as a unique phase of the cancer trajectory and the implications of a growing population of cancer survivors for future cancer care in Ireland but failed to make recommendations for this group (Warde *et al.* 2014).

1.5 Healthcare Throughout the Trajectory of Colorectal Cancer in Ireland

Healthcare services in Ireland are delivered through a combination of public, private and voluntary organisations. Approximately 50% of the Irish population avail of private health insurance, sold by several organisations to those who can afford it (Harvey 2007, DoH Ireland 2016). However, all residents of Ireland are entitled to receive care through the public healthcare system regardless of insurance status. The public healthcare system is funded by general taxation and point of care contributions for certain services, including emergency department visits and in-patient services (Citizens Information 2014). Medical card holders are entitled to free or heavily subsidised health services (Health Service Executive [HSE] 2015). Entitlement to a medical card is means-tested, and usually granted on the basis of income thresholds or in circumstances where an individual would experience undue hardship were it refused (HSE 2015).

Due to the mixed economy of public and private healthcare provision in Ireland, there are three primary pathways to a diagnosis of colorectal cancer. Firstly, BowelScreen offers free screening to men and women between 60 and 69 years every two years. For those who have a positive faecal immunochemical test at the first stage of screening, the majority will receive a colonoscopy within four to six weeks, at which time histological samples are obtained for confirmatory diagnosis (National Screening Service 2017). For those who are not eligible for BowelScreen, but have symptoms suggestive of colorectal cancer, a referral from their general practitioner is required for colonoscopy. Individuals requiring colonoscopy may be referred to a public or private hospital for diagnostic investigations, subsequent treatment and follow-up care. Those with private health insurance are at an advantage over those without, as they may often access diagnostic investigations, treatment and specialist care services quicker than those without insurance in both public and private hospitals (Brady & O'Donnell 2010). This two-tier healthcare system creates potential for disparity in access to treatment. Indeed, those who have private health insurance are likely to undergo colonoscopy within two to six weeks, while half of those who are uninsured have a waiting time of more than six weeks (O'Shea & Collins 2016).

Once a diagnosis of colorectal cancer has been confirmed, most patients will undergo surgical excision of the tumour. Depending on the size and location of the tumour, polypectomy or local excision of the tumour and regional lymph nodes may be performed (Labianca *et al.* 2013). The goal of colorectal cancer surgery is to preserve sphincter function insofar as possible, so survivors may maintain bowel control post-operatively (Kennedy Sheldon 2010, Glimelius *et al.* 2013). However, more extensive tumours require more sophisticated surgical techniques and treatment strategies. This may result in a temporary or permanent ileostomy or colostomy in the aftermath of surgery, which exteriorises the bowel to the anterior abdominal wall, allowing elimination of intestinal waste to an external pouch (Kennedy Sheldon 2010). Patients may require neo-adjuvant chemotherapy, radiotherapy, or both prior to surgery to reduce tumour size and enhance the preservation of sphincter function (Glimelius *et al.* 2013). Finally, those with higher stage disease may require adjuvant chemotherapy to reduce the risk of relapse and enhance overall survival (Schmoll *et al.* 2012, Glimelius *et al.* 2013).

The follow-up surveillance regimen for patients diagnosed with colon or rectal cancer is determined by the stage and treatment of the disease. Much debate surrounds the frequency and intensity of follow-up care, and many best practice guidelines have been published (Cancer Care Ontario 2012, Schmoll *et al.* 2012, Meyerhardt *et al.* 2013, Steele *et al.* 2015, National Comprehensive Cancer Network 2016b, 2016a). The most widely accepted follow-up criteria in Europe are those of Schmoll *et al.* (2012), who recommend colorectal cancer survivors attend clinic every three months for the first three years, and bi-annual visits in years four and five. Follow-up care for cancer survivors may be led by or shared between primary, secondary and tertiary healthcare providers with different specialisations (IoM 2006). At each visit, patients should receive a clinical examination, evaluation of chronic side-effects and carcinoembryonic antigen (CEA) testing. Computed Tomography (CT) should be conducted every six to 12 months, and colonoscopies are recommended at diagnosis, and then every five years unless otherwise indicated by the cancer survivor’s clinical examination (Schmoll *et al.* 2012). However, the American Society of Clinical Oncology recommends colonoscopies one year after the initial surgery (Meyerhardt *et al.* 2013) and every 3-5 years following diagnosis (Labianca *et al.* 2010). There appears to be consensus regarding the need for education and motivation to optimise lifestyle behaviours among colorectal cancer survivors. Most guidelines make recommendations regarding diet, weight management, physical activity, smoking cessation and moderation of alcohol use (Cancer Care Ontario 2012, Schmoll *et al.* 2012, Meyerhardt *et al.* 2013, Steele *et al.* 2015).

In Ireland, colorectal cancer follow-up is managed by the surgeon and/or oncologist who administered treatment, or clinical nurse specialists in colorectal cancer. Physician-led models of care are most common in private hospital settings, while nurse-led models are increasingly used in public hospital settings. Primary care practitioners do not have a formal role in follow-up care in Ireland but would usually be kept abreast of the colorectal cancer survivor’s oncology-related care via routine correspondence from oncology staff. Psychosocial care in oncology is largely provided by advocacy organisations in Ireland and is discussed in greater detail in Section 1.6.

1.6 Psychosocial Support for Cancer Survivors Within and Beyond the Healthcare Setting in Ireland

Following the publication of the 1996 National Cancer Strategy, the DoH commissioned a study to make recommendations on the development and provision of cancer support services (DoH Ireland 1999). The report found significant deficiencies in the provision of formal psychosocial support in the hospital setting due to the opportunistic nature of its provision and its informal structuring. A failure to recognise and manage the psychosocial problems of cancer patients and their families were clear themes within the study. The authors of the report called for access to multidisciplinary psychosocial support services for all cancer patients and use of complementary therapies to improve quality of life. Furthermore, the report raised awareness of the use of unregulated and independent support services without expertise in cancer or links to the health service (DoH Ireland 1999). The 2006 National Cancer Strategy recognised these deficits and proposed that the Irish Cancer Society (ICS), the national cancer charity, should expand its role as a cancer support service and become an umbrella body for all cancer support groups, centres and peer support programmes in Ireland. The 2006 Strategy also recommended that the HSE ensure patients and their families have access to psycho-oncology and psychosocial support (DoH Ireland 2006). However, this recommendation had not been achieved at the time of the current study, as just two hospitals had full- or part-time psycho-oncology services requiring a referral from the patient’s medical team (Warde *et al.* 2014, NCCP 2015).

The ICS has been a major provider of support services for individuals with cancer since its inception in 1963. The ICS provides a range of information and support services for those with cancer and their families, including night nursing, cancer helplines, health promotion campaigns, cancer information literature, public information days and cancer support groups for patients and their families. Following an investigation of the existing cancer support services in Ireland, the ICS agreed they were well-positioned to build effective services to improve the experiences and outcomes of those with cancer and recommended progressing with a project of affiliation for cancer support services (ICS 2010). However, key stakeholders in the advocacy sector believed geographical distribution, lack of transport, and gender and socio-economic biases were barriers to effective cancer support (ICS 2010). Nevertheless, an evaluation of the affiliation programme by Gallagher & O’Keeffe (2012) indicated the process was successfully implemented and had increased cancer patients’ access to services.

Unlike psycho-oncology services, cancer advocacy groups allow patients and survivors to self-refer to support services as required. To further understand the context of psychosocial care for this study, an exploratory investigation of cancer support services available in the HSE Dublin Mid-Leinster Region of Ireland was undertaken in 2014. This region was selected as participants for the main study would be recruited from hospitals and support groups in this area. Support services were identified through the ICS website and publications, *The Directory of Cancer Support Services* (ICS 2012), *In your Area: Local Support Services* (ICS 2014), and the Revenue Commissioner's report of *Bodies Granted Charitable Tax Exemption* (2014). An internet search was conducted to identify any further support groups active within the HSE Dublin Mid-Leinster Region for inclusion in the review. Finally, healthcare professionals working within the hospitals involved in the main study were informally asked to identify support services they referred patients to. The availability of support services and the range of services provided were elicited from each organisation's website and analysed descriptively using the Statistical Package for Social Sciences (SPSS).

In all, 18 cancer support centres, groups and information services were identified in the HSE Dublin Mid-Leinster Region (Figure 1.1). In addition, five ICS Daffodil Centres, and two organisations providing home nursing care, family support and cleaning services for individuals with chronic illness were identified. Similar to Gallagher & O'Keeffe (2012), there was an inconsistent geographical distribution of advocacy-based cancer support services, with more rural counties such as Longford lacking local cancer support services. No organisation offered support groups specifically for cancer survivors. One centre offered a support group for those diagnosed with

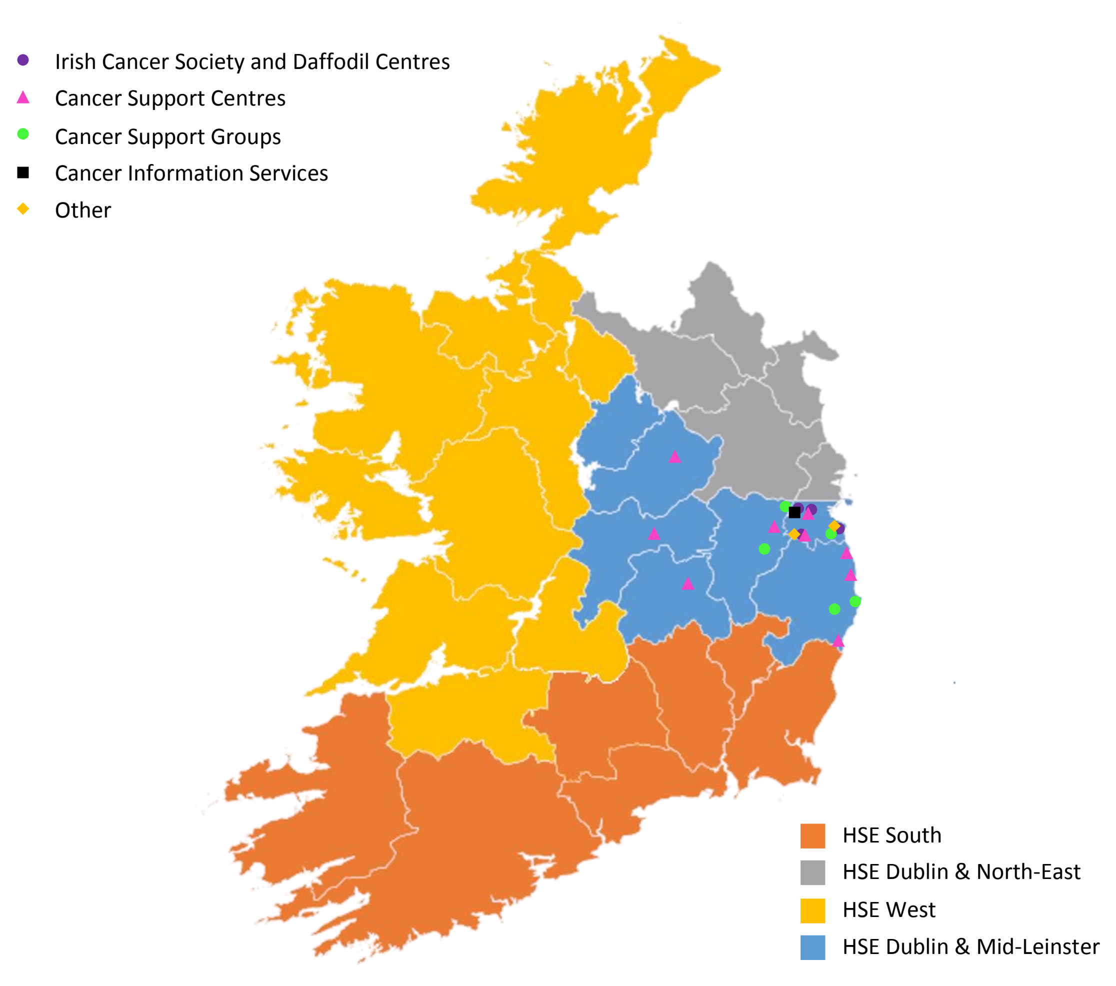

Figure 1.1 Locations of organisations providing cancer advocacy and support services in the HSE Dublin Mid-Leinster region

colorectal cancer, while two provided groups for cancer survivors with ostomies (both malignant and non-malignant). Only three-quarters of the organisations had websites (77.8%, *n*=14), of which two-thirds (64.2%, *n*=9) provided information about the services available within the organisation. No organisation provided online support. Telephone support was available from six centres (33.3%), and four offered nursing services (22.2%). Other services advertised by cancer support organisations included complementary therapies for cancer patients undergoing treatment (55.6%, *n*=10), classes and workshops (50.0%, *n*=9) and drop-in services (22.2%, *n*=4). One organisation advertised a six-week workshop to provide information about living well after cancer (5.6%).

1.7 Format of the Thesis

This thesis consists of nine chapters. **Chapter One** provided background information about the study context, including the motivations for undertaking this study, the epidemiology of colorectal cancer, and the policy, healthcare and advocacy structures in place to support colorectal cancer survivors.

Chapter Two describes the conceptual and theoretical background to the research reported in this thesis. In the first part of the chapter, the methods and results of a concept analysis of colorectal cancer survivorship published in the *European Journal of Oncology Nursing* are presented. The concept analysis paper is followed by a discussion of the emergence, development, operationalisation and conceptual underpinnings of quality of life research. The conceptual framework which guides the current study, the Ashing-Giwa (2005) *Contextual Model of Health-Related Quality of Life* is described, and the aim and objectives of the study are outlined.

Chapter Three presents a comprehensive review of the literature relevant to quality of life and healthcare in colorectal cancer survivorship. It extends the understanding of the consequences of colorectal cancer survivorship described in the concept analysis, exploring survivors' quality of life, including the prevalence and predictors of physical, psychological and social outcomes in Ireland and internationally. The literature describing colorectal cancer survivors' healthcare experiences is synthesised. A critical appraisal and analysis of studies identifying a potential relationship between healthcare experiences and quality of life outcomes is presented. The various demographic, medical and healthcare factors which may influence quality of life are outlined. Chapter Three concludes with a critique of the methodological limitations of the reviewed literature, a summary of the key findings and gaps in the literature, and their implications for the theoretical framework guiding the study.

Chapter Four evaluates the methodological and philosophical issues relevant to the current study. This chapter outlines a definition of mixed methods research and the philosophical concerns arising from the mixing of disparate quantitative and qualitative research methods in this study. The pragmatic approach guiding this mixed methods study is discussed and justified. The final section of this chapter illustrates the sequential explanatory design utilised within this study and considers the potential challenges of such a design.

Chapter Five describes and justifies the quantitative and qualitative approaches of this mixed methods study. The descriptive correlational survey and descriptive qualitative interview methods are explained. Comprehensive descriptions of the nested sampling strategy, survey instruments and data collection procedures are provided. This is followed by a discussion and evaluation of relevant quality, rigour and ethical issues. The final section of the chapter outlines the data analysis techniques implemented in each phase of this study.

Chapter Six communicates the results of the quantitative survey phase of the study. The characteristics of the study sample, their quality of life outcomes, healthcare experiences and unmet needs are presented. The results of univariate parametric and nonparametric statistical analysis to identify the demographic, cancer-related and healthcare outcome variables independently associated with quality of life are presented to inform the development of a multivariate logistic regression model. The chapter concludes with a summary of the procedures and results of a backward stepwise logistic regression model to determine the healthcare factors predicting colorectal cancer survivors' quality of life during follow-up care in tertiary oncology settings in Ireland.

Chapter Seven illustrates the findings of the qualitative interview phase of this study. The chapter is divided into four parts which illustrate survivors' quality of life concerns and healthcare experiences as they progress through the trajectory of cancer diagnosis, treatment and survivorship. Themes relating to survivors' quality of life are presented in relation to their recollections of their quality of life during the period of diagnosis and treatment and their current experiences of physical, psychological and social issues. The themes detailing colorectal cancer survivors' healthcare experiences are presented in a manner illustrating survivors' beliefs about the impact of these experiences during diagnosis, treatment and subsequent follow-up. Finally, the sources and influence of informal survivorship support described by interview participants are reported.

Chapter Eight integrates and discusses the results of the quantitative and qualitative phases of this mixed method study. The socio-demographic, cancer-related and quality of life characteristics of the sample are compared to the general Irish population, normative populations and previous studies of colorectal cancer survivors. The results of the quantitative and qualitative phases of the study are integrated and interpreted logically, according to the mixed methods objectives which guide the study. A model is proposed to explain the healthcare-related factors influencing colorectal cancer survivors' quality of life outcomes in this mixed methods study. This model is informed by the results of this study and the Ashing-Giwa (2005) *Contextual Model of Health-*

Related Quality of Life. The limitations and strengths of this study are considered at the end of Chapter Eight.

Chapter Nine concludes the thesis with a discussion of the implications and recommendations of the study, opening with a summary of the key meta-inferences derived from the mixing and integration of quantitative and qualitative research methods and results. The theoretical and methodological implications of this study are deliberated. The ramifications of the results for current Irish policy, healthcare services, oncology practice and cancer support are considered and corresponding recommendations are proposed. Directions for future research are suggested in light of the study results. A reflection upon the researcher's role, research practice and the outcomes of the study is provided. The thesis closes with a summary of the study's original contribution to the body of colorectal cancer survivorship literature and the major conclusions of this study.

Chapter Two – Conceptual and Theoretical Background

2.1 Introduction

This chapter describes the conceptual and theoretical background to the research reported in this thesis. The results of a concept analysis published in the *European Journal of Oncology Nursing* is presented (Section 2.2). The concept of quality of life is then discussed, including a brief overview of its emergence, development (Section 2.3.1) and operationalisation (Section 2.3.2). The conceptual models which may inform quality of life research in cancer survivorship are briefly discussed (Section 2.3.3) and the theoretical framework which guides the current study is presented and justified (Section 2.3.4). Finally, the aims and objectives of the study are presented (Section 2.4).

2.2 Cancer Survivorship: Advancing the Concept in the Context of Colorectal Cancer

This section presents the results of a concept analysis published in the *European Journal of Oncology Nursing* to define the key attributes and consequences of colorectal cancer survivorship[1]. The original concept analysis was conducted between September 2013 and April 2014, with searches undertaken in November 2013 (Appendix 2.1, Table A2.1). In preparing the concept analysis for publication, the searches were re-run in November 2016 (Table A2.2), and the results of the published analysis are presented here.

Previous concept analyses of cancer survivorship have focused upon survivorship among African-American women (Farmer & Smith 2002), survivorship in chronic illness (Peck 2008) and cancer survivorship (Doyle 2008). These concept analyses predate the seminal report *From Cancer Patient to Cancer Survivor: Lost in Transition* (IoM 2006), which made a critical contribution to the design and implementation of research, healthcare and advocacy services for cancer survivors in the United States of America (USA) and internationally. Doyle (2008) is the most recent concept analysis applied to cancer survivorship and is a seminal publication defining the concept. However, little work has been undertaken to determine the application of Doyle's conceptual attributes to specific groups of cancer survivors. Therefore, this concept analysis aimed to examine the application of Doyle (2008) to cancer survivorship in the context of colorectal cancer. In addition to the attributes and consequences of Doyle (2008), the current concept analysis identified a sixth attribute of

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[1] *This article was accepted for publication by Elsevier in the European Journal of Oncology Nursing on July 10th, 2017 and has been reprinted under the Journal Publishing Agreement. The Version of Record of this manuscript is available online:* Drury A., Payne S. & Brady A.M. (2017) Cancer Survivorship: Advancing the Concept in the Context of Colorectal Cancer. *European Journal of Oncology Nursing* **29**(1), 135-147. DOI: http://dx.doi.org/10.1016/j.ejon.2017.1006.1006.

colorectal cancer survivorship, *Navigating Systems and Resources*, and a fifth consequence, *The Constellation of Met and Unmet Survivorship Needs*. To the researcher's knowledge, this paper is the first to analyse the concept of cancer survivorship in colorectal cancer. The results of this concept analysis provide an evolved understanding of cancer survivorship, including a definition of cancer survivorship in the context of colorectal cancer for the first time.

2.2.1 Background

Colorectal cancer is the third most commonly diagnosed malignancy worldwide, affecting approximately 3.5 million people annually (IARC 2014). Significant improvements in survival have been achieved as a result of evolving treatment modalities and screening initiatives which promote earlier diagnosis. However, substantial increases in the incidence of colorectal cancer have been forecast. In Ireland alone, colon and rectal cancer incidence is expected to increase by between 77% and 156% between 2010 and 2040 (NCRI 2014b). Thus, colorectal cancer survivors account for one of the most rapidly growing groups living with and after cancer.

2.2.2 Defining Cancer Survivorship

The term 'survivorship' is used to denote recovery or life with and beyond a plethora of conditions and circumstances, including cancer (Mullen 1985), sexual abuse (Dallam 2010), the atomic bomb (Preston *et al.* 2007) and the Holocaust (Hursting & Forman 2009). To add to this confusion, the definition of survivorship varies between and within contexts. In cancer survivorship, there is a glaring disparity in the definition of who constitutes a cancer survivor, with different regions and organisations advocating for definitions beginning 1) at diagnosis, 2) after the end of treatment, or 3) after a specified time has elapsed where the individual remains disease free (Reuben 2004, Leigh 2007, Khan *et al.* 2012, Rowland *et al.* 2013). Other considerations in the definition of cancer survivorship are the inclusion or exclusion of individuals who are terminally ill (Khan *et al.* 2012) and survivors' family members and friends (Feuerstein 2007, Leigh 2007). Furthermore, Hebdon *et al.* (2015) delineated a difference between cancer '*survivor*' and '*survivorship*'. The former describes the individual who has had a diagnosis of cancer, while the latter refers to the ongoing healthcare needs of the individual.

In his highly influential paper, *Seasons of Survival*, Fitzhugh Mullen (1985) divided cancer survivorship into three distinct '*seasons*'; acute, extended and permanent. *Acute Survival* begins at diagnosis, characterised by diagnosis, treatment, fear, anxiety and uncertainty about the future. *Extended Survival* begins at the end of treatment or the point of remission. Extended survival is an individual experience, reliant on the individual's adaptability and life situation. Watchful waiting, fear of recurrence, physical limitations and isolation from healthcare professionals are distinguishing elements of this phase. Finally, *Permanent Survival* is characterised by an evolving sense of being cured. However, the individual has been irrevocably affected by their experience of cancer physically, psychologically and socially.

Several concept analyses have examined survival in adulthood. However, these analyses focus on breast cancer survivorship among African-American women (Farmer & Smith 2002), survivorship in chronic illness (Peck 2008), cancer survivorship (Doyle 2008) and the cancer survivor (Hebdon *et al.* 2015) (Table 2.1). Little work has been undertaken to build upon the theories developed, nor to examine the validity of these conceptual models among survivors with different types of cancer. Furthermore, much of the cancer survivorship literature has been influenced by North American perspectives, with publication in the field driven by the seminal works of Mullen (1985) and IoM (2006). Cancer survivorship has only become a priority in Europe relatively recently, as survival rates have improved over the past 20 years (OECD 2015). The understanding of cancer survivorship will continue to evolve and mature as culturally diverse views of the concept emerge. Predicted increases in the rate of colorectal cancer survivorship will underpin continuing empirical attention to the experiences and outcomes of colorectal cancer survivors. It is therefore imperative that such pursuits are grounded in appropriate conceptual foundation. The core attributes of cancer survivorship proposed by Doyle (2008) remain salient, as:

> *"The concept of cancer survivorship is a dynamic, emerging concept pertinent to all cancer care and may be defined as a process beginning at diagnosis and involving uncertainty. It is a life-changing experience, with a duality of positive and negative aspects unique to the individual experience but with universality." (Doyle 2008, p.502).*

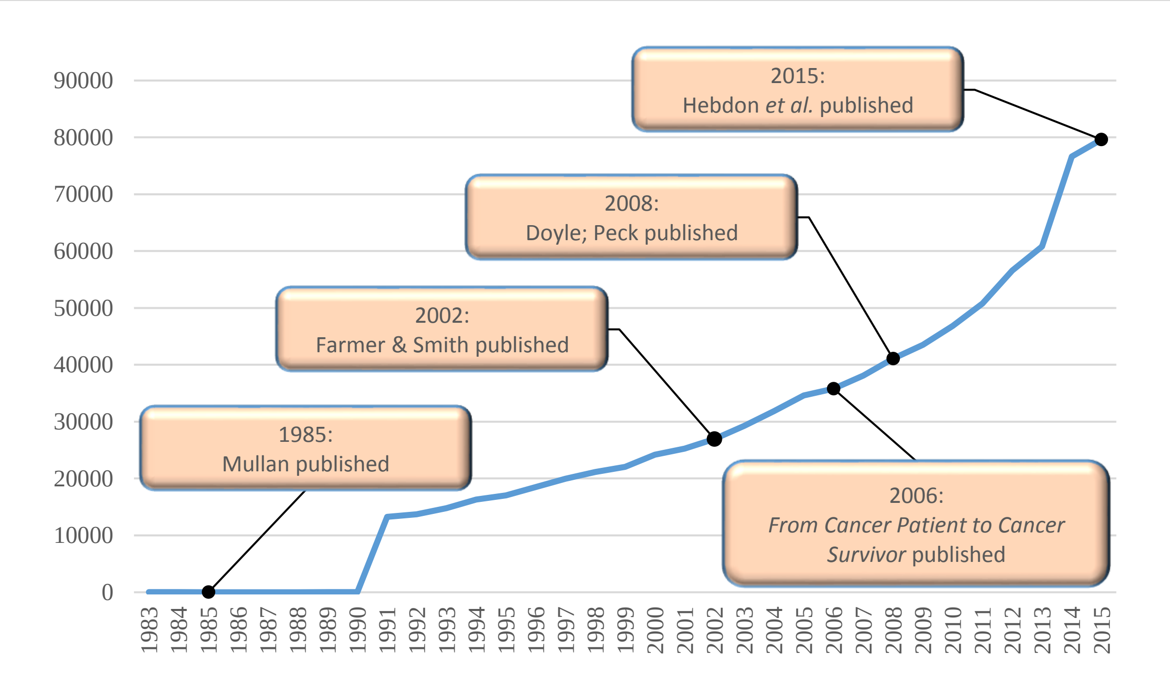
It is necessary to revisit the concept of cancer survivorship to ensure that the antecedents, attributes, consequences and definition of cancer survivorship reflect the experiences of homogeneous tumour groups, as well as cultural, clinical and political maturation of the concept. Therefore, this concept analysis intends to extend the conceptual framework of Doyle (2008), examining its application to the concept of cancer survivorship in the context of colorectal cancer.

2.2.3 Concept Analysis

Concepts are the building blocks of theory (Rodgers 2000b, p.9). Problems arise when concepts are extensively used as ambiguity arises in the definition and terminology describing the concept (Rodgers & Knafl 2000). Without clear conceptual foundation, the quality of subsequent research and theory development is weakened (Weaver & Mitcham 2008). Research on cancer survivorship issues has flourished over the past three decades. However, early interpretations of cancer survivorship may fail to fully encompass conceptual attributes as knowledge in the field develops (Walker & Avant 2005). Figure 2.1 highlights the influential nature of seminal publications by Mullen (1985) and the IoM (2006). A PUBMED search of cancer survivorship terms (Figure 2.1) yielded over one million results, with almost 300,000 papers published since Doyle (2008). Given the growth of literature in the field, the Rodgers (1989) *Evolutionary Method* guides this concept analysis, as it

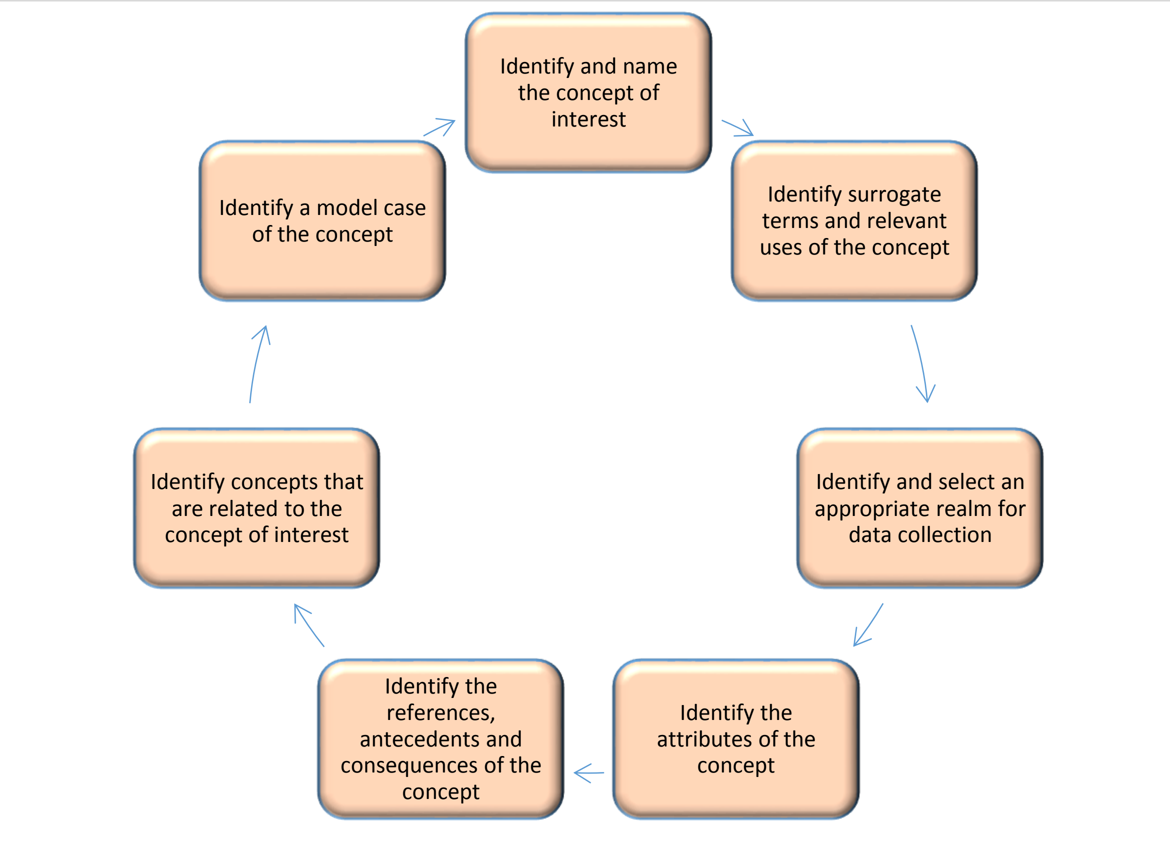
Authors	**Farmer & Smith (2002)**	**Peck (2008)**	**Doyle (2008)**	**Hebdon *et al.* (2015)**
Concept	**Breast Cancer Survivorship for African-American Women**	**Survivorship**	**Cancer Survivorship**	**Survivor, in the Context of Cancer**
Model	Rodgers (1989)	Walker & Avant (2005)	Rodgers (2000a, 2000b)	Walker & Avant (2010)
Antecedents	• Cancer diagnosis	• Person with established future memories • Baseline or stable quality of life • Event/disease/trauma which leads to suffering and forces one to face his/her mortality	• Cancer diagnosis	• Diagnosis of cancer • Treatment of cancer • Being alive
Attributes	• Complex • Individualised • Process • Unique • Relational • Dynamic	• Acceptance of current and past life circumstances • Altered self-image and self-identity which fully incorporates past events • Modified future memories which incorporate new life circumstances	• The process beginning at diagnosis • Uncertainty • Life-changing experience • Duality of positive and negative aspects • Individual experience with universality	An individual: • who is living with a history of malignancy, • who has lived through a difficult experience such as cancer treatment, • has been impacted in positive and negative ways by the experience, and • whose experience is personal and contextual
Consequences	• Physical • Psychosocial • Spiritual • Socio-economic	• Quality of life improved or returned to baseline • Ability to live in harmony with ramifications • Fewer exacerbations as one accommodates lifestyle to fit new future memories • Complete biopsychosocial adaptation • Ability to find meaning in experience, be it spiritual, logical or both • Continued vulnerability be it positive or negative	• Physical health • Psychological health • Social health • Spiritual health	• The individual does not survive unaffected • Experiences physical, emotional, financial and social challenges • Needs support from external sources • Positive outcomes including improved self-advocacy, a sense of well-being and victory of overcoming a challenge.

Table 2.1 Antecedents, attributes and consequences of survivorship and cancer survivorship reported in previous concept analyses



Date	Boolean Search	Results
22/10/2016	(((("Survivors"[Mesh]) OR (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))))	1,020,177

Figure 2.1 Annual publications in the field of cancer survivorship (PUBMED Database 1983-2015)



Source adapted from Rodgers (1989) Concepts, Analysis and the Development of Nursing Knowledge: The Evolutionary Cycle. *Journal of Advanced Nursing* **14**(4), p.333.

Figure 2.2 Rodgers Evolutionary Method of Concept Analysis (1989)

recognises the dynamic, interrelated nature of reality and acknowledges that the use, application and significance of a concept may change over time.

2.2.4 Methods

The Rodgers (1989) *Evolutionary Method of Concept Analysis* comprises eight cyclical stages which facilitate inductive inquiry using a rigourous analytical approach to clarify the concept within the bounds of a particular context (Figure 2.2). Key outcomes of the evolutionary concept analysis are the identification of attributes, antecedents, consequences, referents, surrogate terms, related concepts and a model case. The identification of conceptual *attributes* is a fundamental step in concept analysis, as they compose a definition of the concept which permits appropriate and effective use. Conceptual clarity is fostered as the *antecedents*, c*onsequences*, s*urrogate terms*, *references* and *model case* are described. *Antecedents* are the events which precede occurrence of the concept, while *consequences* refer to the happenings after a concept has transpired. *Referents* denote the circumstances where the concept may be used appropriately. Several *surrogate terms* may be used to describe a concept other than that which has been selected by the researcher, while *related terms* may share some, but not all attributes of the concept. Finally, the identification of a *model case* expands the analysis by providing an example of the concept which includes all attributes.

2.2.5 Data Sources

PUBMED, CINAHL, PsycINFO and The Cochrane Library were systematically searched in November 2016 (Appendix 2.1, Table A2.2). Searches were limited to English language literature, including participants aged 18 years or older. To be eligible for review, publications must have referred to individuals with a diagnosis of colorectal cancer. Literature published prior to IoM (2006) were excluded, as it is a seminal publication which has shaped the direction of cancer survivorship care and research. Furthermore, the concept analysis by Doyle (2008) encompassed literature published prior to 2006. The volume of international grey literature on the subject of cancer survivorship has increased exponentially over the past decade in print and electronic form, thanks to the accessibility of social media platforms and methods of self-publication. Combined with natural language barriers, it would not be possible to obtain an internationally representative sample of grey literature. Therefore, lay perspectives have been excluded from this concept analysis. Nevertheless, this concept analysis makes an important contribution to the body of nursing knowledge. Sources were managed in EndNote. Duplicate and irrelevant studies were excluded following a review of titles and abstracts. This resulted in 170 unique publications (Figure 2.3). Eighty-five were randomly selected for review, accounting for 50% of eligible papers, exceeding the 20% recommended by Rodgers (2000a).

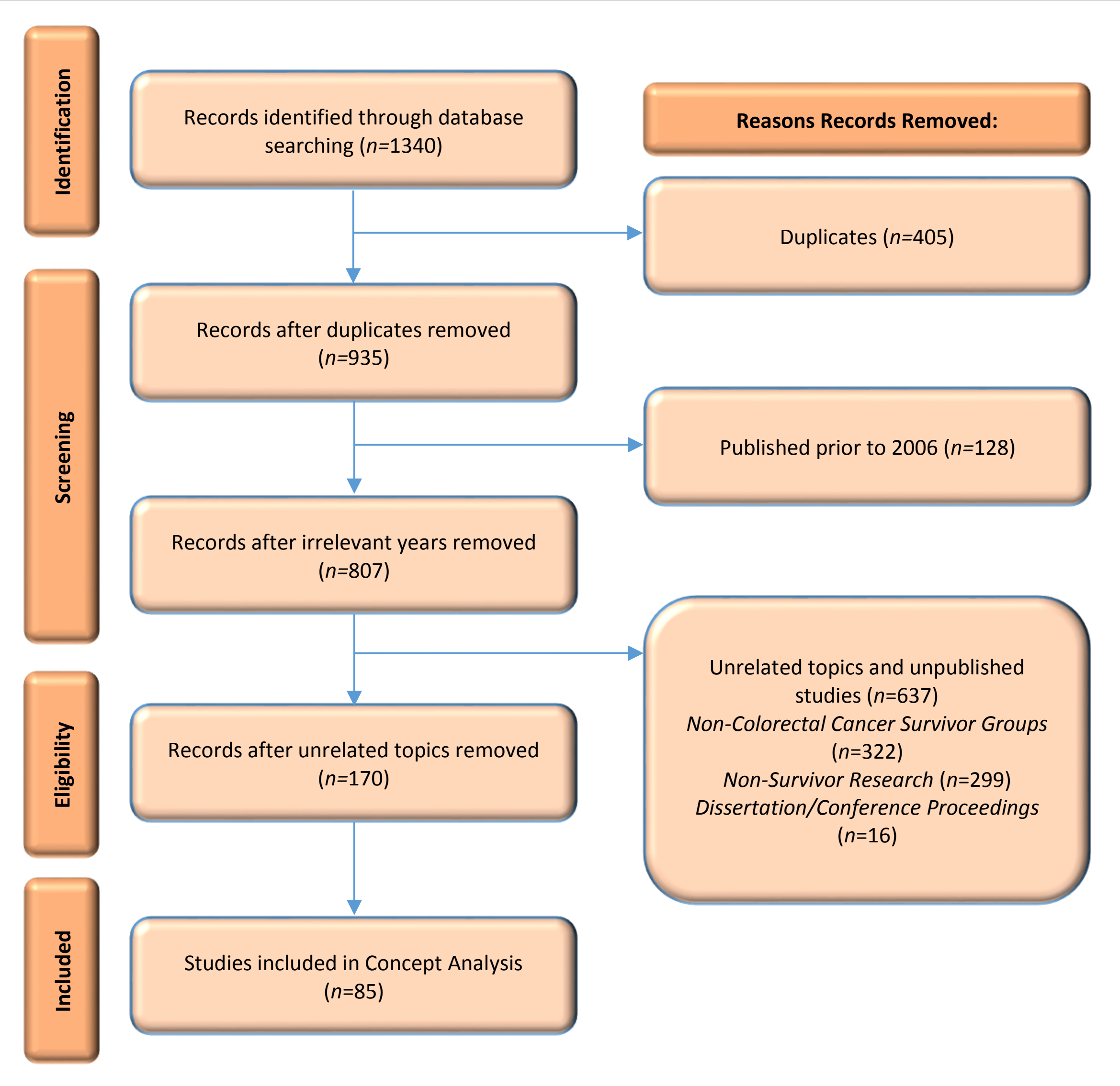


Figure 2.3 Concept analysis Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram

2.2.6 Data Analysis

Thematic analysis of the data was guided by the Braun & Clarke (2006) framework. All included sources were read to gain familiarity with the literature. Included papers were imported to NVivo 10; initial codes were generated and categorised into attributes, antecedents, consequences and referents. The codes within each category were analysed separately to identify potential themes. Codes were organised and reorganised into themes within each category until comprehensive definitions were generated for each category. In keeping with the iterative approach to analysis advocated by Rodgers (1989), the themes were evaluated firstly against the coded extracts and subsequently against the included sources to ensure thematic accuracy and rule out oversight of any additional themes. Finally, the themes were compared to those of Doyle (2008) to establish similarities and differences in the proposed conceptual framework. Annotation, memo and link functions in NVivo 10 were used in conjunction with reflective journaling to ensure critical reflection on the process of data collection and analysis.

2.2.7 Antecedents

The primary antecedent of colorectal cancer survivorship is the staging and diagnosis of a new malignant growth within the tissues of the colon or rectum, which may or may not have a genetic origin. The diagnosis may be preceded by changed bowel habits, including constipation, diarrhoea, or bleeding from the rectum.

2.2.8 Surrogate Terms

Surrogate terms used to describe cancer survivorship include '*living beyond cancer*', '*life after cancer*' and '*living with cancer*'. Terms which are related to cancer survivorship include '*cancer survival*', '*cancer survivor*' and '*remission*'. Although surrogate phrases were deemed suitable alternatives to cancer survivorship, they may fail to encompass survivors who have active disease. The phrases '*living beyond*', '*life after*' and '*living with*' cancer were used in situations where individuals did not wish to identify themselves as cancer survivors (Chambers *et al.* 2012a).

2.2.9 Attributes

The attributes of cancer survivorship identified by Doyle (2008) were used as a framework to present the thematic analysis of the literature pertaining to colorectal cancer survivorship (Table 2.1). The framework is extended with the identification of a further attribute, *Navigating Systems and Resources*. Cancer survivorship in the context of colorectal cancer may be defined as a process which begins at diagnosis, paved with uncertainty, and positive as well as negative experiences. Ultimately, the life-changing experience of illness and recovery are highly individualised, with needs specific to the individual and the experience of colorectal cancer itself. As a result, survivors must become resourceful, learning to navigate the complexities of the healthcare system and the resources available to them.

2.2.9.1 The Process Beginning at Diagnosis

Few published studies define cancer survivorship in the context of their research. Of those who do, most agree cancer survivorship begins at diagnosis, persisting through periods of remission and end of life care (Chambers *et al.* 2012a, McCaughan *et al.* 2012, Appleton *et al.* 2013). However, there are considerable inconsistencies in the timeframe and disease stage inclusion criteria of research studies involving colorectal cancer survivors. Less than half of reviewed studies included colorectal cancer survivors receiving treatment or living with recurrent or metastatic disease (Figure 2.4; Figure 2.5). Few authors explicitly acknowledge diagnosis as the starting point of cancer survivorship, representing the origin of cancer survivorship as a '*transcendence*' or '*transition*' from patient to survivor (Gordon *et al.* 2008, Snyder *et al.* 2008b, Salsman *et al.* 2011, Bains *et al.* 2012, Gordon *et al.* 2012, McCaughan *et al.* 2012, Soerjomataram *et al.* 2012, Appleton *et al.* 2013, Palmer *et al.* 2013). However, survivors themselves recognise the importance of diagnosis and treatment

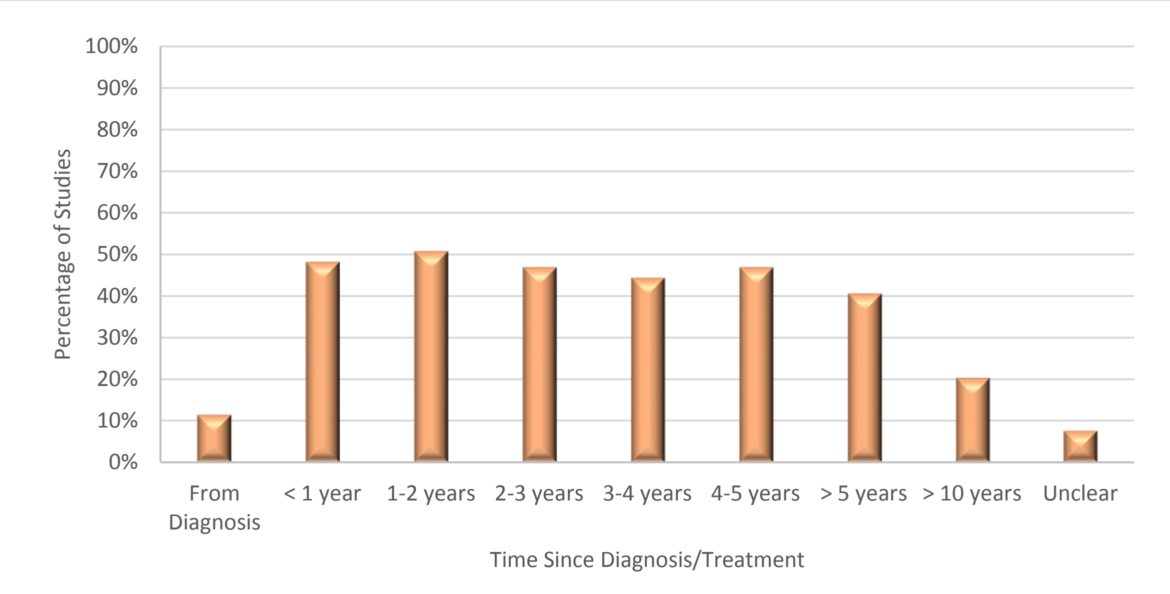


Figure 2.4 Proportion of reviewed studies including colorectal cancer survivors at selected timeframes of survivorship

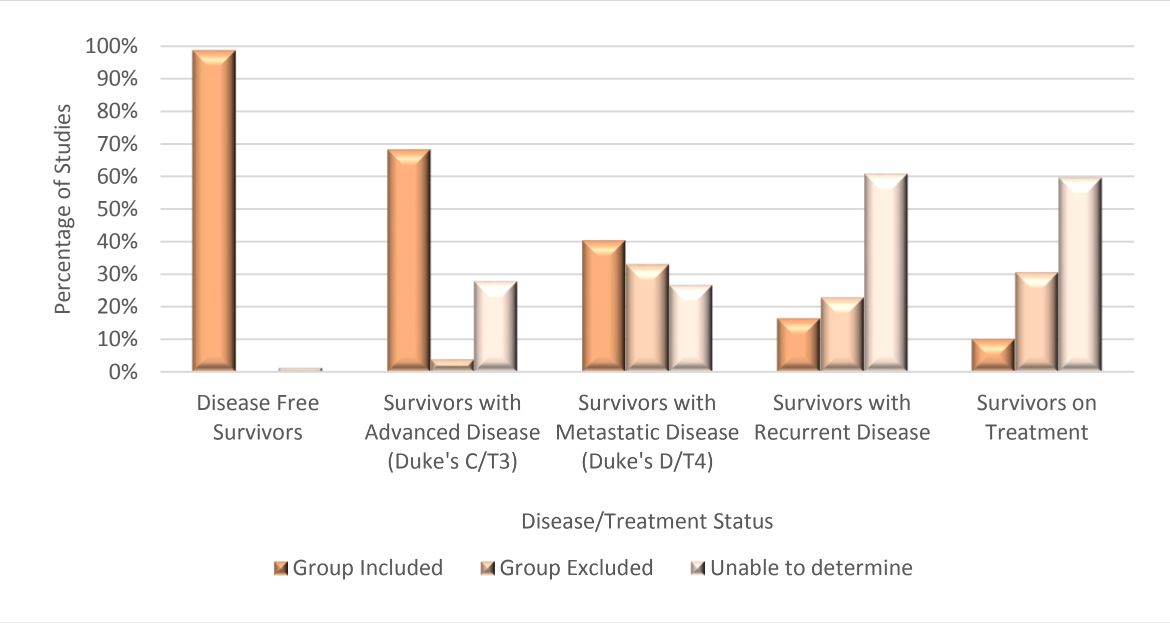


Figure 2.5 Proportion of reviewed studies including colorectal cancer survivors with selected stages of disease

in the continuum of cancer survivorship. Many survivors related the symptoms and difficulties of these periods to their experiences of cancer survivorship (Nikoletti *et al.* 2008, McCaughan *et al.* 2012, Anderson *et al.* 2013, Appleton *et al.* 2013, Palmer *et al.* 2013).

There is consensus that the experience of cancer impacts upon the survivor's remaining life. Survivorship is often described as a process incorporating diagnosis and treatment, progressing into an altered life punctuated by both positive and negative consequences of the disease and its treatment (Chambers *et al.* 2012a, Appleton *et al.* 2013, Palmer *et al.* 2013). The dynamic process of survivorship in colorectal cancer is characterised by multiple mechanisms. Decision-making processes take priority during the diagnosis and treatment phases (Lynch *et al.* 2008b). When treatment is complete, monitoring for recurrence becomes a priority for healthcare professionals (Esplen *et al.* 2007, Cooper *et al.* 2008, Salz *et al.* 2009, Hu *et al.* 2011, Brawarsky *et al.* 2013, Carpentier *et al.* 2013). Meanwhile, the survivor becomes preoccupied with healing, recovery, adjustment, adaptation and coping processes (Esplen *et al.* 2007, Di Fabio *et al.* 2008, Nikoletti *et al.* 2008, Grant *et al.* 2011, Loi 2011, Serpentini *et al.* 2011, Chambers *et al.* 2012b, McCaughan *et al.* 2012, Appleton *et al.* 2013). The recovery process occurs in a manner and pace unique to each individual (Appleton *et al.* 2013). The survivor may engage in post-traumatic growth, using techniques including goal setting, meaning-making and benefit finding to return to, or re-conceptualise '*normal*' life (Nikoletti *et al.* 2008, Salsman *et al.* 2009, Chambers *et al.* 2012a, Soerjomataram *et al.* 2012, Appleton *et al.* 2013, Palmer *et al.* 2013).

2.2.9.2 Uncertainty

Cancer survivors live with a sense of uncertainty from the moment of diagnosis. Bowel dysfunction arising from colorectal cancer treatment is a constant reminder of potential recurrence, as symptoms resemble those experienced before diagnosis (DeSnoo & Faithfull 2006, McCaughan *et al.* 2012, Custers *et al.* 2016). Fear of recurrence may be heightened by inadequate support structures, perceptions of '*abandonment*' by healthcare professionals following treatment, and unexplained deviations from the plan of follow-up care and surveillance (Tofthagen 2010b, McCaughan *et al.* 2012). Survivors may be confronted by the fragility of their survival when a peer experiences recurrence (McCaughan *et al.* 2012). However, the impact of fear of recurrence could be moderated through the adoption of a '*que sera sera*' or '*that's life*' attitude and use of survivorship care plans (McMullen *et al.* 2008, Faul *et al.* 2012, McCaughan *et al.* 2012, Anderson *et al.* 2013).

An ostomy may impact on physical, functional, psychological and social aspects of the survivor's life (Caravati-Jouvenceaux *et al.* 2011, Mols *et al.* 2014). Following ostomy formation, there was a period of trial and error, as survivors learned to cope with altered digestive function and identify appropriate ostomy equipment (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Grant *et al.* 2011, Palmer *et al.* 2013). Survivors spoke of unpredictability when describing the loss of control over the body that came about as a result of the ostomy. Ostomy function varied daily, causing embarrassment and loss of confidence as leakage, incontinence or flatulence from the ostomy were anticipated (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Ramirez *et al.* 2009, Grant *et al.* 2011). Living with an ostomy and the chronic effects of colorectal cancer became a careful balancing act between competing priorities for survivors, as they attempt to resolve the joy of having survived with the sadness of living with the unpredictable, sometimes humiliating consequences of colorectal cancer (McMullen *et al.* 2008).

Survivors may find themselves in a position where they are unable to engage in the work or activities they enjoyed prior to diagnosis due to the physical consequences of colorectal cancer (Gordon *et al.* 2008, Tofthagen 2010b, Domati *et al.* 2011, Grant *et al.* 2011, Thong *et al.* 2011a, McCaughan *et al.* 2012, Sisler *et al.* 2012b, Anderson *et al.* 2013, Hanly *et al.* 2013). The precarious nature of employment caused survivors financial distress, in turn, contributing to poorer psychological well-being (Gordon *et al.* 2008, Baravelli *et al.* 2009, Lundy *et al.* 2009, Grant *et al.* 2011). Furthermore, employment insecurity may result in some colorectal cancer survivors concealing the extent of their disease and risk of recurrence. More than two-thirds indicated they would not inform their employer or health insurance company if they were diagnosed with a hereditary form of colorectal cancer (Esplen *et al.* 2007).

Up to two-thirds of colorectal cancer survivors wish to undergo genetic screening, as they believe it may assist them in planning for their future healthcare, family planning and life enjoyment (Cragun *et al.* 2012). However, the prospect of having a hereditary form of colorectal cancer caused clinically significant symptoms of anxiety and depression in almost two-fifths of colorectal cancer survivors (Esplen *et al.* 2007). Furthermore, survivors revealed difficulties disseminating information about genetic risk to family members, as they struggled with guilt and worry about the risk of cancer for their off-spring (Esplen *et al.* 2007).

The process of survivorship occurs parallel to the normal ageing process (Phipps *et al.* 2008, Ramirez *et al.* 2009, McCaughan *et al.* 2012). Up to four-fifths of colorectal cancer survivors experience co-morbid health conditions, which may be more limiting than living with an ostomy or colorectal cancer for some (McMullen *et al.* 2008, Phipps *et al.* 2008, Soerjomataram *et al.* 2012, Anderson *et al.* 2013, Palmer *et al.* 2013). As a result, colorectal cancer survivors describe difficulties attributing physical and psychosocial symptoms to the experience of cancer, rather blaming age or co-morbidity (Ramirez *et al.* 2009, McCaughan *et al.* 2012).

2.2.9.3 Life-Changing Experience

Colorectal cancer survivors' quality of life may be negatively influenced by the presence of an ostomy, levels of physical activity and the experience of chronic symptoms including pain, fatigue, anxiety, sexual dysfunction and changes in bowel habit, with some variation in these effects between genders (Lynch *et al.* 2007b, Di Fabio *et al.* 2008, Lynch *et al.* 2008a, Peddle *et al.* 2008a, Krouse *et al.* 2009, Ristvedt & Trinkaus 2009, Domati *et al.* 2011, Lynch *et al.* 2011, Chambers *et al.* 2012b, Milbury *et al.* 2013, Thraen-Borowski *et al.* 2013, Sun *et al.* 2015). Despite this, survivors rate their health and quality of life positively, in some cases improving over time to levels comparable to normative populations among long-term survivors (Di Fabio *et al.* 2008, Phipps *et al.* 2008, Ristvedt & Trinkaus 2009, Steginga *et al.* 2009, Caravati-Jouvenceaux *et al.* 2011, Jansen *et al.* 2011a, Serpentini *et al.* 2011, Thong *et al.* 2011a, Thong *et al.* 2011b, Chambers *et al.* 2012a, Chambers *et al.* 2012b, Soerjomataram *et al.* 2012). Several authors suggest positive ratings of quality of life are a consequence of response shift or positive reframing. Although some survivors struggle to come to terms with bodily changes and chronic treatment effects, many are capable of remarkable resilience, reframing the experience of symptoms or presence of an ostomy over time (McMullen *et al.* 2008, McCaughan *et al.* 2012, Palmer *et al.* 2013). Survivors may identify positive consequences of cancer, including appreciation for life, gratitude, strengthening of relationships, changing priorities and hope for the future (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Ramirez *et al.* 2009, Grant *et al.* 2011, Appleton *et al.* 2013). For many, the new normal of bodily function were things to adapt to and live with, and were better than possible alternatives to their situation, such as more aggressive types of cancer and treatment or death (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Ramirez *et al.* 2009, McCaughan *et al.* 2012, Appleton *et al.* 2013).

The diagnosis of colorectal cancer and the implications of treatment were a considerable upheaval in a survivor's life (Appleton *et al.* 2013, Palmer *et al.* 2013). As survivors overcome the diagnosis and treatment periods, the perceived threat to life reduces, and the individual's identity transcends that of patient. The individual may either adopt the identity of survivor or avoid an illness-related identity entirely; instead conceptualising themselves as a person who had cancer (Chambers *et al.* 2012a). The transition in self-identity is unique to each survivor, occurring within a dichotomy of positive and negative experiences (Appleton *et al.* 2013). As colorectal cancer survivors begin to re-evaluate their lives in the aftermath of a life-threatening event, they may appreciate life more than a person who did not have such a life experience, feel psychologically stronger for having endured illness, and have an altruistic desire to give back through peer support, advising healthcare professionals and engaging in research (Baravelli *et al.* 2009, Tofthagen 2010b, Grant *et al.* 2011, Loi 2011, Serpentini *et al.* 2011, McCaughan *et al.* 2012, Appleton *et al.* 2013, Palmer *et al.* 2013, Ho *et al.* 2015).

2.2.9.4 Duality of Positive and Negative Aspects

Adjusting to the period of cancer survivorship is fraught with challenges arising from the complications and long-term effects of colorectal cancer and its treatment and required colorectal cancer survivors to make changes in their lives. Changes in lifestyle are positive and necessary to regain health, enhance life and reduce stress (Pullar *et al.* 2012, Anderson *et al.* 2013, Palmer *et al.* 2013). However, where a colorectal cancer survivor believed they had led a relatively healthy life before diagnosis, lifestyle changes were not considered a helpful behaviour (Mols *et al.* 2012a, Anderson *et al.* 2013). Thus, changes in lifestyle were made with a degree of uncertainty, accompanied by conflicting or confusing information (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Haggstrom *et al.* 2009, Anderson *et al.* 2013).

Although heavy smoking or alcohol intake among colorectal cancer survivors is infrequent, many survivors fail to meet physical activity, body mass index and fruit and vegetable intake recommendations (James *et al.* 2006, Lynch *et al.* 2007a, Hawkes *et al.* 2008, Lynch *et al.* 2008c, Peddle *et al.* 2008a, Peddle *et al.* 2008b, Johnson *et al.* 2009, Wijndaele *et al.* 2009, Grimmett *et al.* 2011, Chambers *et al.* 2012a, Chambers *et al.* 2012b, Pullar *et al.* 2012, Speed-Andrews *et al.* 2012, McGowan *et al.* 2013, Speed-Andrews *et al.* 2013, Thraen-Borowski *et al.* 2013). Achieving recommended levels of physical activity may be difficult if the survivor is experiencing chronic effects of disease, treatment or co-morbidities (Lynch *et al.* 2007a, Hawkes *et al.* 2008, Lynch *et al.* 2008c, Chambers *et al.* 2009, Anderson *et al.* 2013, Palmer *et al.* 2013). Changes in diet are as much to do with attaining a sense of control over bowel function or ostomy output, as it is to control the disease trajectory and prevent recurrence (Esplen *et al.* 2007, McMullen *et al.* 2008, Nikoletti *et al.* 2008, Grant *et al.* 2011, Pullar *et al.* 2012, Anderson *et al.* 2013, Palmer *et al.* 2013, Sun *et al.* 2015). Bowel control is a significant challenge for colorectal cancer survivors, and a systematic regime of medication, dietary management and self-devised management strategies are developed by survivors to manage bowel dysfunction (DeSnoo & Faithfull 2006, Nikoletti *et al.* 2008, Grant *et al.* 2012, Sun *et al.* 2015).

Survivors may outgrow the identity of cancer patient but continue to have difficulties re-integrating to normal life (McCaughan *et al.* 2012, Palmer *et al.* 2013). Returning to normal was a major goal for many colorectal cancer survivors, but unfortunately, it was not always possible due to changes in bodily function (DeSnoo & Faithfull 2006, McCaughan *et al.* 2012, Palmer *et al.* 2013). Rather, survivors described an evolving '*new normal*' from the limbo experienced at the end of treatment, becoming accustomed to persistent side-effects or formation of an ostomy. This new normal required colorectal cancer survivors to follow a steep learning curve and develop new coping strategies (McMullen *et al.* 2008, McCaughan *et al.* 2012). Gendered differences in adjustment and need for support were identified by Grant *et al.* (2011) and McCaughan *et al.* (2012). However, the effect of gender remains debatable. Males tend to downplay symptom effects, support needs and challenges with adjustment, while females admit difficulties with adjustment, but develop strategies to manage symptoms and minimise their impact (Grant *et al.* 2011, McCaughan *et al.* 2012). Despite qualitative studies suggesting male survivors adopt more stoic attitudes to physical and psychosocial issues, quantitative research indicates males may in fact suffer greater distress, have poorer coping skills and experience worse social well-being than their female counterparts (Goldzweig *et al.* 2009, Ristvedt & Trinkaus 2009, Au *et al.* 2012b).

The societal de-stigmatisation of cancer assists survivors to return to conventional daily life within the constraints of their new normality. Individuals felt the increased public awareness of cancer and greater opportunity to openly discuss cancer fostered hope (Appleton *et al.* 2013). However, colorectal cancer remains a taboo subject, not just because it is perceived to be a disease of lifestyle

(Anderson *et al.* 2013), but because there is a societal aversion to faeces (Ramirez *et al.* 2009). Survivors feel it is inappropriate to discuss the consequences of the disease openly, instead using euphemisms to describe their cancer, its treatment and side-effects (DeSnoo & Faithfull 2006). This stigma is heavily intertwined with the idea of '*hiding away*'. Aside from dietary changes, colorectal cancer survivors felt the presence of an ostomy impacted upon their ability to engage in physical and social activities and significantly impacted upon their body image (McMullen *et al.* 2008, Grant *et al.* 2011, Loi 2011, McCaughan *et al.* 2012, Mols *et al.* 2014). Hiding away involved a process of concealing the ostomy or avoiding situations where their ostomy may be seen by others (McMullen *et al.* 2008, Ramirez *et al.* 2009). Hiding away extended to include colorectal cancer survivors who experienced difficulties with bowel dysfunction. Such survivors spoke about the isolation and avoidance of social activities which resulted from erratic changes to bowel patterns and loss of bowel control (DeSnoo & Faithfull 2006, Grant *et al.* 2011). Hiding away impacted upon survivors' relationships with spouses, family members and friends. Furthermore, the need to be close to toilet facilities to avoid accidents and embarrassment limited survivors' ability to travel and engage in daily activities (DeSnoo & Faithfull 2006, Nikoletti *et al.* 2008, Krouse *et al.* 2009, Grant *et al.* 2011, Loi 2011, McCaughan *et al.* 2012).

The frequency of sexual activity declined for over one-third of colorectal cancer survivors, a consequence of sexual dysfunction and negative body image (Ramirez *et al.* 2009, Ellis *et al.* 2010, Domati *et al.* 2011). For those who experienced difficulties with body image and sexuality, they sought to hide away by withdrawing from, avoiding or altering approaches to sexual intimacy, circumventing perceived embarrassment or vulnerability (McMullen *et al.* 2008, Altschuler *et al.* 2009, Ramirez *et al.* 2009, Grant *et al.* 2011). Such strategies contributed to a sense of loss for colorectal cancer survivors. However, this loss could be mediated in some circumstances by identifying alternative self-management strategies, being grateful for life and having a supportive family or spouse (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Ramirez *et al.* 2009, Au *et al.* 2012b, Chambers *et al.* 2012b). Indeed, having an empathetic, supportive spouse was crucial to colorectal cancer survivors' psychosocial adjustment to having an ostomy (Altschuler *et al.* 2009, Goldzweig *et al.* 2009).

Survivors gained confidence by learning to manage bowel dysfunction and other symptoms over time and regaining some aspects of their normal life before cancer (DeSnoo & Faithfull 2006, McCaughan *et al.* 2012). Building confidence entailed identifying patterns in bowel function, making changes in lifestyle and seeking information (McCaughan *et al.* 2012). Goal setting was integral to this process of rebuilding and regaining, bringing survivors a sense of hope, and allowing them to evaluate their progress toward their goals (Anderson *et al.* 2013, Appleton *et al.* 2013, Palmer *et al.* 2013).

2.2.9.5 Individual Experience of Illness and Recovery

Each survivor experiences the process of diagnosis, treatment and recovery uniquely, depending on their coping mechanisms and support structures (McCaughan *et al.* 2012). The transition from life during treatment to life after treatment brings various challenges for each survivor, and the rate at which each individual recovers from and adjusts to these challenges is variable (McCaughan *et al.* 2012, Appleton *et al.* 2013). The idea of '*normality*' after cancer treatment varied substantially, ranging from a desire to return to prior form or devise a new normality. Factors influencing normality are diverse and heavily influence survivors' confidence and growth. These factors include the type and severity of symptoms experienced, and the success and acceptability of self-management strategies employed to regain control of bodily functions (DeSnoo & Faithfull 2006, Grant *et al.* 2011, Bains *et al.* 2012).

Colorectal cancer survivors may experience disparity in care and health outcomes due to ethnicity, age and access to health insurance, adding a further facet to the individual experience of colorectal cancer survivorship (Schneider *et al.* 2007, Haggstrom *et al.* 2009, Steginga *et al.* 2009, Chambers *et al.* 2012b). Similar to other groups of cancer survivors, the timing, need and ability to process cancer-related information is highly individualised; however, healthcare professionals do not always tailor responses to survivor's circumstances (Baravelli *et al.* 2009, Anderson *et al.* 2013). Despite these challenges, resilience and the ability to re-appraise one's life may allow some survivors to appreciate life, in some cases to a greater degree than one who had not experienced cancer (Serpentini *et al.* 2011).

2.2.9.6 Navigating Systems and Resources

Upon diagnosis of colorectal cancer, survivors must learn how to navigate the healthcare system. However, the multitude of healthcare providers, variance in models of care provision and fragmentation of healthcare meant this could be a protracted and complex experience (Snyder *et al.* 2008a, 2008b, Baravelli *et al.* 2009, Haggstrom *et al.* 2009, Gordon *et al.* 2012, Sisler *et al.* 2012b). Survivors may attend multiple physicians for follow-up care, including a medical oncologist, a radiation oncologist, a surgeon, a gastroenterologist and a primary care practitioner, each with different objectives for survivorship care (Baravelli *et al.* 2009, Haggstrom *et al.* 2009). The complexity of the process means that some colorectal cancer survivors fall through the cracks of follow-up; as many as one-quarter do not believe they are receiving cancer-related follow-up care (Haggstrom *et al.* 2009). The difficulty experienced by colorectal cancer survivors in managing and navigating follow-up is further highlighted by Gordon *et al.* (2012), as more than half had difficulty accurately recalling medical appointments over the past six months.

There is a substantial risk that surveillance for cancer recurrence may be prioritised above the management of chronic effects and provision of information and support to survivors (Di Fabio *et* *al.* 2008, Phipps *et al.* 2008, Tofthagen 2010b). Haggstrom *et al.* (2009) report that just seven percent of colorectal cancer survivors attended a medical professional for management of side-effects, compared to 85% who attend for follow-up tests. Inadequate support and symptom management by healthcare professionals result in survivors experiencing confusion (Tofthagen 2010b). Where support from healthcare professionals is inadequate, colorectal cancer survivors believe they must be responsible for their health at the end of treatment and try to devise self-management strategies and self-sufficiency in the absence of medical support (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Grant *et al.* 2011, Palmer *et al.* 2013). On the other hand, egalitarian relationships between healthcare professionals and the survivor eased the complexity of managing residual effects, developing self-management strategies and navigating follow-up care (Appleton *et al.* 2013, Palmer *et al.* 2013). Egalitarian relationships were characterised by ease of access to information and open communication between the survivor and healthcare professional (Appleton *et al.* 2013).

A significant theme in the period following treatment is the met and unmet needs of colorectal cancer survivors. Survivors experienced a broad range of health, information and support needs arising from colorectal cancer. Specific support and information needs for colorectal cancer survivors related to the management of the ostomy and altered bowel function. Diet and lifestyle advice were particularly prominent needs within the reviewed literature, as survivors express frustration about conflicting or confusing information and the trial and error approach to symptom management advocated by healthcare professionals (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Haggstrom *et al.* 2009, Pullar *et al.* 2012, Anderson *et al.* 2013, Ho *et al.* 2015, Sanoff *et al.* 2015). General needs reflect those of the heterogeneous population of cancer survivors relating to the psychological and social consequences of cancer. Few colorectal cancer survivors are explicitly asked about their emotional well-being in the aftermath of treatment, though most find such enquiry useful (Baravelli *et al.* 2009). Furthermore, colorectal cancer survivors highlight difficulties accessing specialist psychological support for both themselves and their family members (Grant *et al.* 2011, Anderson *et al.* 2013). The timing of support and information is crucial, but the point at which the survivor is ready to process such information is highly individualised (Nikoletti *et al.* 2008, Haggstrom *et al.* 2009, Anderson *et al.* 2013).

As colorectal cancer survivors enter the post-treatment period, the frequency of contact with healthcare professionals reduces, thus the level of support diminishes (Tofthagen 2010b, McCaughan *et al.* 2012). Unfortunately, some survivors may not benefit from, or desire to be involved in cancer support groups due to difficulty discussing bowel-related concerns in a general cancer support forum because of embarrassment or lack of sensitivity from others (McMullen *et al.* 2008, Baravelli *et al.* 2009, McCaughan *et al.* 2012). Despite these issues, colorectal cancer survivors demonstrate particular resourcefulness in securing information and support outside the hospital environment, using telephone helplines, information booklets, internet resources, cancer peer support, counselling, complementary/alternative medicine and family support (Lawsin *et al.* 2007, McMullen *et al.* 2008, Nikoletti *et al.* 2008, Ramirez *et al.* 2009, Stein *et al.* 2009, Tofthagen 2010b, McCaughan *et al.* 2012, Anderson *et al.* 2013, Appleton *et al.* 2013).

2.2.10 Consequences

In keeping with the framework of Doyle (2008), the consequences of colorectal cancer survivorship are presented in relation to physical, psychological, social and spiritual health, and an additional theme, *the Constellation of Met and Unmet Survivorship Needs*. Quality of life is a central concept to the consequences of colorectal cancer survivorship. Although quality of life and the burden of chronic symptoms may improve over time, it remains that survivors continue to experience significant challenges in the years following diagnosis and treatment.

2.2.10.1 Physical Health

Colorectal cancer survivors experience an abundance of physical effects as a direct result of cancer and its treatment. Those who survive colorectal cancer live with physical symptoms arising from chemotherapy, bowel surgery and pelvic radiotherapy. Like other tumour groups, colorectal cancer survivors may experience pain, sleep disturbance and fatigue (Schneider *et al.* 2007, Peddle *et al.* 2008a, Phipps *et al.* 2008, Stein *et al.* 2009, Domati *et al.* 2011, Grant *et al.* 2011, Grimmett *et al.* 2011, Jansen *et al.* 2011a, Shun *et al.* 2011, Thong *et al.* 2011b, McCaughan *et al.* 2012, Sisler *et al.* 2012b, Anderson *et al.* 2013, Thong *et al.* 2013). However, side-effects particular to colorectal cancer survivorship include weight changes, sexual dysfunction (erectile problems, vaginal dryness, dyspareunia), upper gastrointestinal disturbances (food intolerance, nausea, vomiting, loss of appetite) and bowel dysfunction (constipation, diarrhoea, abdominal cramping, flatulence, incontinence, urgency, frequency) (Schneider *et al.* 2007, Di Fabio *et al.* 2008, Lynch *et al.* 2008b, McMullen *et al.* 2008, Nikoletti *et al.* 2008, Phipps *et al.* 2008, Ramirez *et al.* 2009, Ristvedt & Trinkaus 2009, Ellis *et al.* 2010, Caravati-Jouvenceaux *et al.* 2011, Grant *et al.* 2011, Grimmett *et al.* 2011, Jansen *et al.* 2011a, Serpentini *et al.* 2011, Thong *et al.* 2011a, Thong *et al.* 2011b, Den Oudsten *et al.* 2012, Sisler *et al.* 2012b, Anderson *et al.* 2013, Milbury *et al.* 2013, Bailey *et al.* 2015, Sanoff *et al.* 2015, Verhaar *et al.* 2015). Colorectal cancer survivors report difficulties with peripheral neuropathy, an irreversible effect of chemotherapy, which causes pain, paraesthesia and cramping of the hands and feet, affecting survivors' mobility and daily activities (Tofthagen 2010b, Palmer *et al.* 2013, Ho *et al.* 2015, Padman *et al.* 2015, Sanoff *et al.* 2015). In addition, those who lived with an ostomy as a consequence of cancer survival were more likely to experience a hernia and skin care issues at the ostomy site (pain, irritation, rash and fungal infection) (Lynch *et al.* 2008b, McMullen *et al.* 2008, Hornbrook *et al.* 2011).

2.2.10.2 Psychological Health

The psychological consequences of cancer survivorship are significant; fear of recurrence, depression, anxiety and distress are enduring issues for some survivors, heightened around the time of clinical appointments (Esplen *et al.* 2007, Lawsin *et al.* 2007, Schneider *et al.* 2007, Lynch *et al.* 2008c, Nikoletti *et al.* 2008, Phipps *et al.* 2008, Krouse *et al.* 2009, Ristvedt & Trinkaus 2009, Stein *et al.* 2009, Loi 2011, Shun *et al.* 2011, Chambers *et al.* 2012b, Faul *et al.* 2012, McCaughan *et al.* 2012, Appleton *et al.* 2013, Dunn *et al.* 2013b, Milbury *et al.* 2013, Thong *et al.* 2013). The physical effects of colorectal cancer treatment, including bowel dysfunction and peripheral neuropathy, had significant negative effects on colorectal cancer survivors' psychological well-being, body image and adaptation to survivorship (DeSnoo & Faithfull 2006, Schneider *et al.* 2007, McMullen *et al.* 2008, Phipps *et al.* 2008, Tofthagen 2010b, Serpentini *et al.* 2011, Thong *et al.* 2011b, Palmer *et al.* 2013, Bailey *et al.* 2015, Ho *et al.* 2015, Padman *et al.* 2015). Despite these consequences, some survivors undergo post-traumatic growth. Many learn to cope with the effects of cancer therapy to the extent where they may no longer consider them major problems, eventually becoming more comfortable with their body image, and deriving strength and resilience from the experience of cancer (Thong *et al.* 2011b, McCaughan *et al.* 2012, Appleton *et al.* 2013).

2.2.10.3 Social Health

The themes of isolation and hiding away were particularly salient to social well-being. Colorectal cancer survivors may experience poorer social well-being, particularly in the first five years following treatment, worsened by changes in employment, financial concerns, inadequate support, symptom distress and the presence of an ostomy or bowel dysfunction (Gordon *et al.* 2008, Baravelli *et al.* 2009, Krouse *et al.* 2009, Ristvedt & Trinkaus 2009, Steginga *et al.* 2009, Tofthagen 2010b, Caravati-Jouvenceaux *et al.* 2011, Domati *et al.* 2011, Grant *et al.* 2011, Jansen *et al.* 2011a, Shun *et al.* 2011, Thong *et al.* 2011a, McCaughan *et al.* 2012, Anderson *et al.* 2013, Hanly *et al.* 2013). As a consequence of the physical effects of colorectal cancer, many survivors reduced their social activities to avoid potential embarrassment and inconvenience in a public place (McMullen *et al.* 2008, Loi 2011, McCaughan *et al.* 2012). Attending social events required careful preparation, therefore toilet mapping and menu planning were important behaviours undertaken to avoid accidents and embarrassment (DeSnoo & Faithfull 2006, Nikoletti *et al.* 2008). The physical and psychological effects of treatment impacted upon survivors' sexual relationships, particularly for females, as some avoided intimacy due to pain and fear of reaction from their partner (McMullen *et al.* 2008, Krouse *et al.* 2009, Ramirez *et al.* 2009, Grant *et al.* 2011, Milbury *et al.* 2013). However, this was not a problem for all survivors, as some expressed gratitude for being alive and having a supportive family or spouse (Nikoletti *et al.* 2008, Ramirez *et al.* 2009, Chambers *et al.* 2012b).

2.2.10.4 Spiritual Health

The uncertainty brought about by colorectal cancer survivorship has a unique effect on survivors' spirituality. Religiosity assists some survivors to cope with the process of survivorship and is associated with more positive quality of life (Loi 2011, Salsman *et al.* 2011). As survivors come to terms with a new normal, they have an opportunity to reappraise their lives, finding new meaning and benefits in survivorship (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Ramirez *et al.* 2009, Domati *et al.* 2011, Appleton *et al.* 2013). Finally, survivors may develop a desire to give back to the healthcare services by providing peer support and assisting healthcare professionals in research (Tofthagen 2010b, Grant *et al.* 2011, Loi 2011, McCaughan *et al.* 2012, Appleton *et al.* 2013, Palmer *et al.* 2013).

2.2.10.5 The Constellation of Met and Unmet Survivorship Needs

Survivors develop a constellation of health, information and support needs as a result of the experience of colorectal cancer. Survivors face new challenges specific to the nature of their disease, encompassing bowel management, ostomy care, health promotion, diet and lifestyle advice; each requiring significant practical and psychological support to facilitate adjustment (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Haggstrom *et al.* 2009, Pullar *et al.* 2012, Anderson *et al.* 2013, McGowan *et al.* 2013, Ho *et al.* 2015). Other unmet information and healthcare needs were similar to those of survivors of other forms of cancer, and included information about diagnosis, investigations, treatments, prognosis, medication management, surveillance, follow-up care, genetic risk, management of chronic side-effects, return to work, financial concerns and who to contact should cancer-related problems arise (Esplen *et al.* 2007, Nikoletti *et al.* 2008, Baravelli *et al.* 2009, Tofthagen 2010b, Vadaparampil *et al.* 2010, Bains *et al.* 2012, Faul *et al.* 2012, Sisler *et al.* 2012b).

Colorectal cancer survivors may feel that information and support needs are not adequately met by healthcare professionals due to reduced contact with healthcare staff following treatment (Phipps *et al.* 2008, Haggstrom *et al.* 2009, Tofthagen 2010b, Grant *et al.* 2011, McCaughan *et al.* 2012, Sisler *et al.* 2012b, Palmer *et al.* 2013). The psychological needs of the survivor may be overlooked due to prioritisation of cancer surveillance activities (Di Fabio *et al.* 2008, Baravelli *et al.* 2009). As a result, survivors may become resourceful, identifying alternative sources of support and information outside the healthcare environment (Nikoletti *et al.* 2008, Anderson *et al.* 2013). Though the quality of these resources may be questionable, survivors may feel they are left with little option but to pursue such information resources, particularly if they are encouraged to follow trial and error approaches to symptom management (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Grant *et al.* 2011, Anderson *et al.* 2013, Palmer *et al.* 2013).

2.2.11 References

Colorectal cancer survivorship may be used to describe the experiences of any individual who has received a diagnosis of colorectal cancer, whether cured or living with a terminal diagnosis. Survivorship affects the individual, their families, friends and the healthcare professionals responsible for diagnosis, treatment, disease surveillance and management of cancer-related issues.

2.2.12 Related Concepts

Quality of life remains one of the most commonly used related concepts within the cancer survivorship literature. However, other concepts used in relation to colorectal cancer survivorship include "*health behaviour*", "*illness perception*", "*symptom burden*", "*survivor identity*", "*psychological distress*", "*post-traumatic stress"*, "*coping*", "*adaptation*", "*adjustment*", "*continuity of care*" and "*unmet need*". Although each of these concepts reflect attributes of colorectal cancer survivorship, they fail to fully encompass the diverse, individual and dynamic nature of the experience.

2.2.13 Model Case

Where a model case possessing all attributes of the concept is identified rather than constructed, the clarification of the concept is enriched. However, selecting a model case in the context of colorectal cancer may introduce potential bias, as it would require the selection of an individual with colon or rectal cancer, thereby failing to fully embody the concept.

2.2.14 Discussion

Historically, cancer survivorship was considered the timeframe one could expect to live after cancer. As oncology professionals sought to increase survival rates, the management of survivorship issues was not prioritised. At the time of Doyle (2008), cancer survivorship was a relatively immature concept garnering greater awareness within the public eye and empirical literature. As cancer survival rates have improved over the past two decades, cancer survivorship has evolved to become more than a measure of time. Reuben (2004) and IoM (2006) have facilitated an expansion in the focus of cancer survivorship research to encompass the survivor, their quality of life and their needs in the aftermath of treatment, as well as epidemiological concerns of survival, morbidity and mortality.

This concept analysis has demonstrated that the attributes and consequences of cancer survivorship within the context of colorectal cancer are ultimately a fine balance between positive and negative effects. Like general populations of cancer survivors, colorectal cancer survivors also experience survivorship as an individualised, life-changing process beginning at diagnosis, paved with uncertainty and duality of positive and negative outcomes which impact upon the physical, psychological, social and spiritual domains of well-being (Farmer & Smith 2002, Doyle 2008). However, within these attributes, there are an abundance of experiences specific to colorectal cancer due to the site of disease and the consequences of its treatment. Unlike Farmer & Smith (2002) and Doyle (2008), fertility issues were not a significant concern in colorectal cancer survivorship due to age-related factors. However, colorectal cancer survivors must adjust to the distinct challenges presented within the themes of loss of control and hiding away which result from bowel dysfunction and ostomy formation. Survivors experience an array of needs to understand their newfound situation as colorectal cancer survivors, and some may eventually experience an altruistic drive to share their experiences and management strategies for the benefit of other survivors and the healthcare professionals who care for them.

This concept analysis is limited by the exclusion of anecdotal and lay literature and non-English publications. Furthermore, much of the literature reports European, Australian and North American perspectives. Therefore, the generalisability of these findings may be limited. However, this is the first concept analysis which situates the concept of cancer survivorship in the context of colorectal cancer. This study highlights the evolution of cancer survivorship, extending the concept to include the attribute, *Navigation of Systems and Resources*, and the consequence, *The Constellation of Met and Unmet Needs* (Figure 2.6). This will be discussed further in Section 2.3.4.

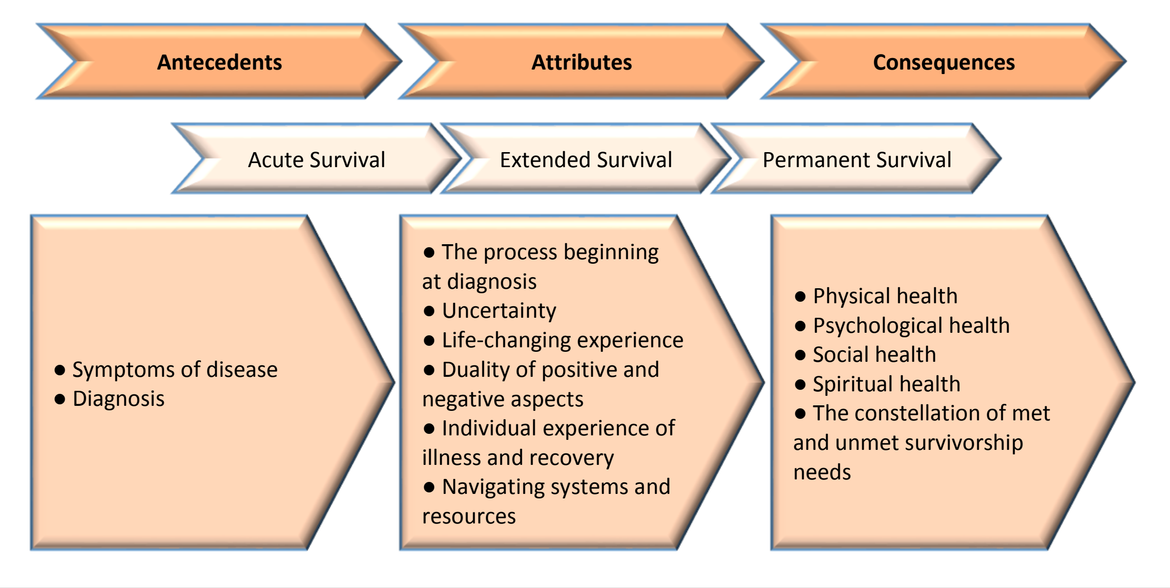


Figure 2.6 Antecedents, attributes and consequences of cancer survivorship in the context of colorectal cancer

Becoming self-sufficient in managing the after-effects of colorectal cancer and regaining a sense of normality are important goals of colorectal cancer survivors' recovery. However, unmet health and information needs are substantial barriers to these objectives. It is imperative that healthcare professionals endeavour to meet colorectal cancer survivors' information and healthcare needs in an individualised manner. This may be achieved through a variety of interventions, including personalised survivorship care plans, treatment summaries, or a consultation at the end of treatment to provide information about survivorship issues and facilitate healthcare navigation in survivorship. Given the consequential importance of quality of life to colorectal cancer survivorship, and its conceptual significance in the current study, the next section of this chapter will discuss the emergence and development of quality of life, its theoretical underpinnings and application within the current study.

2.3 Quality of Life

In keeping with previous concept analysis by Doyle (2008) and Farmer & Smith (2002), the concept analysis indicates that quality of life continued to be a central consequence of cancer survivorship, as survivors experienced significant physical, psychological and social challenges. The current section provides an overview of the concept of quality of life and positions the current study in relation to conceptual and theoretical models which inform its study. Specifically, the section discusses the development (Section 2.3.1) and operationalisation of quality of life in social and healthcare research (Section 2.3.2) and the conceptual models which underpin such research (Section 2.3.3). The section concludes with a summary of the theoretical framework which informs and guides the current study (Section 2.3.4).

2.3.1 The Emergence and Development of Quality of Life Indicators

The concept of quality of life has developed from the social indicators movement and research of social trends in the USA which began in the 1930s (Noll 2004). In the 1960s, American quality of life research focused on subjective well-being and evaluating the individual's perception of social conditions (e.g. happiness and satisfaction) (Rapley 2003, Noll 2004). Meanwhile, European research favoured objective measures of societal quality of life as a whole (e.g. health and unemployment) (Rapley 2003). By the 1980s, researchers such as Calman (1984) sought to reconceptualise quality of life as the correspondence between life expectation and life reality, or '*Gap Theory*'. Health-related quality of life emerged as an independent concept with five dimensions, physical health, mental health, social functioning, role functioning and general health (Ware 1987). However, spiritual well-being is also considered a dimension of quality of life in some contexts (World Health Organisation [WHO] 1998). Ultimately, quality of life has varying meanings for individuals and groups and is defined by the WHO (1995, p.1043) as an:

> *"Individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."*

2.3.2 Quality of Life Measurement

As the concept of quality of life has evolved over the past half-century, much debate has taken place as to whether quality of life should be evaluated subjectively or objectively. Although improvements in objective measures such as survival and mortality indicate medical advances, they fail to capture the health problems which accompany chronic disease and ageing (Ware 1987). Subjective measures of health-related quality of life are considered the most valid means of evaluation, as healthcare professionals may perceive an individual's quality of life more negatively or fail to identify what is truly important to an individual when evaluating quality of life (Slevin *et al.* 1988, Meeberg 1993, Hayhurst *et al.* 2014). A mixed methods approach to the evaluation of quality of life may be complimentary, as interview data can be used to interpret the results of standardised subjective quality of life measures, ascertaining the needs and experiences of colorectal cancer survivors in relation to their quality of life, and provide a fuller and more meaningful understanding of survivors' quality of life outcomes (Tomotake *et al.* 2006, McCabe *et al.* 2008).

Despite the lack of consensus on what constitutes quality of life, there has been a proliferation of generic, disease- and population-specific instruments to measure quality of life and health-related outcomes with little effort to standardise such instruments (Garratt *et al.* 2002, McCabe *et al.* 2008). Generic surveys are designed to capture an individual's broad experience of their health, while disease-specific instruments are sensitive to concerns particular to the disease under study. Concerns surrounding healthcare professionals' ability to objectively assess quality of life result in the growing use of patient-reported outcome measures (PROMs) to assess treatment effectiveness in clinical trials and clinical practice (MacLeod *et al.* 1998, Fayers & Machin 2013). PROMs evaluate clinical, humanistic and economic outcomes (Kozma *et al.* 1993). Humanistic outcomes focus on quality of life issues including physical, psychological, social and functional concerns, symptom experience and self-rated health (Fayers & Machin 2013). It is thought that the use of PROMs in healthcare could enhance the patient voice in directing healthcare improvements, placing a stronger emphasis on patient-led decision making and patient-centred care (Appleby & Devlin 2005, Snyder *et al.* 2013). However, work to determine these hypothesises continues.

In the meantime, discourse questioning variability in quality of life definitions and the absence of a theoretical basis for quality of life instruments continue to proliferate. This debate has led to criticisms of the validity of existing instruments and their ability to capture the individual issues and domains of quality of life which are important to each person (Bowling 1995, Carr & Higginson 2001). An additional challenge for quality of life evaluation is the disproportionate focus on the negative effect of a cancer diagnosis in standardised cancer-related quality of life instruments, which overlook potential positive adjustment among cancer survivors (Ferrell *et al.* 1995). Several researchers have proposed and experimented with possible solutions to these issues, including the use of two or more quality of life measures, comprising generic and disease-specific measures or multi-method means of evaluating quality of life (Bowling 1995, Coons *et al.* 2000, McCabe *et al.* 2008). Within the current study, the use of subjective generic and colorectal cancer survivorship instruments will provide data outlining colorectal cancer survivors' general and disease-specific quality of life outcomes. Qualitative interview data will offer context and information about survivors' experiences of their quality of life and the survivorship issues important to their quality of life.

2.3.3 Conceptual Definitions and Models Underpinning Quality of Life Research

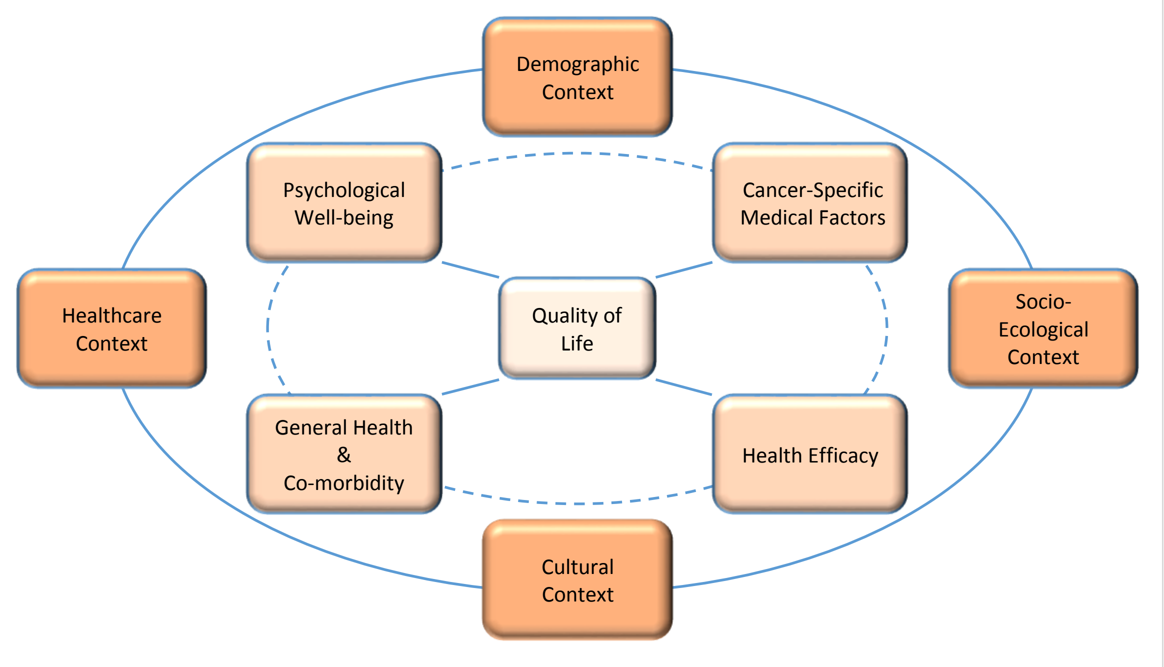
Despite the abundant literature surrounding quality of life research, many authors either fail to provide a clear conceptual basis for their research or opt to use uniquely derived or sporadically used conceptual models (Gill & Feinstein 1994, Bakas *et al.* 2012). Health-related quality of life has been conceptualised within the biomedical and biopsychosocial models of health and within contemporary theories of nursing practice. The biomedical model views health as an absence of disease and focuses on biological rather than psychological or social factors to understand and manage disease. Engel (1977) highlighted a crisis in medicine and psychiatry, as the biomedical model failed to adequately address the roles and responsibilities of these professions, proposing a model which considered the importance of social and psychological factors in addition to biological factors for healthy human functioning. On the other hand, contemporary nursing theorists such as Peplau, Rodgers, Leininger and Parse conceptualise quality of life as a subjective, transient concept, which is context-bound and influenced by health and personal relationships (Plummer & Molzahn 2009). Either way, quality of life is often seen as a by-product of the clinician-patient relationship rather than an outcome or consequence. Although the conceptual basis for the quality of life models proposed by WHO (1980), Wilson & Cleary (1995) and Ferrans *et al.* (2005) emerge from the biomedical and biopsychosocial models of health, their orientation toward symptom and pathology preclude their use in the context of cancer survivorship.

Two models of health-related quality of life have been proposed to guide cancer survivorship research, 1) the Ferrell *et al.* (1995) *Model of Quality of Life, Adapted for Cancer Survivors,* and 2) the Ashing-Giwa (2005) *Contextual Model of Health-Related Quality of Life*. Similar to previously discussed models, the Ferrell *et al.* (1995) Model is heavily entrenched in the biomedical and biopsychosocial models of health, placing importance on the physical, psychological, social and spiritual dimensions of quality of life with little regard for the context in which cancer survivors' experience health. The Ashing-Giwa (2005) Model developed in response to a scarcity of research with minority and underserved populations. Although the Ashing-Giwa (2005) Model is influenced by the traditional health-related biomedical and biopsychosocial models, it has also been informed by quality of life research with cancer survivors and literature from cancer, cancer survivorship, multiculturalism and psychological fields. The Ashing-Giwa (2005) Model provides a comprehensive framework facilitating a thorough exploration of the factors placing cancer patients and survivors at greater risk of experiencing poorer quality of life, considering demographic, socio-ecological, cultural and healthcare contexts.

2.3.4 The Ashing-Giwa Contextual Model of Health-Related Quality of Life

The *Contextual Model of Health-Related Quality of Life* recognises that a range of environmental contexts influence health and illness. Ashing-Giwa (2005) proposed that health-related quality of life is influenced by macro-level contexts (demographic, healthcare, cultural and socio-ecological) and individual-level factors (general health, cancer-related, health efficacy and psychological well-being) (Figure 2.7; Table 2.2). The model was presented by Ashing-Giwa (2005) as a work in progress and has primarily been tested with ethnically and culturally diverse samples of breast and cervical cancer survivors (Ashing-Giwa & Lim 2008, Ashing-Giwa *et al.* 2009, Ashing-Giwa & Lim 2011). Given the significance of healthcare experiences to cancer survivorship within the concept analysis, consideration of the healthcare system and disparities in health were important factors in selecting a model to evaluate quality of life in colorectal cancer survivorship. Therefore, the Ashing-Giwa (2005) model provided a suitable fit for the conceptual basis of the inquiry.

Despite the recognised influence of healthcare contexts upon cancer survivors' quality of life in the Ashing-Giwa Model (2005), the concept analysis identified a dearth of empirical literature in the area of colorectal cancer survivorship which explicitly examines the relative influence of healthcare experiences upon quality of life. Consequently, this forms the focus of the aims and objectives for the current study (Section 2.4). Given this gap in the literature, the *Contextual Model of Health-Related Quality of Life* was implemented in the current study with emphasis and priority placed upon understanding the influence of the healthcare context upon colorectal cancer survivors' quality of life. As the *Contextual Model of Health-Related Quality of Life* is positioned as an evolving work in progress and has predominantly been used to explore quality of life outcomes with



Source adapted from Ashing-Giwa (2005) The Contextual Model of HRQoL: A Paradigm for Expanding the HRQoL Framework. *Quality of Life Research* **14**(2), p.298.

Figure 2.7 The Ashing-Giwa (2005) Contextual Model of Health-Related Quality of Life

Context	Components	Sub-Components
Macro/Systemic Level		
Socio-Ecological	*Socio-Economic Status*	Income, education, employment
	Life Burden	Living situation, neighbourhood character and resources, day-to-day strain
Cultural	*Ethnicity*	Region of ancestral origin(s)
	Ethnic Identity	Level to which ethnicity and cultural heritage defines self
	Acculturation	Language, choice of media, social network and practices
	Interconnectedness	Quality and pressure of family life and social relationships
	Worldview	Attitudes and beliefs
	Spirituality	Faith-based beliefs and practices
Demographic	*Chronological Age, Gender*	Age, gender
Healthcare System	*Access to Healthcare*	Cost, insurance, availability of treatment centres
	Quality of Healthcare	State of the art, satisfaction with care
	Quality of Relationship	Compassion, communication, involvement
Individual Level		
General Health	*Health Status*	Disease status, comorbid illness(es)
Medical Factors	*Cancer Characteristics*	Stage, surgery, chemotherapy, radiation
	Age at Diagnosis	Age at diagnosis
Health Efficacy	*Motivation and Know-How*	Health practices, utilisation, perceived health efficacy, medical adherence
Psychological Well-being	*Level of Functioning*	Depression, anxiety, meaning, resolve
Source adapted from Ashing-Giwa (2005) The Contextual Model of HRQoL: A Paradigm for Expanding the HRQoL Framework. *Quality of Life Research* **14**(2), p.299.		

Table 2.2 Components of the Ashing-Giwa (2005) Contextual Model of Health-Related Quality of Life

ethnically and culturally diverse samples of female cancer survivors, adaptations to the model were deemed necessary and appropriate. Following completion of the literature review, a rationalised version of the model was adapted to guide the selection of variables to explore quality of life outcomes among colorectal cancer survivors in this study. Adaptations to the Model were made to reflect Irish culture, healthcare delivery models and the nature of quality of life outcomes experienced by colorectal cancer survivors. As these adaptations are based on the outcomes of the literature review, they are discussed in greater depth at the end of Chapter Three (Section 3.8.3).

2.4 Study Aims and Objectives

2.4.1 Mixed Methods Aim and Objectives

This mixed method study aims to understand and explore the impact of healthcare experiences upon the quality of life of colorectal cancer survivors receiving follow-up care in tertiary oncology settings in the Republic of Ireland between six months and five years following diagnosis. The overarching mixed method objectives of this study are:

1. To understand colorectal cancer survivors' quality of life between six months and five years following diagnosis in Ireland.

2. To establish the nature and prevalence of adverse physical, psychological and social effects following colorectal cancer treatment in Ireland.
3. To explore colorectal cancer survivors' experiences of healthcare in the aftermath of treatment.
4. To identify the unmet information and supportive care needs of colorectal cancer survivors.
5. To determine the personal and organisational structures used by colorectal cancer survivors to address unmet information and supportive care needs.
6. To ascertain the healthcare-related factors which influence colorectal cancer survivors' quality of life.

2.4.2 Quantitative Objectives

The first, quantitative phase of the study provides comprehensive information about colorectal cancer survivors' post-treatment quality of life and healthcare experiences. The specific objectives of the quantitative phase of the study are:

1. To understand colorectal cancer survivors' physical, psychological and social outcomes.
2. To ascertain colorectal cancer survivors' ratings of continuity of care and support from healthcare professionals and services during post-treatment follow-up.
3. To identify the unmet information and supportive care needs of colorectal cancer survivors.
4. To devise a model of the healthcare-related factors which influence colorectal cancer survivors' quality of life outcomes in the five years following diagnosis.

2.4.3 Qualitative Objectives

The qualitative phase of the study was designed to build upon the results of the quantitative phase, providing context, facilitating explanation of the findings and enhancing the depth of understanding of the issues reported by colorectal cancer survivors. The qualitative study seeks:

1. To explore the impact of physical, psychological and social effects upon colorectal cancer survivors' quality of life.
2. To provide a contextual understanding of the healthcare experiences and unmet needs reported by colorectal cancer survivors in the quantitative study.
3. To map the formal and informal sources of support enlisted by colorectal cancer survivors to address unmet information and supportive care needs.

2.5 Chapter Summary

The conceptual and theoretical background to the study has been illustrated in the current chapter. This chapter has presented the results of a published concept analysis to clarify the attributes and consequences of colorectal cancer survivorship within the empirical literature published since Doyle (2008). Following this, a brief overview of the development of quality of life indicators, measurement methods, definitions and models were described. This section concluded with an outline of the *Contextual Model of Health-Related Quality of Life* (Ashing-Giwa 2005) which provides a theoretical framework for this study. The chapter closed with a statement of the overarching aims and objectives of this study.

The published concept analysis paper presented in this chapter has made a pivotal contribution to the literature by providing the first definition of cancer survivorship within the context of colorectal cancer. In addition to the attributes and consequences identified by Doyle (2008), the current concept analysis identified a sixth attribute of colorectal cancer survivorship, *Navigating Systems and Resources*, and a fifth consequence, *The Constellation of Met and Unmet Survivorship Needs*. Given the importance of healthcare experiences to the attribute *Navigating Systems and Resources* and their centrality to the study aim, the selection of the *Contextual Model of Health-Related Quality of Life* to guide this study is justifiable, as it considers the influence of the healthcare context upon cancer survivors' quality of life, as well as demographic, socio-ecologic and cultural contexts.

Chapter Three – Literature Review

3.1 Introduction

This literature review will provide a critical appraisal of the empirical literature of quality of life in colorectal cancer survivorship. Considering the concept analysis results, this literature review aims to:

1. Understand the quality of life outcomes of colorectal cancer survivors.
2. Estimate the prevalence of physical, psychological and social effects among colorectal cancer survivors.
3. Synthesise the available evidence on colorectal cancer survivors' experiences of healthcare.
4. Critically appraise and synthesise the evidence describing the relationship between colorectal cancer survivors' healthcare experiences and quality of life outcomes.
5. Identify the factors which may influence colorectal cancer survivors' quality of life within the *Contextual Model of Health-Related Quality of Life* (Ashing-Giwa 2005).

The chapter opens with a discussion of the design and methods which guide this literature review (Section 3.2) and the characteristics of the included studies (Section 3.3). The results of the literature review are then presented. Section 3.4 discusses the literature on colorectal cancer survivors' quality of life outcomes, addressing the specific physical, psychological, social and spiritual aspects of quality of life. Given concept analysis finding, this review will give special attention to the literature addressing colorectal cancer survivors' healthcare experience and needs, outlining the knowledge available regarding current models of care, surveillance protocols and factors influencing follow-up in colorectal cancer survivorship (Section 3.5). Section 3.5.4 provides a critical appraisal and analysis of the literature describing the potential relationship between colorectal cancer survivors' quality of life and healthcare experiences. This is followed by a summary of the studies examining colorectal cancer survivors' quality of life outcomes in an Irish context (Section 3.6). Thereafter, the various socio-demographic, cancer-related and healthcare-related factors which may influence the quality of life of colorectal cancer survivors are presented in relation to the Ashing-Giwa (2005) Model (Section 3.7). In the final section, the limitations of the reviewed evidence are evaluated (Section 3.8.1) and the major findings and critical gaps in the literature are summarised (Section 3.8.2). The chapter will conclude with an outline of the adaptations made to the Ashing-Giwa (2005) Model in light of the contextual, conceptual and empirical background to this study (Section 3.8.3).

3.2 Literature Review Design and Methods

Colorectal cancer survivorship is a unique, multifaceted experience, with aspects which may be measured quantitatively and described qualitatively. However, there is an absence of systematic synthesis of findings from these contrasting methods. Systematic reviews have developed over the past 20 years as a significant component in evaluating healthcare interventions. Systematic reviews use systematic, explicit and accountable methods to identify, synthesise and critically evaluate all available research literature on a topic (Cronin *et al.* 2008, Gough 2012). In contrast, traditional narrative literature reviews provide a broad outline of the literature available using less systematic means (Garg *et al.* 2008). Often, less consideration is given to the methods or evaluation criteria used to identify and select the evidence underpinning the narrative review (Gough 2012). This poses a significant source of bias in traditional literature reviews, as such reviews may be coloured by the author's practical experience and knowledge of the literature which places boundaries on the inclusion and representation of studies in the review (Garg *et al.* 2008, Gough 2012). These limitations may prevent readers from thoroughly interpreting the meaning of review findings (Gough 2012). Integrative reviews assimilate findings from different research methodologies using rigourous stages of analysis and synthesis without compromising the epistemological affiliations of the researcher (Soares *et al.* 2014). An integrated review was considered the most appropriate approach for this literature review, as it provides a thorough understanding of quality of life in cancer survivorship, and the various empirical and theoretical perspectives which underpin investigation in the field (Kirkevold 1997).

3.2.1 Search Strategy

Incomplete or biased searches can limit the sources available for review and may result in inaccurate conclusions (Cooper 1998, Conn *et al.* 2003). Therefore, potential search terms corresponding to the major concepts of '*colorectal cancer*' and '*cancer survivorship*' were identified and used to develop the database search strategies. Nineteen health and social sciences databases were consulted (Table 3.1). Initial search strategies were developed to recover the maximum number of relevant results. Search strategies were not limited by the concepts of '*quality of life*', '*unmet needs*' or '*follow-up care*'. The initial searches yielded large volumes of irrelevant studies which mentioned '*survivor*' or '*survivorship*' within the text, therefore searches relating to the concept of '*cancer survivorship*' were limited to title and abstract searches to minimise the number

Databases Searched	
PUBMED	Social Sciences Full Text
EMBASE	AMED
SCOPUS	Academic Search Complete
CINAHL	ASSIA
CINAHL Complete	Social Services Abstracts
PsycINFO	Sociological Abstracts
PsycARTICLES	Web of Science
The Cochrane Library	British Nursing Index
MEDLINE	OmniFile Full Text Mega
ProQuest Nursing and Allied Health Source	

Table 3.1 Databases searched during the literature review

of irrelevant primary studies. Appendix 3.1 outlines the final search strings used and the results obtained for each of the health and social sciences database searched in July 2014. The subject librarian was consulted to discuss the validity of search strategy terms and the justifications for restrictions in the final search strategy (Pond 1999).

3.2.2 Inclusion and Exclusion Criteria

To ensure this integrated review is focused and rigourous, all included studies were expected to meet Participant, Exposure, Outcomes and Study (PEOS) criteria (Table 3.2) (Bettany-Saltikov 2012). Primary studies of interest to this review were identified through sequential evaluation of titles and abstracts against the PEOS criteria. Where the title and abstract of a paper provided insufficient information to exclude the paper, the full text was reviewed. These criteria ensure the findings of the review are not biased by studies which examine acute side-effects of primary treatment and included studies are representative of colorectal cancer survivors who are undergoing ongoing surveillance and colorectal cancer-specific follow-up.

PEOS	Criteria
Participant	Adults diagnosed with colorectal cancer aged 18 years or older who have completed primary cancer treatments.
Exposure	Colorectal cancer survivors who have completed primary treatment, and who are living with or after (i.e. 'surviving') colorectal cancer.
Outcomes	Quality of Life (general, health-related, cancer-specific and/or tumour-specific); Experiences of follow-up care; Unmet needs.
Study	Primary research studies using quantitative research designs, qualitative research designs and mixed methods research designs.

Table 3.2 Participant, Exposure, Outcomes and Study (PEOS) criteria

Included studies were limited to those published in the English language since the release of *From Cancer Patient to Cancer Survivor: Lost in Translation* (IoM 2006). To minimise bias in the review, secondary sources, anecdotal, opinion and clinical papers, case studies, case reports, case-control studies, economic evaluations, pilot or feasibility studies, and intervention implementation and evaluation studies were excluded. As the goal of this review was to understand colorectal cancer survivors' outcomes and experiences, rather than the effect of interventions to improve outcomes, randomised controlled trials were also excluded.

3.2.3 Data Management

References were managed using EndNote, with results from each database search imported to a corresponding library. Once all database searches were complete, the EndNote libraries were merged. Studies were selected for review during a four-stage screening process (Table 3.3). Studies which did not meet the PEOS inclusion criteria at each stage were removed in chronological order; this resulted in a total of 127 unique publications suitable for inclusion in this review (Figure 3.1).

Stage	Process
Stage 1	Duplicate references removed from the EndNote Library.
Stage 2	Studies published prior to 2006 removed from EndNote Library.
Stage 3	Study titles and abstracts assessed against the pre-determined PEOS inclusion criteria.
Stage 4	The full text of papers meeting PEOS inclusion criteria obtained for full-text quality assessment.

Table 3.3 Screening process for study selection

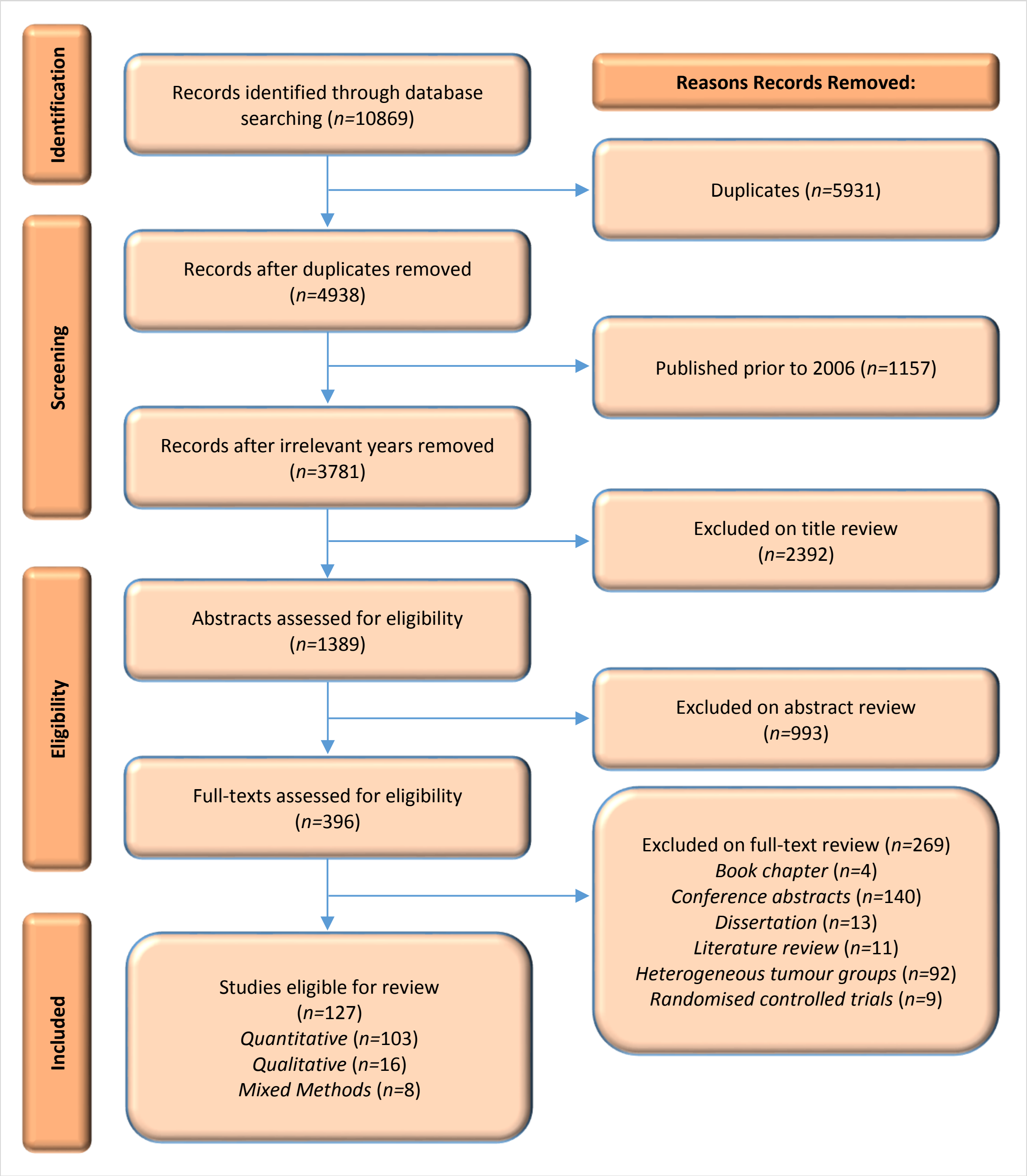


Figure 3.1 Literature review Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram

3.2.4 Data Analysis

Despite the potential for error, data analysis strategies are one of the least developed aspects of the integrative review process (Whittemore & Knafl 2005, Onwuegbuzie *et al.* 2012). The Braun & Clarke (2006) framework was used to guide a thematic analysis of the data. All included sources were read to gain familiarity with the literature. Initial codes were generated during re-reading of the sources and categorised into parent categories of 1) quality of life, 2) healthcare experiences, and 3) factors influencing quality of life. Each category was examined separately; codes were organised and reorganised into themes until comprehensive thematic frameworks were generated for each.

3.3 Characteristics of the Studies Included in the Literature Review

3.3.1 Origin

The characteristics of the 127 selected studies are summarised in Appendix 3.2. Consistent with the origin of the cancer survivorship movement in the USA, it is unsurprising that most studies were conducted in North America (USA: *n*=52; Canada: *n*=7). However, a substantial number of studies have emerged from Australia (*n*=15), The Netherlands (*n*=12) and the United Kingdom (UK; *n*=10). Further European studies have emerged from Germany (*n*=5), Italy (*n*=5), Norway (*n*=3), France (*n*=2), Austria (*n*=1), Denmark (*n*=1) and Sweden (*n*=1). Two studies were conducted in Ireland by the NCRI. Further studies were conducted in Taiwan (*n*=4), Turkey (*n*=2), China (*n*=1), Israel (*n*=1), Jordan (*n*=1) and New Zealand (*n*=1). One multinational study was conducted with samples drawn from Australian and Canadian populations of colorectal cancer survivors. Studies were published between 2006 and 2014 (Figure 3.2).

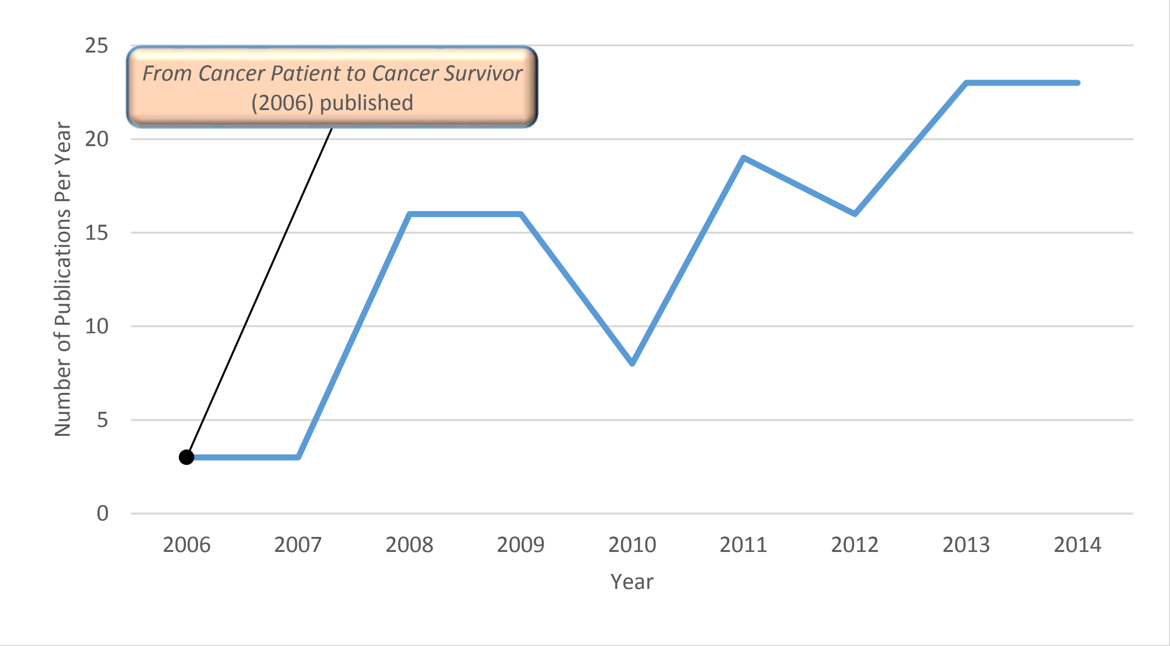


Figure 3.2 Distribution of publications included in the literature review by year (n=127)

3.3.2 Methodology

The studies used largely quantitative methodological approaches (*n*=103), including cross-sectional (*n*=64), longitudinal (*n*=21) and retrospective designs (*n*=18). Sixteen studies used qualitative approaches including grounded theory (*n*=4), ethnography (*n*=2) and phenomenology (*n*=2). Eight studies did not describe a specific qualitative approach. The remaining studies (*n*=8) described mixed methods approaches. However, not all studies reported the results of mixed methods data analysis. Three studies used quantitative results to direct sampling techniques for qualitative research and reported only qualitative findings. Two studies collected qualitative and quantitative data simultaneously via a single questionnaire. Finally, three studies reported the results of quantitative and qualitative data, such that the qualitative data were used to enhance, explain or extend understanding of the quantitative data.

3.3.3 Methods

Quantitative studies of quality of life (*n*=63) used generic (*n*=22), cancer-related (*n*=25), colorectal cancer-specific (*n*=34) and ostomy-specific (*n*=9) survey instruments (Table 3.4). A number of studies assessed quality of life using single instruments (*n*=38), including the Functional Assessment of Cancer Therapy-Colorectal (FACT-C; *n*=12), the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire-Core 30 module (QLQ-C30; *n*=9), the Medical Outcomes Survey (MOS) Short Form-36 (SF-36; *n*=5), the MOS SF-12 (*n*=2), the City of Hope Quality of Life-Ostomy Questionnaire (*n*=5), and the Quality of Life of Cancer Survivors Summary (*n*=1). In addition, the colorectal cancer-specific modules of the EORTC were used by two studies each (EORTC QLQ-CR29, *n*=2; EORTC QLQ-CR38, *n*=2). However, most studies evaluated quality of life using generic instruments and one or more cancer-related, colorectal cancer-specific or ostomy-specific quality of life instruments (*n*=25). Several qualitative studies evaluated quality of life using interview (*n*=14) and focus group methods (*n*=4), either alone (*n*=14), or in addition to a survey (*n*=3) or an alternative qualitative data collection method (*n*=1).

Quality of Life Instrument Type	Instrument	*n*
Generic	*MOS SF-36*	17
	MOS SF-12	3
	EuroQol 5D-5L	1
	MOS SF-6D	1
Cancer-Related	*EORTC QLQ-C30*	23
	Quality of Life of Cancer Survivors	2
Colorectal Cancer-Specific	*EORTC QLQ-CR38*	16
	FACT-C	15
	EORTC QLQ-CR29	2
	EORTC QLQ-LMC21	1
Ostomy-Specific	*City of Hope Quality of Life-Ostomy*	9

Table 3.4 Survey instruments used in studies evaluating health-related quality of life

Twenty-seven studies examined aspects of colorectal cancer survivors' healthcare experience. These studies were largely retrospective cohort designs assessing adherence to follow-up (*n*=2), surveillance protocols (*n*=8) or use of healthcare services (*n*=5) after treatment, with data drawn from a combination of sources, including medical records (*n*=3), cancer registries (*n*=10) and insurance providers (*n*=7). Fourteen studies solicited information directly from colorectal cancer survivors via quantitative (*n*=9), qualitative (*n*=3) or mixed methods (*n*=2) approaches. A single study explored the relationship between continuity of care and quality of life, sampling colorectal cancer survivors from primary care settings in the first year following treatment.

3.3.4 Recruitment and Sampling

Most studies recruited participants from hospital, regional and national cancer registries (*n*=78). Forty-eight studies recruited participants directly from hospital clinics, and one study failed to report recruitment processes. Sample sizes in the reviewed studies ranged from 7 to 62,882. The range of sample sizes varied by methodological approach. Quantitative approaches, including survey (range: *N*=15-3,977) and retrospective cohort designs (range: *N*=49-62,882) naturally had larger sample sizes compared to qualitative (range: *N*=7-60), or mixed methods (range: *N*=12-284) approaches. In quantitative survey studies, response rates ranged from 19%-100%. Studies with clinic-based recruitment protocols were more likely to achieve response rates exceeding 60% (*n*=24, 65%) than those recruiting via cancer registries (*n*=23, 34%).

3.3.5 Participants

Most reviewed studies enrolled colon and rectal cancer survivors (*n*=105); 17 recruited only rectal cancer survivors and five included only colon cancer survivors. Thirty-five studies included survivors who were less than six months since diagnosis, 69 studies included those between one and five years since diagnosis, and 65 included survivors more than five years since diagnosis. Fifty-three studies included individuals with metastatic disease; 37 studies explicitly excluded this group. In 30 cases, it was not possible to determine whether those living with stage IV disease were intentionally excluded. Thirty-nine studies excluded survivors receiving treatment, and just 13 of 75 studies reported the proportion of participants undergoing treatment. In total, 77 studies reported the number of survivors who had received radiotherapy (*n*=57), chemotherapy (*n*=60), surgery (*n*=62) or adjuvant therapy (*n*=21).

3.4 Quality of Life After Colorectal Cancer

The burden of symptoms and quality of life experienced by colorectal cancer survivors may improve with time (Schneider *et al.* 2007, Bouvier *et al.* 2008, Baldwin *et al.* 2009, Chambers *et al.* 2012b, Rees *et al.* 2014). On average, colon and rectal cancer survivors report reasonable quality of life and health, at levels comparable to, or better than normative populations (Schneider *et al.* 2007, Phipps *et al.* 2008, Pucciarelli *et al.* 2008, Ristvedt & Trinkaus 2009, Hoerske *et al.* 2010, Caravati-Jouvenceaux *et al.* 2011, Domati *et al.* 2011, Jansen *et al.* 2011a, Mrak *et al.* 2011, Thong *et al.* 2011b, Dunn *et al.* 2013a, Knowles *et al.* 2013, Tofthagen *et al.* 2013a, Abu-Helalah *et al.* 2014, Rees *et al.* 2014). Despite these positive outcomes, a substantial proportion of colorectal cancer survivors experience distressing physical, psychological, social and spiritual issues. The authors of several international studies suggest survivors undergo '*response shift*', reframing and redefining the acceptability of their quality of life and the influence of disease-related symptoms (DeSnoo & Faithfull 2006, Di Fabio *et al.* 2008, McMullen *et al.* 2008, Serpentini *et al.* 2011, Chambers *et al.* 2012b, McCaughan *et al.* 2012). The transition from acute to extended and permanent phases of survival is multi-faceted, and the challenges of each phase vary. The physical, psychological, social and spiritual domains of quality of life are inter-related, influenced by individual and contextual factors, including cancer-related factors, general health, psychological well-being, health efficacy, and demographic, socio-economic, cultural and healthcare contexts (Ashing-Giwa 2005). The following sub-sections will explore the trajectories and prevalence of physical, psychological, social and spiritual survivorship issues among colorectal cancer survivors and the factors which may influence these outcomes.

3.4.1 Physical Well-Being

Half of survivors may experience one or more symptoms affecting them fairly or very often, with one-third experiencing functional limitations relating to these symptoms (Schneider *et al.* 2007, Phipps *et al.* 2008, Domati *et al.* 2011, Hornbrook *et al.* 2011, Knowles *et al.* 2013, Ronning *et al.* 2014). The concept analysis of colorectal cancer survivorship drew attention to specific physical symptoms experienced by colorectal cancer survivors, including pain, sleep disturbance, fatigue, peripheral neuropathy, sexual dysfunction, gastrointestinal disturbance and bowel dysfunction (Section 2.2.10.1). Similar to patterns observed in overall quality of life, physical well-being may improve over time (Bouvier *et al.* 2008, Thong *et al.* 2011a, Thong *et al.* 2011b, Kilic *et al.* 2012). However, improvements in physical well-being may only be sustained in the short-term. A longitudinal study examining quality of life among colorectal cancer survivors in Germany by Jansen *et al.* (2011a) notes levels of physical well-being began to deteriorate between three and 10 years following treatment and failed to reflect normative population scores at any point of observation. The results of a longitudinal study by Kim *et al.* (2014) in the USA appear to support these findings, reporting colorectal cancer survivors' average physical function scores were within the lowest quartile of comparable normative population scores in the USA. In comparison, studies reporting only positive improvements in survivors' quality of life over time used predominantly cross-sectional survey methods (Thong *et al.* 2011a, Thong *et al.* 2011b, Kilic *et al.* 2012); one utilised a longitudinal survey with survivors up to one year after diagnosis (Bouvier *et al.* 2008). However, the longitudinal studies suggesting a deterioration in survivors' quality of life over time (Jansen *et al.*

2011a; Kim *et al.* 2014) recruited smaller samples of 60 and 117 survivors. Therefore, further longitudinal research with larger samples is required to confirm these results.

3.4.1.1 Pain

Colorectal cancer survivors rank pain as one of the most severe symptoms experienced following treatment, which may interfere significantly with daily activities (Phipps *et al.* 2008, Lowery *et al.* 2013). Estimates of pain prevalence among colorectal cancer survivors vary substantially. Di Fabio *et al.* (2008) and Rees *et al.* (2014) estimate that less than 3% of colorectal cancer survivors experience pain between one and nine years following surgery. However, both studies are limited by small sample sizes of less than 70 participants. Cross-sectional studies with larger samples estimate the prevalence of pain to be between 20% and 46% in extended (≤5 years) and permanent (>5 years) survivorship (Phipps *et al.* 2008, Johnson *et al.* 2009, Lowery *et al.* 2013, Abu-Helalah *et al.* 2014, Schlesinger *et al.* 2014, Thomas *et al.* 2014).

Several factors have demonstrated statistically significant associations with levels of pain among colon and rectal cancer survivors, including younger age, female gender, lower education level, lower income, recurrent disease, co-morbidities, co-occurring symptoms (e.g. peripheral neuropathy, bowel dysfunction, urinary dysfunction) and psychological consequences (e.g. anxiety, depression, suicidal ideation) (Phipps *et al.* 2008, Jansen *et al.* 2011c, Thong *et al.* 2011a, Thong *et al.* 2011b, Bennett *et al.* 2012, Kilic *et al.* 2012, Lowery *et al.* 2013, Tofthagen *et al.* 2013a, Abu-Helalah *et al.* 2014, Li *et al.* 2014). Tumour location and time since diagnosis may also have a significant impact on survivors' experience of pain. Two longitudinal studies have shown short-term improvements in the level of pain reported by colon and rectal cancer survivors up to three years following diagnosis (Bouvier *et al.* 2008, Jansen *et al.* 2011a). However, Bouvier *et al.* (2008) indicate that rectal cancer survivors reported worse pain at the time of diagnosis and similar levels of pain three months post-diagnosis. Furthermore, rectal cancer survivors were at higher risk of experiencing pain than colon cancer survivors in the year following diagnosis. In the longer term, two European longitudinal studies suggest the pain levels reported by colon and rectal cancer survivors two and 10 years post-diagnosis fall in line with the general population (Pucciarelli *et al.* 2008, Thong *et al.* 2011a). Finally, the treatments colorectal cancer survivors received also appeared to contribute to the likelihood of reporting pain. Chemotherapy was associated with more significant pain among younger colorectal cancer survivors, but not those over the age of 70 (Jansen *et al.* 2011c). Radiotherapy or surgery requiring ostomy placement were linked to greater pain in colon and rectal cancer survivors over one year following diagnosis in cross-sectional survey studies of more than 200 survivors (Kilic *et al.* 2012, Abu-Helalah *et al.* 2014). However, Thong *et al.* (2011b) found rectal cancer survivors treated with radiotherapy disclose less pain than those managed surgically up to 10 years after diagnosis.

3.4.1.2 Bowel Dysfunction

Bowel dysfunction encompasses a litany of symptoms including abdominal pain, diarrhoea, constipation, flatulence, faecal urgency, faecal incontinence, incomplete bowel movements, fractionated defecation and bleeding from the rectum, affecting between 1% and 75% of survivors (Table 3.5). The considerable fluctuation in the prevalence of bowel dysfunction in this population may be due to inconsistencies in the instruments used to measure symptoms and the way results are reported. Many studies use the EORTC QLQ-C30, QLQ-CR29 and QLQ-CR38. Unfortunately, most of these studies report the average intensity of symptoms, rather than frequency. Few studies report the percentage of survivors who experienced clinically significant symptom difficulties on each of the EORTC modules (Di Fabio *et al.* 2008, Hoerske *et al.* 2010, Abu-Helalah *et al.* 2014, Rees *et al.* 2014, Thomas *et al.* 2014, Bailey *et al.* 2015). Furthermore, many studies are cross-sectional, examining diverse timeframes of survivorship, limited by small samples (Schneider *et al.* 2007, Di Fabio *et al.* 2008, Phipps *et al.* 2008, Domati *et al.* 2011, Serpentini *et al.* 2011, Knowles *et al.* 2013, Lowery *et al.* 2013, Abu-Helalah *et al.* 2014, Mols *et al.* 2014, Rees *et al.* 2014, Thomas *et al.* 2014). A limited number of studies enquired about rectal bleeding and fractionated defecation (Schneider *et al.* 2007, Serpentini *et al.* 2011). However, each of these studies used uniquely derived items to assess these symptoms. Therefore, the results should be interpreted with caution.

Symptom	Range	References
Cramps	3-13%	(Schneider *et al.* 2007, Lowery *et al.* 2013, Rees *et al.* 2014, Bailey *et al.* 2015)
Constipation	0-37%	(Schneider *et al.* 2007, Phipps *et al.* 2008, Serpentini *et al.* 2011, Knowles *et al.* 2013, Abu-Helalah *et al.* 2014, Rees *et al.* 2014, Thomas *et al.* 2014, Bailey *et al.* 2015)
Diarrhoea	3-39%	(Schneider *et al.* 2007, Phipps *et al.* 2008, Serpentini *et al.* 2011, Knowles *et al.* 2013, Rees *et al.* 2014, Thomas *et al.* 2014)
Incontinence	3-38%	(Di Fabio *et al.* 2008, Nikoletti *et al.* 2008, Serpentini *et al.* 2011, Chambers *et al.* 2012b, Sisler *et al.* 2012b, Knowles *et al.* 2013, Bailey *et al.* 2015)
Urgency	32-73%	(Nikoletti *et al.* 2008, Serpentini *et al.* 2011, Knowles *et al.* 2013)
Flatulence	19-75%	(Nikoletti *et al.* 2008, Serpentini *et al.* 2011, Knowles *et al.* 2013, Abu-Helalah *et al.* 2014)
Fractionated Defecation	72%	(Serpentini *et al.* 2011)
Incomplete Evacuation	5-75%	(Di Fabio *et al.* 2008, Nikoletti *et al.* 2008, Serpentini *et al.* 2011, Knowles *et al.* 2013)
Rectal Bleeding	1%	(Schneider *et al.* 2007)

Table 3.5 Prevalence of bowel function symptoms reported in the colorectal cancer survivorship literature

Compared to normative populations, colon and rectal cancer survivors are at greater risk of constipation and diarrhoea up to 15 years following diagnosis (Pucciarelli *et al.* 2008, Caravati-Jouvenceaux *et al.* 2011, Jansen *et al.* 2011a). Statistically worse gastrointestinal disturbances have been identified among colorectal cancer survivors who are female, married, or younger (Hoerske *et al.* 2010, Jansen *et al.* 2011a, Kilic *et al.* 2012, Li *et al.* 2014, Bailey *et al.* 2015). Co-morbidity, rectal disease, higher staging, recurrent or metastatic disease, shorter time since treatment and radiotherapy each contribute to worse bowel dysfunction (Schneider *et al.* 2007, Di Fabio *et al.* 2008, Phipps *et al.* 2008, Hoerske *et al.* 2010, Thong *et al.* 2011a, Thong *et al.* 2011b, Chambers *et al.* 2012b, Knowles *et al.* 2013, Abu-Helalah *et al.* 2014). Although the prevalence of bowel dysfunction is lower in longer-term survivors, rectal cancer survivors experience more frequent bowel dysfunction symptoms compared to normative populations and colon cancer survivors in cross-sectional and longitudinal studies (Di Fabio *et al.* 2008, Pucciarelli *et al.* 2008, Chambers *et al.* 2009, Caravati-Jouvenceaux *et al.* 2011, Knowles *et al.* 2013, Abu-Helalah *et al.* 2014, Li *et al.* 2014). Moreover, faecal urgency is detrimental to quality of life among rectal cancer survivors in cross-sectional studies of survivors between six months and seven years post-treatment, causing embarrassment, and necessitating the use of incontinence wear to prevent leakage (Nikoletti *et al.* 2008, Knowles *et al.* 2013, Bailey *et al.* 2015).

For many survivors, the prospect of a temporary or permanent ostomy is daunting, contributing to significant physical, psychological and social upheavals. Up to one-third of colorectal cancer survivors with ostomies report stoma-related problems (Fucini *et al.* 2008, Skeps *et al.* 2013, Abu-Helalah *et al.* 2014, Mols *et al.* 2014, Bailey *et al.* 2015). Physical consequences for ostomates include greater abdominal pain and cramps, noticeable ostomy-related noise and odour, peristomal skin complaints, micturition problems, and greater possibility of late surgical complications than survivors who have never had an ostomy (Schneider *et al.* 2007, Lynch *et al.* 2008b, McMullen *et al.* 2008, Grant *et al.* 2011, Hornbrook *et al.* 2011, McMullen *et al.* 2011, Palmer *et al.* 2013, Sun *et al.* 2013, Abu-Helalah *et al.* 2014, Mols *et al.* 2014, Ramirez *et al.* 2014, Sun *et al.* 2014). Furthermore, in focus groups to describe long-term survivors' adaptation to and concerns about living with an ostomy, Grant *et al.* (2011) revealed some survivors may feel like they must give up physical activities they enjoy to mitigate the risk of leakage and avoid embarrassment. However, further investigation of this finding is warranted with survivors from other international contexts.

Some survivors may struggle to care for their ostomy due to physical or functional limitations and are thus at higher risk of ostomy-related skin concerns (McMullen *et al.* 2011). For those who have a temporary ostomy, qualitative research suggests reversal is a highly anticipated event (DeSnoo & Faithfull 2006, Palmer *et al.* 2013). However, following ostomy reversal, survivors may experience further bowel-related symptoms, including pain, incontinence and diarrhoea compared to survivors who have never had an ostomy (DeSnoo & Faithfull 2006, Schneider *et al.* 2007, Abu-Helalah *et al.* 2014). Despite the adverse consequences of ostomy placement, two cross-sectional surveys by the Eindhoven Cancer Registry in the Netherlands found rectal cancer survivors with an ostomy are less likely to experience sexual dysfunction, constipation or diarrhoea than those who do not have an ostomy (Orsini *et al.* 2013, Mols *et al.* 2014). Furthermore, current and former ostomates may take steps to reduce their risk of incontinence through use of anti-diarrhoeal medications and dietary manipulation (DeSnoo & Faithfull 2006, McMullen *et al.* 2008), which may partially explain the positive results of Orsini *et al.* (2013) and Mols *et al.* (2014).

3.4.1.3 Upper Gastrointestinal System Disturbances

In addition to ostomy- and non-ostomy-related bowel dysfunction, colorectal cancer survivors may experience significant symptoms of the upper gastrointestinal system. Food intolerance, nutrition problems, loss of appetite, changes in taste, sore or dry mouth and nausea or vomiting may affect between three and 37% of colon and rectal cancer survivors (Table 3.6). Food intolerance was a particular problem described by colorectal cancer survivors in qualitative interviews and focus groups, which necessitated significant dietary adjustments to manage bowel or ostomy function (Grant *et al.* 2011, Ball *et al.* 2013). In addition, nausea, vomiting and appetite loss worsened significantly among post-treatment colorectal cancer survivors, particularly those who were older, female, had recurrent disease or were treated with chemotherapy or radiotherapy (Jansen *et al.* 2011a, Jansen *et al.* 2011c, Kilic *et al.* 2012, Abu-Helalah *et al.* 2014, Thomas *et al.* 2014). Reports of nausea and vomiting were greater among colorectal cancer survivors who had higher stage or metastatic disease in a cross-sectional survey of 241 survivors in Jordan (Abu-Helalah *et al.* 2014). Two further cross-sectional survey studies in the UK and China suggested nausea and vomiting were associated with weight loss among more than one-tenth of colorectal cancer survivors (Knowles *et al.* 2013, Li *et al.* 2014). However, in similar studies conducted in The Netherlands and Turkey, weight loss was also influenced by disease and treatment characteristics including higher tumour stage, metastatic disease, greater bowel dysfunction and surgery requiring a permanent ostomy (Thong *et al.* 2011a, Kilic *et al.* 2012).

Symptom	Range	References
Taste Changes	3-10%	(Rees *et al.* 2014, Bailey *et al.* 2015)
Dry/Sore Mouth	3-15%	(Rees *et al.* 2014, Bailey *et al.* 2015)
Food Intolerance	11-37%	(Phipps *et al.* 2008, Domati *et al.* 2011)
Nausea/Vomiting	3-27%	(Chambers *et al.* 2012b, Rees *et al.* 2014, Thomas *et al.* 2014)
Nutrition Problem	3-5%	(Rees *et al.* 2014)
Weight Loss	13%	(Knowles *et al.* 2013)

Table 3.6 Prevalence of upper gastrointestinal symptoms reported in the colorectal cancer survivorship literature

3.4.1.4 Fatigue and Sleep Disturbance

Insomnia and fatigue are significant symptoms associated with malignancy in all stages of survivorship, which may significantly impact upon survivors' daily activities (Shun *et al.* 2011, Sun *et al.* 2014). Insomnia may affect between three and 56% of colorectal cancer survivors (Knowles *et al.* 2013, Rees *et al.* 2014, Thomas *et al.* 2014); four-fifths may disclose problems with fatigue (3-83%) (Schneider *et al.* 2007, Phipps *et al.* 2008, Buffart *et al.* 2012, Chambers *et al.* 2012b, Sisler *et al.* 2012b, Thong *et al.* 2013, Rees *et al.* 2014, Schlesinger *et al.* 2014, Thomas *et al.* 2014). Two cross-sectional survey studies of colorectal cancer survivors suggest the intensity and intrusiveness of fatigue are mild (Shun *et al.* 2011, Abu-Helalah *et al.* 2014). However, both male and female ostomates may experience greater sleep disruption due to fear of leakage or the need to care for the ostomy overnight (Baldwin *et al.* 2009, Grant *et al.* 2011). Furthermore, comparisons between normative populations and colorectal cancer survivors indicate cancer survivors experience more restrictive levels of fatigue (Caravati-Jouvenceaux *et al.* 2011, Jansen *et al.* 2011a, Thong *et al.* 2013). The disparity of findings may be related to the timeframes of survivorship, or the instruments used to assess fatigue in the studies. Two studies examined fatigue using fatigue-specific questionnaires (Shun *et al.* 2011, Thong *et al.* 2013). The remaining studies measured fatigue with single items drawn from generic or disease-specific instruments (Caravati-Jouvenceaux *et al.* 2011, Jansen *et al.* 2011a, Abu-Helalah *et al.* 2014), or qualitative methods to describe factors influencing sleep disruption (Baldwin *et al.* 2009, Grant *et al.* 2011).

Insomnia and fatigue are associated with younger age, female gender, being unmarried and treatment with chemotherapy (Phipps *et al.* 2008, Hoerske *et al.* 2010, Jansen *et al.* 2011a, Jansen *et al.* 2011c, Thong *et al.* 2013, Li *et al.* 2014, Thomas *et al.* 2014). In addition, the groups of survivors who reported the highest levels of fatigue were those with type D (distressed) personality, co-morbid conditions, an ostomy, history of another cancer diagnosis, recurrent or metastatic disease, shorter time since diagnosis or treatment with radiotherapy (Fucini *et al.* 2008, Chambers *et al.* 2009, Jansen *et al.* 2011c, Shun *et al.* 2011, Thong *et al.* 2011b, Kilic *et al.* 2012, Thong *et al.* 2013, Abu-Helalah *et al.* 2014, Li *et al.* 2014). Several cross-sectional survey studies have highlighted the positive impact of physical activity upon fatigue intensity and sleep disruption (Peddle *et al.* 2008a, Grimmett *et al.* 2011, Buffart *et al.* 2012, Vallance *et al.* 2014). Reinforcing this, a German study by Schlesinger *et al.* (2014) suggests compliance with recommended physical activity levels, body mass index (BMI) parameters, dietary intake and not smoking were related to lower fatigue among colorectal cancer survivors. However, a similar study by Grimmett *et al.* (2011) in the UK did not support this finding and discovered that moderate alcohol consumption or having a BMI in the overweight category were related to lower levels of fatigue than consuming no alcohol or having a normal BMI. An explanation for the deviation in these findings may lie in the fact that the study by Grimmett *et al.* (2011) examined survivors who had been diagnosed within the past five years, while Schlesinger *et al.* (2014) recruited longer-term survivors five to nine years post-diagnosis. Grimmett *et al.* (2011) suggest that the protective effect of being overweight may be related to the effect of weight loss associated with post-treatment side-effects. As these contrasting findings are based on the results of two studies, further longitudinal studies are warranted to understand the trajectory of post-treatment fatigue and the effect of BMI and alcohol consumption on this outcome.

3.4.1.5 Sexual Dysfunction

Between one- and two-thirds of colorectal cancer survivors may experience some form of sexual dysfunction following pelvic radiotherapy and surgery, regardless of gender (Table 3.7). Sexual

Symptom	Range	References
Any Sexual Dysfunction	29-67%	(Di Fabio *et al.* 2008, Phipps *et al.* 2008, Domati *et al.* 2011, Au *et al.* 2012a, Sisler *et al.* 2012b, Milbury *et al.* 2013, Rees *et al.* 2014, Bailey *et al.* 2015)
Dyspareunia	12-42%	(Gosselink *et al.* 2006, Au *et al.* 2012a, Den Oudsten *et al.* 2012, Milbury *et al.* 2013)
Vaginal Dryness	20-32%	(Au *et al.* 2012a, Den Oudsten *et al.* 2012, Milbury *et al.* 2013, Bailey *et al.* 2015)
Erectile Dysfunction	13-92%	(Gosselink *et al.* 2006, Ellis *et al.* 2010, Au *et al.* 2012a, Den Oudsten *et al.* 2012, Ball *et al.* 2013, Milbury *et al.* 2013, Mols *et al.* 2013, Abu-Helalah *et al.* 2014, Sendur *et al.* 2014, Bailey *et al.* 2015)
Ejaculation Problem	60%	(Den Oudsten *et al.* 2012)

Table 3.7 Prevalence of sexual dysfunction symptoms reported in the colorectal cancer survivorship literature

dysfunction and lower libido were some of the most severe symptoms reported by colorectal cancer survivors in the USA and Jordan (Phipps *et al.* 2008, Abu-Helalah *et al.* 2014, Bailey *et al.* 2015). However, there was significant variance in the prevalence of sexual dysfunction among males (erectile dysfunction: 13-92%). Vaginal dryness and dyspareunia may be experienced by between one- and two-fifths of female colorectal cancer survivors respectively. As already discussed, variable prevalence rates across studies may be linked to the use of diverse instruments to assess sexual dysfunction. For example, in studies which assessed erectile dysfunction using single items derived from generic or disease-specific quality of life instruments, prevalence ranged from 13-58% (Gosselink *et al.* 2006, Den Oudsten *et al.* 2012, Abu-Helalah *et al.* 2014, Bailey *et al.* 2015). Meanwhile, studies which collected data using the International Index of Erectile Function reported much higher, although still varying, prevalence rates (45-84%) (Ellis *et al.* 2010, Au *et al.* 2012a, Milbury *et al.* 2013, Sendur *et al.* 2014). Similar patterns were identified among studies investigating female sexual dysfunction (Gosselink *et al.* 2006, Au *et al.* 2012a, Den Oudsten *et al.* 2012, Milbury *et al.* 2013, Bailey *et al.* 2015).

When comparing the frequency and intensity of perceived sexual dysfunction among male and female colorectal cancer survivors, five studies have reported greater dysfunction and worse sexual enjoyment among women (Pucciarelli *et al.* 2008, Den Oudsten *et al.* 2012, Kilic *et al.* 2012, Milbury *et al.* 2013, Li *et al.* 2014), while three report worse dysfunction among men (Phipps *et al.* 2008, Hoerske *et al.* 2010, Thong *et al.* 2011a). Treatment modalities appear to be an important factor in determining these outcomes. Consistent evidence indicates that males who have undergone more destructive surgery requiring an ostomy report more negative sexual function and enjoyment (Ellis *et al.* 2010, Hoerske *et al.* 2010, Thong *et al.* 2011a, Den Oudsten *et al.* 2012, Kilic *et al.* 2012, Knowles *et al.* 2013, Milbury *et al.* 2013, Orsini *et al.* 2013, Mols *et al.* 2014, Sendur *et al.* 2014). A single cross-sectional survey study from the USA highlights the associations between pelvic radiotherapy, pain and vaginal dryness in female survivors due to radiation-induced atrophy (Milbury *et al.* 2013). Given these effects, it is unsurprising that male and female colorectal cancer survivors consistently report lower sexual function, enjoyment and activity than normal populations (Thong *et al.* 2011a, Thong *et al.* 2011b, Den Oudsten *et al.* 2012, Milbury *et al.* 2013, Orsini *et al.* 2013).

Older age, unmarried status, and lower educational levels are risk factors for greater sexual dysfunction (Pucciarelli *et al.* 2008, Den Oudsten *et al.* 2012, Kilic *et al.* 2012, Orsini *et al.* 2013, Bailey *et al.* 2015). However, both Thong *et al.* (2011a) and Hoerske *et al.* (2010) report older colorectal cancer survivors have better sexual function than younger counterparts. These findings may be explained by the fact that younger survivors are more likely to receive chemotherapy or radiotherapy, which is associated with sexual difficulties (Sigurdsson *et al.* 2009, Grant *et al.* 2011). Enjoyment of sexual activities is hindered by factors including older age, employment status, education levels, co-morbidity and depressive symptoms (Au *et al.* 2012a, Den Oudsten *et al.* 2012, Kilic *et al.* 2012, Li *et al.* 2014). Further cancer-related factors associated with increasing sexual dysfunction are a diagnosis of rectal cancer, shorter time since treatment, higher tumour stage, radiotherapy, more destructive surgery, more treatment modalities and higher symptom burden, including fatigue, depression and urinary problems (Fucini *et al.* 2008, Pucciarelli *et al.* 2008, Ellis *et al.* 2010, Grant *et al.* 2011, Thong *et al.* 2011a, Thong *et al.* 2011b, Au *et al.* 2012a, Den Oudsten *et al.* 2012, Kilic *et al.* 2012, Milbury *et al.* 2013, Orsini *et al.* 2013, Mols *et al.* 2014, Sendur *et al.* 2014). A single qualitative study of female colorectal cancer survivors in the USA suggests some survivors resume sexual activity following treatment, developing strategies to accommodate bodily changes (Ramirez *et al.* 2009). However, two qualitative studies with female (Ramirez *et al.* 2009) and male (Ball *et al.* 2013) colorectal cancer survivors suggest not all survivors consider sexual dysfunction problematic as they placed a lower priority on sexual intimacy or attributed changes in function to natural ageing processes. However, further research is necessary to determine whether this is true of larger populations of colorectal cancer survivors internationally.

3.4.1.6 Peripheral Neuropathy

Peripheral neuropathy is a condition of the peripheral nervous system associated with sensory and motor alterations of the hands, feet and perioral area which cause paraesthesia, pain and gait disturbances (Bennett *et al.* 2012, Mols *et al.* 2013, Tofthagen *et al.* 2013a). Peripheral neuropathy has become a significant complication of colorectal cancer treatment since the introduction of Oxaliplatin to adjuvant chemotherapy regimens and may result in the early cessation of therapy in up to two-fifths of those with symptoms (Bennett *et al.* 2012). Research exploring the impact of peripheral neuropathy upon the well-being of colorectal cancer survivors is in its infancy. However, the limited literature is dominated by cross-sectional and longitudinal quantitative research methods using multiple symptom assessment instruments, contributing to variable prevalence rates in the literature (Table 3.8). Studies of colorectal cancer survivors estimate peripheral neuropathy prevalence rates of 11-37% (Kidwell *et al.* 2012, Lowery *et al.* 2013, Mols *et al.* 2013, Rees *et al.* 2014), rising to between 85% and 100% among those treated with Oxaliplatin (Bennett

Symptom	Range	References
Peripheral Neuropathy	9-89%	(Kidwell *et al.* 2012, Lowery *et al.* 2013, Mols *et al.* 2013, Tofthagen *et al.* 2013a, Rees *et al.* 2014)
Tingling in Hands	19-100%	(Bennett *et al.* 2012, Kidwell *et al.* 2012, Mols *et al.* 2013, Tofthagen *et al.* 2013a)
Cramps in Hands	21-30%	(Bennett *et al.* 2012, Mols *et al.* 2013)
Numbness in Hands	19-82%	(Kidwell *et al.* 2012, Mols *et al.* 2013, Tofthagen *et al.* 2013a)
Cramps in Feet	29-40%	(Bennett *et al.* 2012, Mols *et al.* 2013)
Numbness in Feet	21-80%	(Kidwell *et al.* 2012, Mols *et al.* 2013, Tofthagen *et al.* 2013a)
Aching or Burning Feet	45-85%	(Bennett *et al.* 2012, Mols *et al.* 2013, Tofthagen *et al.* 2013a)
Sensitivity to Cold	56-100%	(Bennett *et al.* 2012, Tofthagen *et al.* 2013a)
Difficulty Distinguishing Temperature	96%	(Mols *et al.* 2013, Tofthagen *et al.* 2013a)
Difficulty Holding a Pen or Small Objects	11-40%	(Bennett *et al.* 2012, Mols *et al.* 2013)
Difficulty Standing or Walking	44-84%	(Mols *et al.* 2013, Tofthagen *et al.* 2013a)
Difficulty Walking or Climbing Stairs	8-40%	(Bennett *et al.* 2012, Mols *et al.* 2013)
Difficulty Driving	7-24%	(Bennett *et al.* 2012, Mols *et al.* 2013, Tofthagen *et al.* 2013a)
Orofacial Neuropathy	50-80%	(Bennett *et al.* 2012)

Table 3.8 Prevalence of peripheral neuropathy symptoms reported in the colorectal cancer survivorship literature

et al. 2012, Tofthagen *et al.* 2013a). However, these studies are limited by small samples sizes and response rates of less than 50% (Bennett *et al.* 2012, Kidwell *et al.* 2012, Lowery *et al.* 2013, Tofthagen *et al.* 2013a). Furthermore, the results of Mols *et al.* (2013) must be interpreted with caution, as participants diagnosed since 2007 were assumed to have been treated with Oxaliplatin. Bias may arise as this assumption discounts the effect of time since diagnosis and the possibility that some of those diagnosed since 2007 may not have been treated with Oxaliplatin due to clinical contra-indications. Despite this limitation, the study offers a valuable insight into the prevalence of the symptoms of peripheral neuropathy within the population of colorectal cancer survivors due to its large sample size and strong response rate.

The most commonly reported symptoms of peripheral neuropathy are numbness or tingling in the hands or feet. Survivors treated with Oxaliplatin were more likely to report sensory symptoms of peripheral neuropathy (Kidwell *et al.* 2012, Mols *et al.* 2013). The prevalence of these specific symptoms among those treated with Oxaliplatin varies widely, with prevalence rates ranging from 15-29% (Mols *et al.* 2013), 34-72% (Tofthagen *et al.* 2013a), and as high as 90-100% (Bennett *et al.* 2012). In the wider population of colorectal cancer survivors, Mols *et al.* (2013) and Kidwell *et al.* (2012) suggest 19-28% of all colorectal cancer survivors report these symptoms. Peripheral neuropathy interferes with daily activities in up to one-third of colorectal cancer survivors, with symptoms triggered by exposure to the cold while eating, drinking, opening the fridge or freezer or outdoor temperatures (Bennett *et al.* 2012, Mols *et al.* 2013, Tofthagen *et al.* 2013a, Sun *et al.* 2014). Other factors associated with peripheral neuropathy included depressive symptoms, sleep disturbance, pain and time since treatment (Kidwell *et al.* 2012, Tofthagen *et al.* 2013a). Socio-demographic variables were not found to be linked with reports of peripheral neuropathy (Tofthagen *et al.* 2013a).

As peripheral neuropathy is an irreversible side-effect of treatment, survivors must find ways to manage their symptoms. Survivors may use an array of pharmacological and non-pharmacological therapies, including non-steroidal anti-inflammatories, opioids, anti-depressant and anti-convulsant drugs, light exercise, health management strategies, heat and massage therapy. However, for some, these strategies fail to provide symptom relief, and additional measures to adjust and cope with peripheral neuropathy symptoms were necessary (Bennett *et al.* 2012, Tofthagen *et al.* 2013a).

3.4.1.7 Other Physical Symptoms

Additional symptoms experienced by colorectal cancer survivors which are not so widely investigated include urinary dysfunction, amenorrhea, hernia, fistula, dyspnoea, alopecia, taste changes and watering eyes (Gosselink *et al.* 2006, Fucini *et al.* 2008, McMullen *et al.* 2008, Liu *et al.* 2010, Grimmett *et al.* 2011, Jansen *et al.* 2011a, Jansen *et al.* 2011c, Thong *et al.* 2011a, Kilic *et al.* 2012, Cercek *et al.* 2013, Sun *et al.* 2013, Abu-Helalah *et al.* 2014, Bailey *et al.* 2015). However, there is limited information available about each of these symptoms in the literature, negating in-depth analysis of their implications for colorectal cancer survivors.

3.4.2 Psychological Well-Being

Surviving colorectal cancer may have positive and negative psychological outcomes, incorporating fear of recurrence, depression, anxiety, distress, post-traumatic growth and development of coping strategies (Section 2.2.10.2). Generally, international research suggests colorectal cancer survivors' psychological well-being is most detrimentally affected during treatment but seems to improve considerably after treatment (Bouvier *et al.* 2008, Salsman *et al.* 2009, Hoerske *et al.* 2010, Chambers *et al.* 2012b, Kilic *et al.* 2012, Rees *et al.* 2014). Unlike physical and functional domains of quality of life, there is consistent evidence from European studies implying colorectal cancer survivors experience more positive emotional well-being than normative populations (Pucciarelli *et al.* 2008, Serpentini *et al.* 2011, Thong *et al.* 2011a, Orsini *et al.* 2013). However, a small-scale American study (Phipps *et al.* 2008) and a single German study (Jansen *et al.* 2011a) fail to corroborate these findings. This discrepancy may be explained by differences in the average age of samples, as Jansen *et al.* (2011a) recruited survivors between two and five years younger than Pucciarelli *et al.* (2008), Thong *et al.* (2011a), Serpentini *et al.* (2011), and Orsini *et al.* (2013). This suggests younger colorectal cancer survivors may experience greater difficulties with psychological consequences of cancer and its treatment.

3.4.2.1 Psychological Distress

Like physical symptoms, the prevalence of psychological distress among colorectal cancer survivors varies substantially, ranging from 1-44% up to 10 years following diagnosis (Lynch *et al.* 2008c, Phipps *et al.* 2008, Shun *et al.* 2011, Andrykowski *et al.* 2013, Dunn *et al.* 2013b, Mols *et al.* 2014). Longitudinal studies of survivors up to five years post-diagnosis report similar prevalence rates (7-44%), with a trend for decreasing prevalence over time (Lynch *et al.* 2008c, Dunn *et al.* 2013b). Two longitudinal studies conducted by the Queensland Cancer Registry suggest that one-fifth of survivors reporting clinically significant levels of psychological distress report consistently lower levels, while between two-fifths and two-thirds experience consistently high or increasing levels of distress (Lynch *et al.* 2008c, Dunn *et al.* 2013b). However, these results are derived from a single sample of survivors in a regional cancer registry and require corroboration from further international studies.

Socio-demographic and health-related characteristics contributing to higher levels of psychological distress are younger age, male gender, unmarried status, changed employment status, lower socio-economic status, no private health insurance, poorer social, family or spousal support, greater co-morbidity, higher disease stage and worse functional status (Lynch *et al.* 2008c, Goldzweig *et al.* 2009, Chambers *et al.* 2012b, Andrykowski *et al.* 2013, Dunn *et al.* 2013b, Abu-Helalah *et al.* 2014). Both functional and psychosocial symptoms contributed to greater psychosocial distress; fatigue, cancer threat appraisal, anxiety and embarrassment were each associated with rising levels of distress (Lynch *et al.* 2008c, Abu-Helalah *et al.* 2014). Although drawn from the same sampling frame from the Queensland Cancer Registry, the Chambers *et al.* (2012b) finding that levels of psychological distress peaked in survivors who have stage II disease, compared to those with stage I or stage III disease was not replicated in the trajectories of psychological distress described by Dunn *et al.* (2013b). It is difficult to critique differences in sample characteristics which may explain these inconsistent findings, as Dunn *et al.* (2013b) fails to disclose critical demographic and cancer-related characteristics. However, each study utilised differing data analysis techniques. Chambers *et al.* (2012b) sought to analyse the baseline demographic, health and psychosocial factors to predict quality of life and psychosocial distress at five years post-treatment. By comparison, Dunn *et al.* (2013b) sought to map the trajectories of psychosocial distress over the same five-year period.

Few reviewed studies examined somatisation, the manifestation of psychological distress as physical symptoms. However, somatisation is associated with more significant anxiety and depression, higher stage of disease, greater socio-economic disadvantage and worse social support (Chambers *et al.* 2009, Chambers *et al.* 2012b, Dunn *et al.* 2013b). Furthermore, while the intensity of somatisation experienced by colorectal cancer survivors has been found to reduce in the three years following diagnosis, no difference in somatisation scores were observed between diagnosis and five years later (Chambers *et al.* 2009, Chambers *et al.* 2012b, Dunn *et al.* 2013b). It should be noted that much of the literature of psychological distress in colorectal cancer survivorship, including somatisation is drawn from Australian research (Lynch *et al.* 2008c, Chambers *et al.* 2009, Chambers *et al.* 2012b, Dunn *et al.* 2013b). Although some studies are available from Europe, USA, the Middle-East and Asia, many are limited by smaller sample sizes and cross-sectional approaches (Phipps *et al.* 2008, Goldzweig *et al.* 2009, Shun *et al.* 2011, Andrykowski *et al.* 2013, Abu-Helalah *et al.* 2014, Mols *et al.* 2014).

3.4.2.2 Fear of Recurrence

Fear of recurrence has a detrimental effect on the psychological well-being of cancer survivors, potentially exacerbated by follow-up appointments or confrontation with others' experiences of recurrence (McMullen *et al.* 2008, Taylor *et al.* 2011, McCaughan *et al.* 2012). No large-scale study to date estimates the prevalence of fear of recurrence among colorectal cancer survivors. Phipps *et al.* (2008) reported between two-thirds and three-quarters of 30 participants feared a new or recurrent cancer diagnosis. On the other hand, Nikoletti *et al.* (2008) suggest prevalence may be as low as seven percent. A body of qualitative evidence consistently highlights the similarities between the pre-diagnosis symptoms of colorectal cancer and post-treatment bowel dysfunction which may trigger fear of recurrence for some survivors (DeSnoo & Faithfull 2006, Taylor *et al.* 2011, McCaughan *et al.* 2012, Anderson *et al.* 2013). Furthermore, while pain has not been found to influence fear of recurrence (Lowery *et al.* 2013), a more extensive longitudinal study is required to confirm these findings, as this was a cross-sectional pilot study of 99 colorectal cancer survivors.

Longitudinal interviews conducted by McCaughan *et al.* (2012) to explore gendered differences in coping behaviours concluded female survivors were more likely to dwell on uncertainties associated with recurrence. However, many males and females realise that there is little they can do to prevent recurrence and do not wish to allow fear to interfere with their recovery (Taylor *et al.* 2011, McCaughan *et al.* 2012). The grounded theory of the effect of fear of recurrence upon post-operative recovery by Taylor *et al.* (2011) suggests colorectal cancer survivors reduce fear of recurrence by '*guarding*' themselves through a regime of body monitoring, risk reduction and reassurance from others. These findings are supported by a subsequent grounded theory of post-operative recovery (Beech *et al.* 2012). Taylor *et al.* (2011) state that if strategies to guard against recurrence became compulsive, survivors might experience greater anxiety and fear. On the other hand, if survivors reached a point where they were confident in managing their body and the psychological consequences of cancer, fear of recurrence could be mitigated to some degree (Taylor *et al.* 2011).

Future perspective and illness perception are concepts related to fear of recurrence, concerned with survivors' worries about their future health and the perceived threat and emotional impact of illness (Aaronson 2005, Andrykowski *et al.* 2013). Several studies provide reliable evidence suggesting colorectal cancer survivors with ostomies report more negative future perspectives and illness perceptions (Hoerske *et al.* 2010, Thong *et al.* 2011b, Kilic *et al.* 2012, Li *et al.* 2014, Mols *et al.* 2014). Few studies examine the relationship between illness perceptions, future perspectives and socio-demographic, health or cancer-related factors among colorectal cancer survivors. Recent publications suggest future perspectives may be negatively influenced by demographic and health-related factors, including younger age, female gender, co-morbidity, higher tumour stage, metastatic disease, less time since completion of treatment and radiotherapy treatment (Thong *et al.* 2011a, Thong *et al.* 2011b, Kilic *et al.* 2012). Illness perceptions may also be negatively affected by personality type, negative affectivity and lower socio-economic status (Andrykowski *et al.* 2013, Mols *et al.* 2014). Similar to psychological distress, studies evaluating future perspectives and illness perceptions among colorectal cancer survivors are largely drawn from studies conducted in collaboration with the Eindhoven Cancer Registry (Thong *et al.* 2011b, Andrykowski *et al.* 2013, Mols *et al.* 2014). Although smaller scale studies are emerging from Turkey, Germany and China (Hoerske *et al.* 2010, Kilic *et al.* 2012, Li *et al.* 2014), further research is required to examine whether cultural beliefs may influence these outcomes.

Colorectal cancer survivors' appraisal of cancer threat was not found to change over time (Chambers *et al.* 2009), yet greater time since diagnosis was related to increased acceptance of disability among a cohort of 110 survivors up to 16 years post-diagnosis (Chao *et al.* 2010). A cross-sectional survey of 55 colorectal cancer survivors by Salsman *et al.* (2009) partially explain this, as survivors may undergo some degree of post-traumatic growth despite experiencing ongoing post-traumatic stress following treatment. Salsman *et al.* (2009) suggest the two are not correlated. Unlike illness perceptions and future perspectives, having an ostomy was not associated with greater post-traumatic stress symptoms, but older age and greater physical and psychosocial symptoms were (Ristvedt & Trinkaus 2009, Salsman *et al.* 2009). Conversely, depression and anxiety were not accurate predictors of post-traumatic growth, but older age and higher education were (Salsman *et al.* 2009). These findings suggest that although older colorectal cancer survivors may experience greater post-traumatic stress, they may also have a greater capacity for post-traumatic growth in the aftermath of treatment irrespective of whether they experience anxiety and distress. However, as the sample examined in this study is relatively small (*n*=55), further longitudinal research with larger samples is necessary to verify this finding.

3.4.2.3 Anxiety and Depression

Anxiety and depression are widely researched in cancer survivorship. However, there is conflicting evidence surrounding colorectal cancer survivors' risk of anxiety and depression compared to normative populations. A large Dutch study reported survivors are at higher risk of experiencing anxiety and depression than their counterparts in the general population (Thong *et al.* 2013). Meanwhile, a smaller, earlier study of colorectal cancer survivors in Italy concluded that survivors have significantly less anxiety and depressed mood than population norms, particularly older survivors (Serpentini *et al.* 2011). Several factors may explain these deviations. Firstly, the sample surveyed by Serpentini *et al.* (2011) was smaller, analysing a cross-sectional group of survivors between two and 15 years post-diagnosis, of whom almost half had stage I disease. In contrast, fewer than one-third of Thong *et al.* (2013) participants had stage I disease, and the sample was separated into two groups (<5 years or ≥5 years post-diagnosis). It is entirely possible that those who were further from diagnosis may experience less disease-related anxiety and depression (Chambers *et al.* 2009, Salsman *et al.* 2009). Therefore, the pooling of data by Serpentini *et al.* (2011) may limit the generalisability of these findings.

There is considerable consensus across several large-scale studies of European and American colorectal cancer survivors that the prevalence of depression falls between 18% and 25% (Krouse *et al.* 2009, Buffart *et al.* 2012, Andrykowski *et al.* 2013, Thong *et al.* 2013, Abu-Helalah *et al.* 2014). In contrast, longitudinal (Lynch *et al.* 2008c, Chambers *et al.* 2012b) and cross-sectional (Nikoletti *et al.* 2008) studies of Australian colorectal cancer survivors report prevalence rates as low as four to nine percent. Among ostomates, depressive symptoms are evident in as many as two-fifths more than five years after treatment (Krouse *et al.* 2009). Likewise, several studies report frequencies of 20-28% for anxiety in survivors between one and 10 years post-diagnosis (Buffart *et al.* 2012, Andrykowski *et al.* 2013, Thong *et al.* 2013, Mols *et al.* 2014, Rees *et al.* 2014, Bailey *et al.* 2015). However, four of these six reports are from the Patient-Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship (PROFILES) system, which is linked to the Eindhoven Cancer Registry (Buffart *et al.* 2012, Andrykowski *et al.* 2013, Thong *et al.* 2013, Mols *et al.* 2014). These studies may use overlapping data, introducing a source of bias to the literature. Despite this, recent British and American studies support the findings of results reported from the PROFILES data (Rees *et al.* 2014, Bailey *et al.* 2015). In a pattern similar to the depression literature, Australian and Asian studies have reported much lower rates of anxiety among colorectal cancer survivors, ranging between two and 13% (Lynch *et al.* 2008c, Nikoletti *et al.* 2008, Shun *et al.* 2011, Chambers *et al.* 2012b, Abu-Helalah *et al.* 2014).

Cultural factors or differences in familial and professional support may contribute to lower rates of anxiety and depression in Australian and Asian studies. However, comparative multinational studies are necessary to determine this hypothesis. Further explanations for variability in the prevalence of anxiety and depression in international studies may relate to the survey instruments used. Most notably, studies reporting the lowest rates of anxiety and depression used the Brief Symptom Inventory (Lynch *et al.* 2008c, Chambers *et al.* 2012b), while higher rates were reported by those using the Hospital Anxiety and Depression Scale (Buffart *et al.* 2012, Andrykowski *et al.* 2013, Thong *et al.* 2013, Mols *et al.* 2014).

Socio-demographic factors associated with greater anxiety and depression included younger age, female gender, lower education, lower socio-economic status, less social support, having a type D personality, co-morbidity, higher stage of disease and shorter time since diagnosis (Krouse *et al.* 2009, Shun *et al.* 2011, Mols *et al.* 2012a, Andrykowski *et al.* 2013, Dunn *et al.* 2013b, Milbury *et al.* 2013, Thong *et al.* 2013, Abu-Helalah *et al.* 2014, Bailey *et al.* 2015). However, two longitudinal survey studies suggest a greater decline in anxiety occurs among those with metastatic stage disease (Chambers *et al.* 2012b, Rees *et al.* 2014). Other factors associated with increased anxiety, but not depression, were unmarried status, greater social difficulty, treatment with chemotherapy, diagnosis of a second primary cancer, and symptoms of back pain, diarrhoea, fatigue and embarrassment (Jansen *et al.* 2011c, Chambers *et al.* 2012b, Thong *et al.* 2013, Abu-Helalah *et al.* 2014). Factors which were related to greater prevalence of depression, but not anxiety, were rural residence, changed employment status, not having a pet, not having health insurance, experience of early post-operative complications, diarrhoea and anxiety (Jansen *et al.* 2011c, Serpentini *et al.* 2011, Chambers *et al.* 2012b, Abu-Helalah *et al.* 2014). The evidence surrounding the influence of an ostomy on colorectal cancer survivors' experience of anxiety and depression is mixed. Although Mols *et al.* (2014) concluded no effect, other cross-sectional studies suggest greater anxiety and depression among females with ostomies (Krouse *et al.* 2009). Greater depression was noted among ostomates in small and large-scale quantitative and mixed methods studies (Krouse *et al.* 2009, Grant *et al.* 2011, Abu-Helalah *et al.* 2014).

3.4.2.4 Body Image

Due to substantial treatment-related changes in bodily function, body image is one of the psychosocial consequences which has received widespread attention in colorectal cancer survivorship research. Adverse perceptions of body image are reported by 14-47% of colorectal cancer survivors (Schneider *et al.* 2007, Phipps *et al.* 2008, Sisler *et al.* 2012b, Bailey *et al.* 2015). Previous studies consistently highlight how changes in body image can have a detrimental impact on colorectal cancer survivors' intimate relationships, levels of anxiety and social well-being due to concerns about bowel dysfunction and odour (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Ramirez *et al.* 2009, Grant *et al.* 2011, Abu-Helalah *et al.* 2014). Ostomy formation is a frequently cited factor contributing to negative body image, affecting survivors' sexual relationships and psychological and social well-being (Gosselink *et al.* 2006, Schneider *et al.* 2007, Fucini *et al.* 2008, Pucciarelli *et al.* 2008, Krouse *et al.* 2009, Ramirez *et al.* 2009, Hoerske *et al.* 2010, Grant *et al.* 2011, Kilic *et al.* 2012, Palmer *et al.* 2013, Li *et al.* 2014, Mols *et al.* 2014, Ramirez *et al.* 2014). As described in Section 2.2.9.4, survivors hide away by concealing the ostomy or avoiding situations where the ostomy could be seen by others to avoid embarrassment or vulnerability. This contributed to withdrawal from or altered approaches to sexual intimacy with their partners (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Altschuler *et al.* 2009, Ramirez *et al.* 2009, Grant *et al.* 2011). Characteristics such as female gender, younger age, co-morbidity, diagnosis of rectal cancer, higher stage disease, shorter time since treatment, radiotherapy, chemotherapy or greater sexual dysfunction were associated with poorer body image perceptions (Di Fabio *et al.* 2008, Pucciarelli *et al.* 2008, Krouse *et al.* 2009, Hoerske *et al.* 2010, Grant *et al.* 2011, Thong *et al.* 2011a, Thong *et al.* 2011b, Kilic *et al.* 2012, Knowles *et al.* 2013, Abu-Helalah *et al.* 2014, Bailey *et al.* 2015).

3.4.3 Social Well-Being

The experience of colorectal cancer and its physical and psychological consequences have considerable repercussions for survivors' social well-being, influencing social activities, financial status, and personal, professional and intimate relationships (DeSnoo & Faithfull 2006, Di Fabio *et al.* 2008, McMullen *et al.* 2008, Krouse *et al.* 2009, Ramirez *et al.* 2009, Grant *et al.* 2011, Jansen *et al.* 2011a, Jansen *et al.* 2011c, Shun *et al.* 2011, Kilic *et al.* 2012, McCaughan *et al.* 2012, Milbury *et al.* 2013). The impact of colorectal cancer on social well-being is worst between diagnosis and the early post-treatment period, as survivors adjust to disease- and treatment-related changes in bodily function (Jansen *et al.* 2011a, Kilic *et al.* 2012, Rees *et al.* 2014). Qualitative studies suggest that colorectal cancer survivors may achieve mastery of bodily changes following treatment, regaining some aspects of their normal life before cancer (DeSnoo & Faithfull 2006, McCaughan *et al.* 2012). Unfortunately, conflicting evidence from European studies fails to verify whether colorectal cancer survivors experience greater (Pucciarelli *et al.* 2008, Thong *et al.* 2011a) or worse (Caravati-Jouvenceaux *et al.* 2011, Domati *et al.* 2011, Jansen *et al.* 2011a) social well-being than comparable general populations. Of the studies comparing colorectal cancer survivors' quality of life to normative populations, one utilised a prospective longitudinal design (Jansen *et al.* 2011a), the remaining undertook cross-sectional surveys. All except Thong *et al.* (2011a) were limited by low response rates or relatively small sample sizes (Pucciarelli *et al.* 2008, Domati *et al.* 2011, Jansen *et al.* 2011a). Moreover, the instruments used to measure quality of life may confuse conclusions, as several use generic quality of life instruments which fail to adequately capture the effect of cancer-related symptoms on various aspects of quality of life (Caravati-Jouvenceaux *et al.* 2011, Domati *et al.* 2011, Thong *et al.* 2011a). Finally, cultural influences may also impact upon survivors' social well-being, particularly the availability and importance placed upon familial and societal support during illness. Therefore, further evidence is required internationally to clarify the discrepancies in these findings.

3.4.3.1 Financial Difficulty and Returning to Work

Between one- and two-fifths of survivors may experience financial hardship after colorectal cancer (Gordon *et al.* 2008, Costrini 2011, Abu-Helalah *et al.* 2014, Thomas *et al.* 2014), of whom one-fifth may have financial difficulty pre-dating their cancer diagnosis (Gordon *et al.* 2008). Although the extent of financial difficulty may reduce over time (Kilic *et al.* 2012, Li *et al.* 2014), a cross-sectional study of 312 long-term colorectal cancer survivors suggests this group may experience greater financial difficulty that individuals who have not had cancer up to 10 years after diagnosis (Jansen *et al.* 2011c). In studies of working-age colorectal cancer survivors, most participants took temporary leave from the workforce when diagnosed (Gordon *et al.* 2008, Carlsen *et al.* 2013, Hanly *et al.* 2013, Hauglann *et al.* 2014). Up to two-fifths leave the workforce permanently (Domati *et al.* 2011, Hanly *et al.* 2013) and one-third return to work on reduced working hours (Gordon *et al.* 2008, Hanly *et al.* 2013).

A retrospective study of the employment status of 4,343 colorectal cancer survivors on a weekly basis in the first year following diagnosis in Denmark revealed that those who successfully return to the workforce are more likely to have further illness-related absences from work (Carlsen *et al.* 2013). The physical and psychological implications of a cancer diagnosis may affect the survivor's ability to work. Therefore, younger survivors may experience greater financial difficulty (Li *et al.* 2014). However, other factors including male gender, rural dwelling, shorter time since treatment, metastatic disease, and treatment with radiotherapy are related to financial difficulties (Krouse *et al.* 2009, Kilic *et al.* 2012, Knowles *et al.* 2013, Abu-Helalah *et al.* 2014, Li *et al.* 2014, Thomas *et al.* 2014). Despite the financial implications of a change in work status, socio-economic status was not found to influence employment or sickness absence one year following diagnosis. Indeed, lower disposable income was associated with a greater likelihood of illness absence, retirement, and a lower probability of returning to work (Carlsen *et al.* 2013). Earlier withdrawal from the workforce was linked to lower levels of education, manual-type work, co-morbidity, childlessness, rectal cancer, higher disease stage, post-operative complications and radiotherapy or chemotherapy treatment (Gordon *et al.* 2008, Carlsen *et al.* 2013, Hauglann *et al.* 2014). In addition, survivors who were on sick leave, unemployed or working reduced hours before diagnosis were more likely to exit the workforce early (Gordon *et al.* 2008, Carlsen *et al.* 2013, Hauglann *et al.* 2014). Although health insurance was associated with the likelihood of leaving the workforce permanently, it was not associated with any differences in financial concerns reported by colorectal cancer survivors (Li *et al.* 2014). Health insurance status may be indicative of socio-economic status in the study by Li *et al.* (2014), which appears to contradict the findings of Carlsen *et al.* (2013) regarding lower socio-economic status and permanent departures from the workforce. Variations in models of healthcare provision (universal/semi-private/private) between Denmark and China may also account for these differences. A lack of information about colorectal cancer survivors' treatment history limited the interpretation of studies examining return to work patterns among colorectal cancer survivors and represents an area requiring further investigation (Carlsen *et al.* 2013, Hanly *et al.* 2013, Hauglann *et al.* 2014).

3.4.3.2 Impact of Colorectal Cancer Survivorship Upon Social Activities

The physical consequences of colorectal cancer may result in withdrawal from normal social activities due to concerns about bowel or ostomy management in the early stages of survivorship (DeSnoo & Faithfull 2006, Grant *et al.* 2011, McCaughan *et al.* 2012, Sisler *et al.* 2012b). Males and females with ostomies experience greater difficulty with isolation, personal relationships, intimacy, travel and social activities due to embarrassment arising from bowel dysfunction (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Krouse *et al.* 2009, Grant *et al.* 2011, Taylor *et al.* 2011, McCaughan *et al.* 2012, Ramirez *et al.* 2014, Sun *et al.* 2014). To negotiate social situations, colorectal cancer survivors needed to map toilets and carry a protection package including clothing and cleaning supplies in the event of an accident (Nikoletti *et al.* 2008, Grant *et al.* 2011, McCaughan *et al.* 2012, Ball *et al.* 2013, Sun *et al.* 2013, Ramirez *et al.* 2014). In addition to the extensive dietary modifications required to manage bowel dysfunction, these necessities created additional barriers to survivors' participation in social activities (Lynch *et al.* 2008b, Ball *et al.* 2013, Ramirez *et al.* 2014, Sun *et al.* 2014). However, as colorectal cancer survivors gained confidence in bowel management strategies, so too did their willingness to re-engage aspects of their pre-diagnosis social life (DeSnoo & Faithfull 2006, McCaughan *et al.* 2012). Regardless of survivors' perceptions of their quality of life, support from healthcare professionals, family and friends were imperative to survivors' confidence, psychological well-being and re-engagement with social activities (McMullen *et al.* 2008, Grant *et al.* 2011). The importance of support networks are discussed further in Section 3.4.3.3.

3.4.3.3 Support Networks

Support from the members of colorectal cancer survivors' social and professional networks facilitate survivors' adjustment to a *'new normal'* after treatment (Ramirez *et al.* 2009, Taylor *et al.* 2011, Appleton *et al.* 2013, Le *et al.* 2014). Two qualitative studies in the UK suggest colorectal cancer survivors may feel abandoned by healthcare professionals and support structures after treatment. As the frequency of contact with healthcare professionals decreased, so too did survivors' perception of access to information and support, contributing to psychological distress in some cases (Taylor *et al.* 2011, McCaughan *et al.* 2012). However, tangible and intangible support from survivors' family and community take on greater importance during this period, helping survivors to cope with symptoms, adhere to surveillance programmes and achieve a sense of normality (McMullen *et al.* 2008, Altschuler *et al.* 2009, Ramirez *et al.* 2009, McMullen *et al.* 2011, Taylor *et al.* 2011, Appleton *et al.* 2013, Le *et al.* 2014). Fortunately, few colorectal cancer survivors experience negative changes in relationships with their family or social network after diagnosis; some may find new strength in their relationships (Nikoletti *et al.* 2008). For the most part, survivors felt assured that support from family members was certain (Le *et al.* 2014). Although males report lower levels of support overall, they are likely to derive greater support from their spouse and religious resources, while females are more likely to obtain support from their circle of friends (Goldzweig *et al.* 2009, Krouse *et al.* 2009). Spousal support is integral to female survivors' resumption of sexual activity and adjustment to the presence of an ostomy (Altschuler *et al.* 2009, Ramirez *et al.* 2009).

Few studies investigate the role of cancer survivors' social networks in recovery following colorectal cancer. Religious communities appear to play an important role in survivors' psychological well-being, as survivors may derive strength from the prayers of others (Le *et al.* 2014). However, specific discussion of cancer survival with friends could cause survivors anxiety and vulnerability when they received unsolicited or inappropriate advice about their disease, deterring survivors from engaging in such discussions (Taylor *et al.* 2011). Peer support from other survivors held positive and negative potential. Survivors benefited from the support and advice of disease-free survivors, feeling free to discuss specifics of their disease (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Beech *et al.* 2012, Anderson *et al.* 2013, Palmer *et al.* 2013, Le *et al.* 2014, Sun *et al.* 2014). However, fear of recurrence and survivor guilt could be triggered when confronted with others' experiences of cancer recurrence. Therefore, some survivors expressed caution about participating in such programmes (McMullen *et al.* 2008).

Up to four-fifths of early-stage colorectal cancer survivors report using some form of complementary or alternative medicine to cope with their cancer, including food supplements, and spiritual or non-spiritual mind-body methods. Factors associated with the use of complementary and alternative medicine included younger age, female gender, higher education, chemotherapy, radiotherapy, fatigue, anxiety, psychological distress and fear of recurrence (Stein *et al.* 2009).

3.4.4 Spiritual Well-Being

Few studies examine spiritual well-being in colorectal cancer survivors. In many cases, findings relating to spiritual well-being arose incidentally within qualitative quality of life research. Therefore, the information is narrow in scope, exploring meaning-making, benefit finding, resilience and altruism (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Ramirez *et al.* 2009, Grant *et al.* 2011, Beech *et al.* 2012, Appleton *et al.* 2013, Palmer *et al.* 2013). Two studies from Taiwan and the USA suggest colorectal cancer survivors experience high levels of spirituality and spiritual well-being (Au *et al.* 2012b, Bulkley *et al.* 2013). Many survivors express a new-found appreciation for life, drawing strength from religious faith and rediscovering life-priorities (DeSnoo & Faithfull 2006, Jansen *et al.* 2011b, Taylor *et al.* 2011, Appleton *et al.* 2013, Bulkley *et al.* 2013). However, one-third of survivors are at risk of low life satisfaction, heightened by factors including younger age, lower education, poor social support, worse cancer threat appraisal and lower optimism (Dunn *et al.* 2013a).

Quantitative studies suggest religious faith and spiritual meaning or peace may enhance quality of life, psychological well-being, coping, resourcefulness and adherence to colorectal cancer surveillance programmes, even though they are not related to survivors' concerns about future health (Salsman *et al.* 2011, Au *et al.* 2012b, Bulkley *et al.* 2013, Le *et al.* 2014, Li *et al.* 2014). Neither demographic nor cancer-related variables affect the spirituality of rectal cancer survivors; however, spirituality was related to greater communication, sexual relationships and sexuality (Au *et al.* 2012b). It is estimated almost two-thirds of colorectal cancer survivors experience moderate or high levels of benefit finding, in which the survivor reassigns positive value to the experience of illness, through the identification of beneficial aspects of the experience (Jansen *et al.* 2011b). Benefit finding was associated with lower levels of depression, but not quality of life in a survey of 483 colorectal cancer survivors in Germany (Jansen *et al.* 2011b). The findings of focus groups conducted by Grant *et al.* (2011) in the USA support those of Jansen *et al.* (2011b), as benefit finding is discussed by colorectal cancer survivors regardless of their quality of life scores.

3.4.5 Summary: Quality of Life After Colorectal Cancer

The theme *Quality of Life After Colorectal Cancer* has described the overall trajectories of quality of life after colorectal cancer, and the experience, prevalence and factors associated with disease-related side-effects. The theme highlights that although colorectal cancer survivors' quality of life may improve over time, a substantial proportion of survivors may live with physical, psychological and social symptoms. Younger survivors appear to be at greater risk of experiencing psychological and social difficulties. Analysis of the literature suggests that older survivors may be better equipped to address psychological distress, anxiety and depression, and may have a greater capacity to engage in post-traumatic growth. However, these results are derived from cross-sectional studies of small samples, and further longitudinal work with larger samples is required to confirm these findings. Response shift or positive reframing are cited by several authors as an explanation for colorectal cancer survivors' positive evaluations of quality of life despite significant symptom burden. Furthermore, survivors may derive benefits from their experience, including post-traumatic growth, resilience and altruism.

Nevertheless, there are significant inconsistencies in the prevalence of physical and psychological symptoms. These inconsistencies may be due to the variety of quality of life and symptom assessment instruments. For the most part, symptom prevalence was assessed using items derived from generic, cancer-related and colorectal cancer-specific quality of life instruments. Even in studies using symptom-specific instruments, multiple instruments were used to assess the same concept, most notably for peripheral neuropathy, anxiety and depression. A further limitation of the reviewed literature is the predominantly quantitative approach to quality of life evaluation (*n*=75). Although a small number of studies explore colorectal cancer survivors' quality of life and symptom experiences from qualitative (*n*=13) and mixed methods (*n*=6) perspectives, there limited understanding of survivors' experiences of living with the side-effects of colorectal cancer, particularly pain, peripheral neuropathy, anxiety and depression. The value of qualitative evidence in this literature is clear from the detail available regarding survivors' fear of recurrence and the cross-domain impact of physical symptoms upon psychological and social well-being.

Given the inconsistencies in symptom prevalence, it is necessary to explore these issues in the current study, to provide context for survivors' healthcare experiences and their relation to quality of life outcomes. The use of a mixed methods approach provides the opportunity to probe survivors' experiences of quality of life and living with the disease-related consequences in greater depth, providing a more meaningful understanding of survivors' quality of life and the needs and healthcare experiences which may influence them. In the next theme, the literature describing colorectal cancer survivors' experiences of healthcare is discussed.

3.5 Healthcare Experiences of Colorectal Cancer Survivors

The concept analysis established follow-up care as a key attribute of colorectal cancer survivorship, highlighting how the complexity, fragmentation and variance of follow-up healthcare may cause uncertainty and confusion among survivors. Clinical time constraints may result in the prioritisation of surveillance for recurrence over assessment and management of chronic symptoms arising from cancer treatment, creating unmet health and information needs for survivors (Section 2.2.9.6). Therefore, the purpose of this section is to synthesise the literature pertaining to colorectal cancer survivors' healthcare experiences and the factors associated with these experiences.

3.5.1 Models of Care

Due to the complex, multi-modal nature of treatment for colorectal cancer, follow-up healthcare for cancer survivors may be led by or shared between primary, secondary and tertiary healthcare providers with different specialisations (IoM 2006). A grounded theory study by Appleton *et al.* (2013) suggests egalitarian partnerships with multidisciplinary healthcare professionals in survivorship care are pivotal to colorectal cancer survivors' recovery. Although many survivors speak favourably of their follow-up care, a number of qualitative studies suggest survivors develop feelings of abandonment, loss of autonomy, insufficient continuity of care or lack clarity on their plan of care as the frequency of contact with healthcare professionals reduces after treatment (Haggstrom *et al.* 2009, Taylor *et al.* 2011, Beech *et al.* 2012, McCaughan *et al.* 2012, Sisler *et al.* 2012b, Palmer *et al.* 2013, Johansson *et al.* 2014, Pisu *et al.* 2014). However, several studies suggest health efficacy may be an important mediator of expectations of care after treatment. Some survivors adopt responsibility for their recovery, implementing health behaviour goals, self-management strategies, engaging with decision-making and organisation of follow-up appointments (Cardella *et al.* 2008, Taylor *et al.* 2011, Beech *et al.* 2012, Appleton *et al.* 2013, Palmer *et al.* 2013, Sun *et al.* 2014). However, the generalisability of these findings are limited by their predominantly qualitative nature. In addition, these studies were mostly conducted in British (Taylor *et al.* 2011, Beech *et al.* 2012, McCaughan *et al.* 2012, Appleton *et al.* 2013) and North American settings (Cardella *et al.* 2008, Haggstrom *et al.* 2009, Sisler *et al.* 2012b, Palmer *et al.* 2013, Pisu *et al.* 2014, Sun *et al.* 2014), which operate universal and privatised models of healthcare, respectively. Therefore, further research is needed internationally to determine the transferability of findings to other contexts, and with larger, quantitative samples.

The speciality of the healthcare professional leading cancer-related follow-up care varies internationally and continues to change as models of follow-up care evolve (Snyder *et al.* 2008b, 2008a). Currently, medical oncologists or primary care practitioners are most often responsible for follow-up care in Europe and the USA (Snyder *et al.* 2008b, Baravelli *et al.* 2009, Sisler *et al.* 2012b, Mols *et al.* 2014). However, most colorectal cancer survivors report follow-up from multiple healthcare professionals, with varying outcomes between disciplines (Baravelli *et al.* 2009, Haggstrom *et al.* 2009, Sisler *et al.* 2012b, Mols *et al.* 2014). For example, a Canadian study of 246 colorectal cancer survivors found primary care-led follow-up was associated with lower illness interference and greater continuity of care (Sisler *et al.* 2012b). However, for survivors receiving primary care-led follow-up, multivariate modelling suggested quality of life was a significant predictor of continuity of care (n=106) (Sisler *et al.* 2012b). An earlier survey study by Haggstrom *et al.* (2009) reported that survivors attending primary care-led follow-up in the USA were less likely to have medical tests, but more liable to have physical examinations and receive lifestyle and disease-prevention information compared to those in oncologist-led follow-up. Nevertheless, perceptions about quality of care did not differ between disciplines or specialties (Haggstrom *et al.* 2009).

Although few studies examine the implications of nurse-led follow-up in colorectal cancer survivorship, evidence from qualitative studies suggest specialist nurses play a fundamental role in ostomy-related education, psychosocial support and symptom management (McMullen *et al.* 2008, Anderson *et al.* 2013, Sun *et al.* 2014). Nurses are an under-recognised resource for follow-up care in some cultural contexts; up to half of colorectal cancer survivors expressed a preference for surveillance appointments to be managed by physicians in a mixed method study conducted in Australia (Baravelli *et al.* 2009). Aside from local guidelines which specify the profession or speciality of the healthcare professional leading survivors' follow-up care, factors such as age, co-morbidity, ethnicity, time since treatment and stage of disease play a role in determining the multidisciplinary network and frequency of contact with healthcare professionals (Snyder *et al.* 2008a, 2008b). Survivors enrolled in shared-care are more likely to be younger, female, have greater co-morbidity and more advanced disease (Snyder *et al.* 2008a). Older survivors with more comorbidities visit their primary care practitioner more often, while those with higher stage disease have greater contact with their oncologist (Snyder *et al.* 2008b, Haggstrom *et al.* 2009). Although these studies provide a profile of the survivors who receive follow-up from particular healthcare professionals, all were conducted in the USA which has a predominantly privatised healthcare system, limiting the generalisability of results. There is a need to better understand colorectal cancer survivors' preferences, patterns and perceptions of care in other countries so that interventions to support survivors may be optimised to address differences in health service provision models.

3.5.2 Follow-up Surveillance

As outlined in Section 1.5, the frequency of follow-up surveillance after colorectal cancer decreases with time since diagnosis, but in general, comprises two to four clinic visits per year for five years, with coinciding CEA testing, CT scanning and colonoscopy. Although colorectal cancer survivors are cognisant of the need for ongoing monitoring for recurrence, a number of retrospective cohort studies suggest between four and 75% of colorectal cancer survivors do not receive recommended surveillance (Cooper & Payes 2006, Cardella *et al.* 2008, Cooper *et al.* 2008, Di Fabio *et al.* 2008, Hu *et al.* 2011, Brawarsky *et al.* 2013, Palmer *et al.* 2013, Standeven *et al.* 2013, Pisu *et al.* 2014, Salz *et al.* 2014). Rates of under-surveillance vary for colonoscopy (6-58%), CT (14-91%), CEA (18-71%) and clinical consultations (8-30%), but may be influenced by planned delays in surveillance which are not captured by hospital audit systems (Cooper & Payes 2006, Cardella *et al.* 2008, Cooper *et al.* 2008, Kunitake *et al.* 2010, Hu *et al.* 2011, Foley *et al.* 2012, Sisler *et al.* 2012a, Brawarsky *et al.* 2013, Standeven *et al.* 2013, Watanabe-Galloway *et al.* 2014). Conversely, over one-fifth of survivors receive surveillance above the recommended levels, and up to 27% may not receive any follow-up care (Cooper *et al.* 2008, Haggstrom *et al.* 2009, Mols *et al.* 2014). These findings could be due to survivors' lack of awareness of healthcare professionals' roles in shared models of care or a lack of continuity of care (Cardella *et al.* 2008, Johansson *et al.* 2014, Sun *et al.* 2014). No matter the reason, such shortfalls in care underscore the need for healthcare professionals to agree each provider's responsibility in surveillance and follow-up, as up to 80% of recurrences are diagnosed via routine surveillance (Standeven *et al.* 2013).

Socio-demographic, socio-economic and cancer-related characteristics influence the likelihood of adequate surveillance. Survivors who are younger, have private health insurance, are of higher socio-economic status and have fewer co-morbidities are consistently more likely to receive recommended surveillance (Cooper *et al.* 2008, Kunitake *et al.* 2010, Salz *et al.* 2010, Hu *et al.* 2011, Foley *et al.* 2012, Parsons *et al.* 2012, Sisler *et al.* 2012a, Brawarsky *et al.* 2013, Le *et al.* 2014). Furthermore, those with colon cancer, higher stage disease, greater risk of recurrence and treated with chemotherapy are more likely to undergo recommended colonoscopy, CEA and CT surveillance (Cooper *et al.* 2008, Sigurdsson *et al.* 2009, Salz *et al.* 2010, Hu *et al.* 2011, Foley *et al.* 2012, Sisler *et al.* 2012a, Brawarsky *et al.* 2013, Le *et al.* 2014, Pisu *et al.* 2014, Tan *et al.* 2014, Watanabe-Galloway *et al.* 2014).

The frequency of appointment with and ease of access to primary care practitioners, oncologists and surgeons is correlated with the probability of appropriate surveillance (Salz *et al.* 2010, Sisler *et al.* 2012a, Brawarsky *et al.* 2013, Pisu *et al.* 2014). A single retrospective cohort study conducted in the USA suggests male and married colorectal cancer survivors are more likely to achieve recommended levels of surveillance (Hu *et al.* 2011); however, further research is required to confirm these findings. The effect of urban or rural residence in adherence to follow-up is disputable, with an equal number of studies favouring rural (Sigurdsson *et al.* 2009, Foley *et al.* 2012, Sisler *et al.* 2012a) and urban (Cooper *et al.* 2008, Hu *et al.* 2011, Watanabe-Galloway *et al.* 2014) residence. Although all studies used retrospective cohort designs and were mostly conducted in North America, it should be noted that the studies which reported greater adherence to follow-up by rural residents included samples that were smaller and younger on average, with a shorter time since diagnosis. It is conceivable that younger, more recently diagnosed survivors would be more likely to engage in prescribed follow-up due to the association of these characteristics with fear of recurrence (Section 3.4.2.2).

Finally, ethnic disparities in surveillance are well-documented in American cancer survivorship literature. African-Americans are less likely to receive colonoscopy or CEA testing (Cooper *et al.* 2008, Hu *et al.* 2011, Brawarsky *et al.* 2013). While rates of surveillance reduce over time for all ethnic groups, the rate of decline was most significant among ethnic minority groups in the USA (Brawarsky *et al.* 2013). However, other explanations for non-adherence to surveillance guidelines include planned or unplanned clinical delays in testing, survivors' interest, knowledge and understanding of the rationale for surveillance, and willingness to participate in surveillance (Salz *et al.* 2009, Standeven *et al.* 2013, Pisu *et al.* 2014).

3.5.3 Barriers and Facilitators of Follow-up Care

The concept analysis established a wealth of health, information and support needs experienced by colorectal cancer survivors. Information needs were generic and specific and included the need for diagnostic and prognostic information, lifestyle advice, psychosocial support and supportive care specific to the side-effects of colorectal cancer. Survivors have an implicit trust in healthcare professionals to assist them in recovery and may therefore take a submissive approach to information acquisition due to perceived clinical time constraints, uncertainty about the questions to ask and hope to retain a positive outlook upon their prognosis (Di Fabio *et al.* 2008, Baravelli *et al.* 2009, Taylor *et al.* 2011, Beech *et al.* 2012, Ball *et al.* 2013, Johansson *et al.* 2014, Sun *et al.* 2014). Survivors receive a substantial amount of information about recovery and long-term effects.

However, consumption and processing of this information is a challenge, as much is delivered verbally in tandem with diagnostic and treatment milestones (Johansson *et al.* 2014).

Difficulty understanding information provided by healthcare professionals is amplified by competing time constraints in clinical settings, provision of information that is not tailored to survivors' needs, low levels of health literacy, insufficient supporting documentation, lack of continuity of care, conflicting information from various healthcare practitioners and survivors' lack of understanding of the rationale for recommended interventions. Together, these barriers result in confusion, isolation, a loss of autonomy and a lack of preparation for survivorship issues (Nikoletti *et al.* 2008, Ramirez *et al.* 2009, Beech *et al.* 2012, Bennett *et al.* 2012, Anderson *et al.* 2013, Appleton *et al.* 2013, Husson *et al.* 2014, Johansson *et al.* 2014, Sun *et al.* 2014). Uncertainty about who to contact for advice or assistance, and doubts about the validity of problems eroded survivor's autonomy, perceptions of continuity of care and confidence to make contact with healthcare practitioners between appointments (Cardella *et al.* 2008, Baravelli *et al.* 2009, Beech *et al.* 2012, Sisler *et al.* 2012b, Johansson *et al.* 2014).

Colorectal cancer survivors average four visits to oncology specialists and primary care practitioners each year (Mols *et al.* 2014). For many survivors, surveillance activities take priority over psychosocial care, with 45-93% of survivors reporting insufficient evaluation of physical or psychosocial symptoms (Esplen *et al.* 2007, Di Fabio *et al.* 2008, McMullen *et al.* 2008, Nikoletti *et al.* 2008, Phipps *et al.* 2008, Baravelli *et al.* 2009, Haggstrom *et al.* 2009, Vadaparampil *et al.* 2010, Grant *et al.* 2011, Beech *et al.* 2012, McCaughan *et al.* 2012, Pullar *et al.* 2012, Sisler *et al.* 2012b, Anderson *et al.* 2013, Ball *et al.* 2013, Knowles *et al.* 2013). Studies from the USA and UK suggest surveillance activities may be prioritised over the management of non-critical side-effects during follow-up, even though concerns about side-effects such as sexual dysfunction become more prominent during this period when the threat to life is less acute (Ramirez *et al.* 2009, Ellis *et al.* 2010, Ball *et al.* 2013). Indeed, female survivors verbalised regret over the lack of emphasis placed on the importance of using vaginal dilators to reduce the impact of radiotherapy-related sexual dysfunction (Ramirez *et al.* 2009).

Access to formal support from healthcare professionals diminishes in the aftermath of treatment due to less frequent appointments (Taylor *et al.* 2011, Beech *et al.* 2012, McCaughan *et al.* 2012, Sisler *et al.* 2012b, Johansson *et al.* 2014). At this point, survivors may increase contact with primary care practitioners due to ease of access and established relationships (Haggstrom *et al.* 2009, Salz *et al.* 2009, Beech *et al.* 2012, Mols *et al.* 2014). Despite this, survivors do not always view primary care practitioners as a reliable or reassuring source of cancer-related information due to the generalist nature of their practice (Beech *et al.* 2012). Survivors with ostomies are likely to have more frequent interactions with oncology healthcare professionals due to the need for surgical intervention and ostomy-related complications (Liu *et al.* 2010, Mols *et al.* 2014). Although there is little difference in satisfaction with follow-up care between those with or without ostomies, ostomates may receive greater support from healthcare professionals due to the implications of having an ostomy (Mols *et al.* 2014). It follows that colorectal cancer survivors without ostomies may require formal psychosocial support from other sources, such as counselling or support groups. However, the small number of studies examining patterns of support suggest few survivors engage with these resources due to a lack of local availability or awareness of support services (Sisler *et al.* 2012b, Anderson *et al.* 2013, Ball *et al.* 2013, Abu-Helalah *et al.* 2014, Salz *et al.* 2014).

Strategies which have been proposed to enhance survivors' follow-up care include transparency from healthcare practitioners regarding long-term treatment effects, fostering greater patient involvement in treatment-related decisions and use of survivorship care plans (Baravelli *et al.* 2009, Appleton *et al.* 2013). Survivorship care plans may enhance the implementation of shared-care models, ensuring dissemination of accurate diagnostic, treatment and surveillance information to the patient and other care providers, thereby improving the survivor's autonomy, and offering reassurance regarding long-term effects and risk factors for recurrence or secondary cancers (Baravelli *et al.* 2009). However, competent, experienced practitioners who provided comprehensive information and taught self-management skills created positive experiences for colorectal cancer survivors (Sun *et al.* 2014).

3.5.4 The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life

This chapter has illuminated the prevalence of physical, psychological and social issues in colorectal cancer survivorship (Section 3.4). Further insights include survivors' perceptions of reduced support from healthcare professionals after treatment and potential prioritisation of surveillance activities; hindering symptom management (Section 3.5.3) and contributing to unmet health, information and support needs (Section 2.2). Despite this knowledge, a topic that is seldom explicitly addressed in the colorectal cancer survivorship literature is the impact of healthcare experiences on colorectal cancer survivors' quality of life. This section will critically appraise and synthesise the small number of studies which provide an insight into the relationship between healthcare experiences and quality of life outcomes among colorectal cancer survivors.

Thirteen studies alluded to potential associations between colorectal cancer survivors' healthcare experiences and quality of life outcomes. Table 3.9 (p.72-83) summarises the aims, methods and findings of these studies, and provides a critical appraisal of the strengths, limitations and the results of interest to this review. The studies discussed in this section were conducted in the UK (*n*=5), USA (*n*=3), Australia (*n*=2), Canada (*n*=1) and Italy (*n*=1). Studies were largely qualitative (*n*=8) and used phenomenological (*n*=2), grounded theory (*n*=3) or unspecified qualitative approaches (*n*=3). Six of eight qualitative studies collected data via interviews, one conducted focus groups and

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Anderson et al. (2013), UK ***Aim:*** To explore colorectal cancer survivors' perceived needs for diet and physical activity advice, and beliefs about the role of lifestyle in reducing the risk of disease recurrence.				
• Qualitative study. • Focus groups (*n*=6) and a health behaviours questionnaire. • Purposive sample of 40 colorectal cancer survivors 1-48 months post-treatment recruited via Bowel Cancer UK. • Framework analysis.	• Participants desired personalised advice on diet, physical activity and lifestyle. • Diet information was generic and confusing, failing to consider survivors' individual needs and background. • A number of acceptable formats for information were identified. • The end of treatment and 6-month follow-up were considered most suitable times for information, as survivors began to consider concerns about long-term health.	• Sample recruited from multiple regions across Scotland and England. • Equal distribution of male and female participants. • Wide range of age groups included (27-84 years). • Focus groups conducted by a single, experienced researcher.	• No explicit theoretical or philosophical framework for the study. • Insufficient detail on focus group topic guide. • Participants were less than 2 years post-treatment; results may not be transferable. • Participants were highly-educated; results may not reflect experiences of more disadvantaged people. • Diagnosis, staging, treatment history and ostomy status of participants not described.	• Unmet information needs were linked to a range of physical and psychological concerns. • Insufficient or poorly understood dietary information created a fear of eating and potential bowel dysfunction. • Clinical Nurse Specialists provided general reassurance and support, rather than specific diet/lifestyle advice and support. • Healthcare professionals' suggestions that poor diet caused disease made survivors feel stigmatised.
Appleton et al. (2013), UK ***Aim:*** To explore the experience of living beyond colorectal cancer, and the physical, psychological and social aspects associated with adjustment to everyday life.				
• Qualitative phenomenology. • Face-to-face semi-structured interviews. • Convenience sample of 13 colorectal cancer survivors between 6 months and 5 years post-treatment, recruited via hospital-based follow-up clinics. • Interpretative phenomenological analysis.	• Adjustment to everyday life was supported by various techniques, including support from family, friends and healthcare staff, and physical and psychosocial self-management strategies. • A sense of meaning in life was achieved through a return to normal activities, altruism, and reframing one's circumstances and experiences.	• Describes conceptual and philosophical background. • Sample included survivors between 5 months and 5 years post-treatment. • Semi-structured interview guide described. • Interview transcripts independently analysed by three researchers.	• Participants recruited from a single treatment centre in the UK; results may not be transferable to other settings. • Participants self-selected for the study. • Diagnosis, staging, treatment history and ostomy status of participants not described.	• Egalitarian partnerships with members of the multidisciplinary team were pivotal to survivors' recovery and adjustment. • Egalitarian partnerships were characterised by open communication and ease of access to information and support from healthcare professionals, which facilitated person-centred care.

Table 3.9 Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Beech et al. (2012), UK ***Aim:*** To explain the experience of recovery following surgery for colorectal cancer.				
• Qualitative grounded theory. • Longitudinal, semi-structured interviews at 4 timepoints over one year. • Theoretical sample of 12 colorectal cancer survivors between 2 weeks and 12 months post-surgery, recruited by surgical clinical nurse specialists. • Grounded theory analysis (Strauss & Corbin 1998).	• Recovery from colorectal cancer surgery encompasses physical, psychological and social processes, occurring in three phases: disrupting the self, repairing the self and restoring the self. • Symptoms and medical procedures threaten the body and personal identity. • Autonomy undermined by hospital practice. • Repairing the self occurs through actions and interactions to restore the body, confidence, autonomy and personal identity. • Restoring the self is a duality between a sense of wellness and a sense of illness. Although both may co-exist, one usually dominates. • Wellness is fostered through the enjoyment of life. • Illness is characterised by preoccupation with illness and continued illness-related disruptions in daily life.	• Theoretical sampling and data collection techniques align with grounded theory philosophy. • Data collection conducted by a single researcher.	• Participants recruited from a single treatment centre in the UK; results may not be transferable to other settings. • Participants were excluded if they had chemotherapy or radiotherapy. Therefore, findings may not be transferable to these groups. • Data analysis conducted by a single researcher. • The potential influence of the researcher's experience as a cancer nurse upon the data collection and analysis process were not described. • Diagnosis, staging and ostomy status of participants were not reported.	• Survivors welcomed rapid progression from diagnosis to treatment, but efficiency was linked to impersonal care and undermined autonomy. • Highly regimental follow-up dissuaded survivors from contacting healthcare professionals between appointments. • A lack of information/ understanding caused survivors to doubt the validity or urgency of their symptoms further discouraging contact with healthcare professionals between appointments. • Time-constrained follow-up appointments hindered survivors seeking information from healthcare professionals. • Persistent symptoms and a perceived lack of information or support from healthcare professionals contributed to a lingering sense of illness and impacted survivors' well-being.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Bennett et al. (2012), Australia ***Aim:*** To explore and compare differences in self-assessed and healthcare professional-assessed neuropathic symptoms among colorectal cancer survivors treated with Oxaliplatin.				
• Mixed methods. • *Healthcare Professional Assessment:* National Cancer Institute Common Toxicity Criteria for Adverse Events. • *Patient Self-Report*: Patient Neurotoxicity Questionnaire & participant interview. • Consecutive purposive sample of 20 stage III-IV colorectal cancer survivors experiencing persistent neuropathic symptoms 1 year after treatment, identified via hospital records. • Descriptive and correlational statistical analysis and interview content analysis.	• 60% of participants reported severe neurotoxicity in surveys and interviews. • 10% of the sample were classified as having severe neurotoxicity by healthcare professionals. • 85% of the sample had objective evidence of sensory neuropathy in nerve conduction studies.	• Survivors who had neuropathic symptoms preceding Oxaliplatin treatment were excluded. • A valid and sensitive measure of self-reported neurotoxicity was used. • A valid and internationally recognised clinical assessment tool was used. • Interviews conducted by a healthcare practitioner experienced in symptomatic assessment and qualitative research methods. • Interviewer blinded to healthcare professional's neurotoxicity assessment. • Participants' disease-related characteristics reported.	• Small, convenience sample recruited from a single Australian oncology department limit the generalisability of results. • Participants were predominantly female and diagnosed with colon cancer. • Potential limitations of the study not described by the authors. • Internal consistency of the questionnaire not reported.	• Survivors were not prepared for the impact and length of recovery from symptoms of neurotoxicity; symptoms often worse and more prolonged than initially expected. • Healthcare professionals may underestimate the severity of peripheral neuropathy symptoms experienced by colorectal cancer survivors.
Di Fabio et al. (2008), Italy ***Aim:*** To explore colorectal cancer survivors' quality of life during long-term follow-up, and surgeons' awareness of patient needs.				
• Quantitative cross-sectional survey. • *Quality of Life Instrument:* EORTC QLQ-C30; EORTC QLQ-CR38. • *Patient Needs Instrument:* Questionnaire developed for the study.	• Quality of Life among colorectal cancer survivors without co-morbidity or recurrence was satisfactory. • Bowel dysfunction and sexual dysfunction were the most prevalent symptoms among participants of this study.	• Valid and reliable instruments used to assess quality of life. • Reasonable response rates were achieved at some sites (62-69%). However, it is not possible to ascertain the response rate at 2 of the 4 units where recruitment was undertaken.	• Small, convenience sample recruited from a single Italian hospital limits generalisability of results. • Participants in the surgeon sample were mostly male.	• Similar proportions of colorectal cancer survivors and surgeons agree surveillance is an important part of follow-up. • Surgeons were more likely to believe symptom assessment is a priority of follow-up.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Di Fabio et al. (2008), Italy (Continued) ***Aim:*** To explore colorectal cancer survivors' quality of life during long-term follow-up, and surgeons' awareness of patient needs.				
• 62 colorectal cancer survivors 14-74 months post-diagnosis (response rate: 90%), identified via hospital records. • 14 general surgeons involved in the care of colorectal cancer survivors. • Nonparametric statistical analysis.	• Patients and surgeons have high levels of agreement regarding the importance of surveillance activities in follow-up. • Few surgeons believed emotional aspects of colorectal cancer should be assessed during follow-up.		• The psychometric properties of the unmet needs questionnaire were not evaluated; however, it underwent face validity testing with patients and surgeons before the study. • Potential participation bias and socially desirable responses as participants were supervised by the researcher/physician while completing the survey.	• Survivors more likely to believe assessment of surgical wounds, digestive problems and emotional problems were key tasks of follow-up. • Physical symptoms such as sexual dysfunction may be overlooked due to prioritisation of surveillance. Two participants disclosed sexual dysfunction for the first time during the survey.
Johansson et al. (2014), Sweden ***Aim:*** To explore illness perceptions among colorectal cancer survivors and their partners during the early recovery phase in relation to contemporary cancer care settings.				
• Qualitative grounded theory. • Semi-structured interviews. • Nested sample of 9 colorectal cancer survivors 3-10 months post-treatment invited to participate from a sampling frame of survey participants (response rate 64%). • Constant comparative analysis.	• Efficient access to treatment was a positive experience for colorectal cancer survivors and their partners. However, this contributed to rapid delivery of large amounts of information, which survivors' and their partners were unable to process and comprehend. • Following discharge from treatment, partners and survivors experienced uncertainty and loneliness due to reduced contact with healthcare professionals.	• Theoretical sampling and data collection techniques align with grounded theory philosophy. • Semi-structured interview guide reported. • Interviews were conducted with couples in some cases, and individual survivors and their partners separately in others, providing greater insight into the potential risk of response bias. However, differences or similarities in findings between those participants who were interviewed alone or within couples were not described.	• Small sample recruited from a single hospital in western Sweden; transferability of findings may be limited. • The cross-sectional nature of data collection and small sample size may limit the full theoretical understanding of the research issue and the quality of the subsequent grounded theory. • Study inclusion and exclusion criteria were not reported. • It is unclear if survivors and partners who participated in separate interviews were partners of the same couple.	• Rapid delivery of large amounts of information caused challenges of comprehension. • Partners and survivors experienced uncertainty and loneliness due to reduced contact with healthcare professionals in follow-up. • The absence of a clear point of contact prevented survivors exercising autonomy and responsibility for their care. • Lack of continuity of care contributed to conflicting and confusing information, difficult healthcare navigation and feelings of abandonment by the healthcare system.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Johansson et al. (2014), Sweden (Continued) ***Aim:*** To explore illness perceptions among colorectal cancer survivors and their partners during the early recovery phase in relation to contemporary cancer care settings.				
	• Continuity of follow-up care was most problematic for partners due to uncertainty about the trajectory of follow-up, unpredictability of the disease and information insecurity. • There was a mismatch between the illness perceptions of survivors and their partners, as survivors sought to move forward, partners saw cancer as a permanent, life-changing event.	• Sample recruited from a sampling frame of survey respondents.	• Survivors were older (61-87 years) and mostly female. Thus, findings may not be transferable to younger or male survivor dyads. • Participants were 3-10 months post-treatment; therefore, findings may not be transferable to longer-term survivors. • Staging and treatment history of participants was not reported. • Conceptual categories did not achieve theoretical saturation, but the authors stated the categories were theoretically sufficient.	• Partners believed a lack of continuity of care caused survivors physical and psychological distress. • Shortcomings in disease-related information and communication contributed to mismatches in illness perceptions between survivors and partners. • A lack of continuity of care exacerbated informational insecurity, as submissive patients did not seek further information despite confusion or unmet needs.
McCaughan et al. (2012), UK ***Aim:*** To explore and compare the experience and coping behaviour of men and women after chemotherapy for colorectal cancer.				
• Qualitative study. • Longitudinal semi-structured interviews at 6 and 12 months post-chemotherapy. • 38 colorectal cancer survivors 6 and 12 months post-chemotherapy invited to participate at their first oncology appointment in a regional cancer centre (response rate: 68%). • Miles & Huberman (1994) qualitative data analysis.	• Men and women reacted similarly to recovery; the themes described included experience of a new normal, living with uncertainty and supportive care needs. • Survivors continued to experience symptoms which affected their daily lives. • Gendered differences regarding the impact of and response to ongoing symptoms were evident.	• Large sample recruited using purposive sampling methods. • Sampling strategy recruited participants with consideration of variances in socio-demographic and cancer-related characteristics. • Participants of this study were recruited from the point of diagnosis and followed up longitudinally at 4 time points over an 18-month period.	• Sample recruited from a single, regional cancer centre in Northern Ireland; transferability of findings may be limited. • The authors do not identify a particular approach to qualitative research for this study, presumed a descriptive approach.	• Female survivors perceived an absence of support from healthcare professionals and the healthcare system following treatment which caused them distress.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
McCaughan et al. (2012), UK (Continued) ***Aim:*** To explore and compare the experience and coping behaviour of men and women after chemotherapy for colorectal cancer.				
	• Women who continued to experience side-effects engaged in strategies to manage symptoms. • Men engaged in practices to downplay the effect of their symptoms.		• Although there was a high participation rate at baseline (68%), 63% of baseline participants continued to the final wave of data collection. • Information about the diagnosis and staging of participants' disease was not reported.	• Female survivors wanted greater professional support to cope with disease-related physical and psychological symptoms. They did not believe support groups were a suitable alternative, as they could be a source of distress if a peer experienced recurrence. • Male survivors did not express the same need for symptom-related support, with many suggesting their symptoms were not a problem.
McMullen et al. (2008), USA ***Aim:*** To describe the greatest challenges reported by long-term colorectal cancer survivors with ostomies.				
• Quantitative cross-sectional survey. • *Quality of Life Instrument*: City of Hope Quality of Life for Ostomy Patients Survey. • *Greatest Challenges of an Ostomy:* Open-ended item. • 178 colorectal cancer survivors with ostomies, more than 5 years post-diagnosis, identified from regional and hospital cancer registries in 3 regions (response rate: 56%). • *Survey data analysis*: Descriptive and parametric statistical tests.	• Altered bowel function associated with a permanent ostomy created additional psychological and social challenges requiring adaptation. • Social isolation experienced by survivors was linked to challenges in the management and care of the ostomy in public places. • However, many survivors develop coping strategies and adapt to the physical changes and practical implications of an ostomy in the long-term.	• Participants recruited from multiple sites across North West USA. • Participants were identified and recruited from hospital and regional cancer registries. • A minimum of three researchers independently analysed responses to open-ended questions.	• The findings reported in this paper are part of a larger mixed methods study. However, the authors do not describe how these results relate to the results of other quantitative or qualitative phases of the study. • The quantification of responses to the open-ended survey item prevents an understanding of the greatest challenges experienced by survivors with an ostomy in any sufficient depth.	• Supportive, informative and competent healthcare teams supported survivors to address the challenges of living with an ostomy and were vital to survivors' successful adaptation to life with an ostomy. • Insufficient or conflicting information and education about ostomy care before discharge caused survivors anxiety and distress.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
McMullen et al. (2008), USA (Continued) ***Aim:*** To describe the greatest challenges reported by long-term colorectal cancer survivors with ostomies.				
• *Open-ended question analysis:* Content analysis and quantification of themes.				• A lack of continuity of care resulted in healthcare professionals being unaware of the survivor's treatment history and lacking sensitivity to their needs. This caused some survivors distress or a loss of confidence in their healthcare provider.
Nikoletti et al. (2008), Australia ***Aim:*** To describe the bowel problems, self-care practices and information needs of patients who have recovered from the acute effects of sphincter-saving surgery.				
• Quantitative cross-sectional survey. • *Questionnaire*: Likert scale items developed for the study, based on clinical observations and previous literature. Questionnaire administered via structured interviews. • 101 colorectal cancer survivors who underwent sphincter-saving surgery 6-24 months ago, identified from hospital and private clinical databases (response rate: 71%). • Descriptive statistical analysis.	• 71% of survivors experienced one or more changes in bowel habits post-operatively. • The most frequent unmet information needs related to diet (51%) and symptom management, including diarrhoea (32%), bloating, wind, gas (29%), pain (22%) and incomplete evacuation of the bowel (19%).	• Multi-site study in Australia, recruiting participants from the clinical databases of two teaching hospitals and two private clinics.	• Questionnaire was pilot tested, but the validity and reliability of instrument were not reported. • Pilot study responses (*n*=10) included in the main study. • Variance in response rates between recruitment sites acknowledged, but not reported. • Response rates could not be determined at one hospital and one clinic, which accounted for 25% of the sample. • Participants were mostly male and urban residents. • Information about the diagnosis and staging of participants' disease were not reported.	• One-third of survivors attended a healthcare professional for advice or treatment for bowel dysfunction. • Oncologists (18%) or general practitioners (17%) were the most common sources of information about bowel dysfunction. • Doctors were considered the most appropriate source of information about bowel dysfunction (46%), followed by continence advisors (22%) and nurses (21%). • Between 25-80% of participants had unmet needs relating to bowel dysfunction.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Nikoletti et al. (2008), Australia (Continued) ***Aim:*** To describe the bowel problems, self-care practices and information needs of patients who have recovered from the acute effects of sphincter-saving surgery.				
			• Study did not inquire whether survivors who received information and support were satisfied with its sufficiency. • Potential limitations of the study not acknowledged by the authors.	
Ramirez et al. (2009), USA ***Aim:*** To examine the experiences of sexual challenges and adaptations made by female colorectal cancer survivors following ostomy formation.				
• Qualitative phenomenology. • Semi-structured interviews. • 30 female colorectal cancer survivors with ostomies, more than 5 years post-diagnosis, invited to participate from a sampling frame of survey participants (response rate: 41%). • Grounded theory approach to data analysis (Charmaz 2006).	• The impact of an ostomy upon female sexuality was categorised in four ways: – Eleven survivors resumed sexual relationships post-surgery, describing changes in their approach to intercourse, using strategies to hide and manage the ostomy. Having a supportive partner was integral to resuming sexual activity. – Seven survivors could not have sexual intercourse due to radiotherapy and surgery effects and identified alternative approaches to intimacy. While these approaches were acceptable to some; for others, a failure to resume sexual relationships was distressing.	• The researchers implemented strategies to ensure inclusion of survivors who were younger and from ethnic minority groups. • The interview schedule was reported. • Four researchers conducted independent data analysis.	• The findings reported in this paper are part of a larger mixed methods study. However, the authors do not describe how these results relate to those of the quantitative phase of the study. • Interview participants were recruited from two of the three clinical sites involved in the quantitative study. Therefore, results may not be transferable to the island site excluded from this phase of the study. • Participants were mostly older and of white ethnicity; therefore, results may not be transferable to younger and minority female survivors.	• One participant implied she did not understand the purpose of using a vaginal dilator during and after treatment. She ceased using it due to pain. She suggested that if she had understood the role of regular use of the vaginal dilator in maintaining long-term sexual health she may have continued its use. She described immense difficulty, loss and sadness relating to her inability to have regular sexual intercourse with her partner, as it was an important part of her relationship before surgery.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Ramirez et al. (2009), USA (Continued) ***Aim:*** To examine the experiences of sexual challenges and adaptations made by female colorectal cancer survivors following ostomy formation.				
	– Three survivors described age-related changes in sexuality (*n*=3). – Nine survivors did not desire sexual intimacy (*n*=9). • For women in the two latter groups, the ostomy did not affect sexual relationships, as it was not a central component of their romantic relationships before surgery.		• There was a low response rate to interview invitations (41%), which was drawn from a survey sampling frame with a response rate of 52%. • Potential for response bias; those who have problems with sexual intimacy or who do not wish to discuss intimate complications may decline participation. • Grounded theory analysis does not align with the phenomenological philosophy of the study.	
Sisler et al. (2012b), Canada ***Aim:*** To examine how colorectal cancer survivors evaluate the continuity and quality of care in primary care models of post-treatment follow-up.				
• Quantitative cross-sectional survey. • *Quality of Life:* FACT-C; The Illness Intrusiveness Rating Scale. • *Continuity of Care*: Patient Continuity of Care Questionnaire. • 246 colorectal cancer survivors with stage II or III disease 1-2 years post-diagnosis, identified from a regional cancer registry (response rate: 68%). • Descriptive, inferential and multivariate regression statistical analysis.	• 47% of survivors named a single healthcare professional as the main provider of care. • 43% of survivors named a primary care practitioner as the main provider of care. • Those whose care was managed by a primary care practitioner (*n*=106) evaluated their continuity of care highly on the five subscales.	• A clear description of the healthcare system and context in which the study was conducted. • Valid and reliable instruments were used to evaluate quality of life and continuity of care. • A pilot study was undertaken to ensure clarity, relevance and feasibility of the questionnaire. • The study achieved a reasonable response rate (68%).	• Sample size requirements not estimated. • Regression analysis to determine factors influencing continuity of care was performed a on sub-sample of survivors who received primary care-led follow-up (*n*=106); therefore, findings are not representative of survivors in hospital-based, nurse-led or oncologist-led models of follow-up.	• Lower FACT-C quality of life scores and male gender were predictive of poorer evaluations of continuity of care among colorectal cancer survivors whose follow-up care was led by a primary care practitioner.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Sisler et al. (2012b), Canada (Continued) ***Aim:*** To examine how colorectal cancer survivors evaluate the continuity and quality of care in primary care models of post-treatment follow-up.				
	• Lower FACT-C quality of life scores and male gender were predictive of poorer evaluations of continuity of care in the primary care follow-up group (*n*=106).		• Socially desirable responses to continuity of care items is a potential limitation of the study as survivors were still undergoing follow-up.	
Sun et al. (2014), USA ***Aim:*** To describe the healthcare experiences of long-term colorectal cancer survivors with permanent ostomies.				
• Mixed methods. • Focus groups. • Nested sample of 33 colorectal cancer survivors with ostomies, more than five years post-diagnosis, invited to participate from a sampling frame of survey participants. • Thematic analysis.	• Survivors experienced both positive and negative healthcare experiences. • Survivors expressed a need for ongoing access to ostomy nurses to support ostomy care and self-management. • Survivors desired peer support and access to resources to support the management of ongoing treatment and disease-related symptoms.	• Sampling strategy recruited participants with due consideration of their quality of life score (High/Low). • Focus group topic guide reported. • Focus groups moderated by a single facilitator. • Interview transcripts independently analysed by 3 researchers; final themes independently audited and transcribed by other members of the research team.	• The findings reported in this paper are part of a larger mixed methods study. However, the authors do not describe how these results relate to those of the quantitative phase of the study. • Focus group participants were recruited from two of the three clinical sites involved in the quantitative study. Therefore, results may not be transferable to those of the island site who were excluded in this phase. • Participants were of white ethnicity; therefore, results may not be transferable to survivors of ethnic minority backgrounds.	• Participants desired greater control over decision-making about treatment. However, the rapid progression from diagnosis to treatment undermined their autonomy, and they relied on healthcare professionals to direct them toward the most appropriate treatment. • Healthcare professionals who took time to provide detailed explanations of surgical treatments were spoken of positively, supporting survivors to make informed decisions.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Sun et al. (2014), USA (Continued) ***Aim:*** To describe the healthcare experiences of long-term colorectal cancer survivors with permanent ostomies.				
				• Nurses' ostomy management experience was important to survivors' adaptation and adjustment to the ostomy and its care. Inexperienced nurses hindered survivors' adjustment and caused distress and frustration to the survivor.
Taylor et al. (2011), UK ***Aim:*** To explain how fear of recurrence can affect individuals recovering from curative colorectal cancer surgery.				
• Qualitative grounded theory. • Longitudinal semi-structured interviews at 6 and 12 months post-surgery. • Purposive theoretical sample of 16 colorectal cancer survivors 6-12 months after curative surgery, recruited by colorectal cancer clinical nurse specialists in 3 hospitals. • Constant comparative analysis.	• All survivors described awareness of potential disease recurrence. However, the degree and frequency of its interference with the survivor's life varied. • Some survivors expressed anxiety about and preoccupation with potential cancer recurrence, despite successful treatment and early-stage disease. These survivors adopted behaviours to foster confidence in their body, including '*guarding*', through body monitoring, risk management and seeking reassurance.	• Multi-site study in the UK, recruiting participants from 3 hospitals. • Theoretical sampling and constant comparative data analysis align with grounded theory methods. • The interview schedule was reported.	• Participants were excluded if they had chemotherapy, radiotherapy or a permanent stoma post-operatively, therefore findings may not be transferable to these groups. • Participants were less than 1 year after treatment; therefore, findings may not be transferable to longer-term survivors. • Potential limitations of the study not acknowledged by the authors.	• Survivors described a reliance upon healthcare professionals for support and reassurance following treatment. However, this support reduced as time since treatment increased. • Survivors who felt they had continued access to support from healthcare professionals did not express quite so much fear, as they felt they would be supported should any problems arise. • Follow-up appointments triggered anxiety in survivors.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

Design/Methods/Sample/Analysis	Findings	Strengths	Limitations	Main Findings Relevant to This Review
Taylor et al. (2011), UK (Continued) ***Aim:*** To explain how fear of recurrence can affect individuals recovering from curative colorectal cancer surgery.				
	• Some participants managed to implement strategies which reduced anxieties associated with risk of recurrence, including moving on or finding a sense of resolution in their recovery.			• In some cases, survivors avoided asking questions or seeking information from healthcare professionals due to a fear of receiving unfavourable information or results.

Table 3.9 (Continued) Summary of studies appraised in The Potential Impact of Healthcare Experiences and Unmet Needs Upon Colorectal Cancer Survivors' Quality of Life (n=13)

another undertook a qualitative survey. Two studies described mixed methods approaches and three studies reported the results of cross-sectional surveys. Most studies included survivors who were less than one (*n*=5) or two years (*n*=2) post-treatment. Therefore, it must be considered that these groups may still be establishing strategies to adapt to survivorship and have information and support needs particular to this period. Four studies recruited survivors who were more than five years since treatment, who were no longer the subject of formal surveillance; of these, three focused solely on survivors with permanent ostomies. Finally, three studies included participants up to five years post-treatment, who would have been involved in routine follow-up surveillance.

Five qualitative studies in this review alluded to the potential influence of therapeutic relationships with healthcare professionals upon colorectal cancer survivors' quality of life and well-being. In a phenomenological study to ascertain the lived experience of colorectal cancer survivorship up to five years following treatment, cross-sectional interviews with 13 survivors conducted by Appleton *et al.* (2013) in the UK illuminated survivors' positive experiences of egalitarian relationships with healthcare professionals. Egalitarian relationships were characterised by partnership, openness and person-centredness, which were pivotal to survivors' recovery, as they facilitated survivors' adjustment at practical and psychological levels following treatment and permitted survivors to share their experiences with healthcare professionals without embarrassment. Furthermore, ease of access to information enhanced survivors' autonomy and empowered them in decision-making processes (Appleton *et al.* 2013). However, the beneficial experience of egalitarian partnerships described in this study has not been widely replicated in similar studies conducted in the UK (Beech *et al.* 2012, McCaughan *et al.* 2012) and Sweden (Johansson *et al.* 2014). The contradictory results of these studies may be attributed to organisational differences in support structures, ethos, staff workload or staff morale, as the participants of Beech *et al.* (2012), McCaughan *et al.* (2012), Appleton *et al.* (2013) and Johansson *et al.* (2014) were each recruited from single research sites.

There is growing attention to the concept of continuity of care in the colorectal cancer survivorship literature, which encompasses continuity of information, relationships with providers and healthcare management (Sisler *et al.* 2012b). In their grounded theory study of illness perceptions in contemporary cancer care settings, Johansson *et al.* (2014) used the concept of '*Being Left in Echoing Silence*' to describe the period following discharge from hospital. This period was marked by a sense of unpredictability, informational insecurity and abandonment by the healthcare professionals which caused survivors and their partners anxiety and distress. Although the sample size of Johansson *et al.* (2014) was small (*n*=9), precluding data saturation, the results of qualitative studies with larger samples by Taylor *et al.* (2011) (*n*=16) and McCaughan *et al.* (2012) (*n*=38) add weight to their conclusions. All three described links between declining support from healthcare professionals following treatment, and psychological distress or fear of recurrence. Indeed, the grounded theory of fear of recurrence proposed by Taylor *et al.* (2011) suggested that survivors who had continued access to healthcare professionals described less intrusive fears of recurrence, as they believed they would be supported should recurrence occur (Taylor *et al.* 2011).

A lack of continuity of care has been linked to healthcare professionals' insensitivity to survivors' needs and difficulties with healthcare navigation, which give rise to survivors' loss of confidence in healthcare professionals and a sense of abandonment or isolation from support (McMullen *et al.* 2008, Johansson *et al.* 2014, Sun *et al.* 2014). More than half of the 246 colorectal cancer survivors surveyed by Sisler *et al.* (2012b) were under the care of multiple healthcare professionals and unable to identify a single main provider of care in a study to evaluate continuity and quality of follow-up care in Canada. However, due to the design of the Sisler *et al.* (2012b) study, it was not possible to conclude whether survivors experienced greater or poorer continuity of care where they were under the care of multiple healthcare professionals or oncology specialists. In this study, continuity of care data was collected from survivors receiving follow-up from primary care practitioners (*n*=106). It is possible that the high ratings of continuity of care within this group may be attributed to long-standing relationships and familiarity with primary care practitioners which preceded their cancer diagnosis. The generalisability of these findings may be limited, as primary care led follow-up is not yet a widely used model of care for cancer survivorship internationally, and the universal model of healthcare coverage in Canada is not replicated in other countries. Despite these limitations, the study makes a unique contribution to the cancer survivorship literature, as it is the first study to describe the importance of lower quality of life scores on the FACT-C scale in predicting lower continuity of follow-up care among colorectal cancer survivors in a primary care setting.

There are a small number of qualitative studies which suggest colorectal cancer survivors' unmet information needs are related to physical and psychological distress during the follow-up period. Taylor *et al.* (2011) and Beech *et al.* (2012) are examples of high-quality grounded theory studies, incorporating cyclical theoretical analysis and sampling strategies in longitudinal interviews. The grounded theory of illness perceptions proposed by Johansson *et al.* (2014) embodies concepts echoing fear of recurrence (Taylor *et al.* 2011) and recovery (Beech *et al.* 2012). However, the small sample size, cross-sectional interviews and achievement of data sufficiency rather than data saturation may prevent a full theoretical understanding of illness perceptions, undermining the quality of the subsequent grounded theory (Johansson *et al.* 2014). Nonetheless, the challenges of obtaining information about the implications of colorectal cancer for long-term health and well-being have been central concepts within several grounded theory studies ('*Seeking Reassurance*'; Taylor *et al.* 2011, '*Repairing the Self*'; Beech *et al.* 2012, '*Experiencing Compressed Time*', '*Being Left in Echoing Silence*', '*Seeing the Cancer Diagnosis*' and '*Leaving the Cancer Diagnosis Behind*'; Johansson *et al.* 2014). These and other studies suggest a lack understanding of the physical effects underpinning these information needs contribute to unrealistic expectations of recovery and psychological distress, as survivors come to terms with unanticipated, limiting side-effects including sexual dysfunction, bowel dysfunction and peripheral neuropathy (Ramirez *et al.* 2009, Beech *et al.* 2012, Bennett *et al.* 2012, Anderson *et al.* 2013).

Several studies have attributed the challenges of obtaining information to the structure and nature of modern healthcare services. Rapid access and progression through diagnosis and treatment were welcomed by survivors initially. In the longer-term, it seemed this momentum undermined the partnership and person-centredness characteristic of egalitarian partnerships, hindering survivors' autonomy and participation in care-related decision-making (Taylor *et al.* 2011, Beech *et al.* 2012, Anderson *et al.* 2013, Johansson *et al.* 2014, Sun *et al.* 2014). The highly structured biomedical framework and schedule of surveillance could negatively impact colorectal cancer survivors' well-being in several ways, acting as a trigger point for fear of recurrence and hindering accurate symptom assessment, symptom management and information provision (Taylor *et al.* 2011, Beech *et al.* 2012). Finally, and perhaps most critically, when combined with a lack of information and preparation for survivorship, surveillance-focused follow-up could inhibit survivors seeking support between scheduled appointments as they doubt the validity or importance of their concerns (Beech *et al.* 2012). Beech *et al.* (2012) suggest such obstacles hinder recovery, as survivors continue to experience an enduring sense of illness, living with unresolved symptoms and the ongoing threat of cancer. Supplementing these findings, both Taylor *et al.* (2011) and Appleton *et al.* (2013) suggest that survivors who benefit from ongoing support within egalitarian partnerships experience less fear of recurrence and more positive adaptation during their recovery.

Up to 75% of colorectal cancer survivors may experience one or more symptoms of bowel dysfunction (Table 3.5). However, less than one-third (32.7%) attended a healthcare professional for advice or treatment in an Australian study of 101 colorectal cancer survivors examining self-management strategies and information needs relating to bowel dysfunction (Nikoletti *et al.* 2008). Two more recent studies highlighted disparities between healthcare professionals' and colorectal cancer survivors' perceived needs in follow-up care (Di Fabio *et al.* 2008) and assessments of the severity and impact of peripheral neuropathy upon survivors' well-being (Bennett *et al.* 2012). However, these studies involved small, convenience samples of 20-101 colorectal cancer survivors, which may limit the generalisability of the findings. Furthermore, the validity and reliability of the questionnaires utilised by Di Fabio *et al.* (2008) and Nikoletti *et al.* (2008) to assess survivors' needs cannot be evaluated, as each used original questionnaires, and their respective psychometric properties were not reported. Nonetheless, in the absence of more robust evidence, these findings raise concerns firstly, for the unmet needs of survivors who may not seek formal support to manage the symptoms they continue to experience, and secondly, for survivors who seek, but fail to receive sufficient intervention for symptom management from healthcare professionals. It follows that such experiences may contribute to the sense of abandonment and psychological distress which have been described by colorectal cancer survivors after treatment in other studies (Taylor *et al.* 2011, McCaughan *et al.* 2012, Johansson *et al.* 2014).

3.5.5 Summary: Healthcare Experiences of Colorectal Cancer Survivors

The theme *Healthcare Experiences of Colorectal Cancer Survivors* has illustrated the breadth of information available within the colorectal cancer survivorship literature on the topic of healthcare experiences. It is evident from the reviewed literature that colorectal cancer survivors' healthcare needs and experiences are a growing area of interest. Since IoM (2006), there has been a growth in the number of annual publications addressing healthcare experiences in colorectal cancer survivorship (Figure 3.3). However, there are significant knowledge gaps and methodological limitations within the literature which offer the opportunity for further exploration.

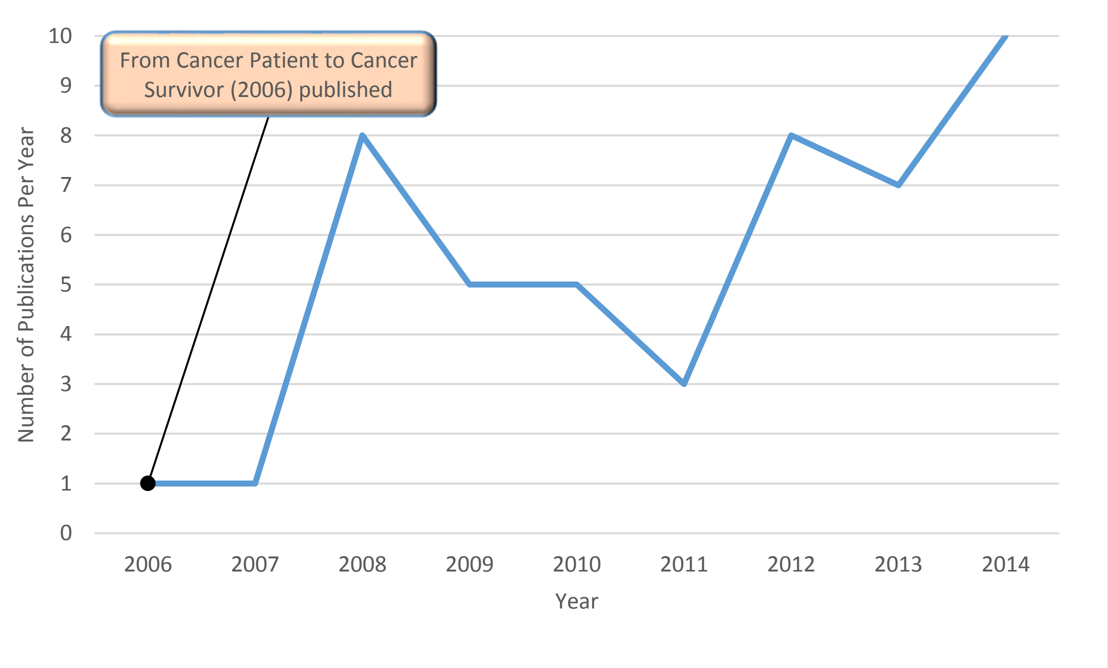


Figure 3.3 Frequency of publications relating to aspects of healthcare in colorectal cancer survivorship since 2006 (n=48)

From this review, it appears that colorectal cancer survivors describe their follow-up care favourably. However, the dynamic of the relationship between healthcare professionals and colorectal cancer survivors may influence the survivor's recovery, and by extension, their quality of life due to the multiplicity of professionals involved, variability in the models and patterns of care, and prioritisation of surveillance activities over symptom management. Cancer survivors may feel unsupported in the aftermath of treatment as the frequency of consultations with healthcare professionals reduces. Unmet information and support needs during this period pose a significant challenge and may be a source of physical and psychosocial distress to survivors, particularly if survivors are unaware of or confused about the lines of communication and support available to them between scheduled appointments. As an emerging concept in the survivorship literature, continuity of care seems to have a role in survivors' experience of unmet need and subsequent quality of life outcomes. However, the scarcity of published evidence makes it difficult to ascertain the nature of the interaction between healthcare experiences and quality of life, and the factors which may influence this interaction. This represents a significant area which would benefit from further examination.

From a methodological perspective, the literature which has informed this theme is predominantly the product of singular methodological approaches. The literature describing the models of follow-up care and patterns of follow-up and surveillance in colorectal cancer survivorship are primarily retrospective cohort designs from North American settings (*n*=13) which fail to encompass survivors' perceptions or experiences of care. Of those studies which incorporate methods to elicit survivors' opinions about healthcare into the study design, the majority use qualitative data collection techniques (*n*=11) or original survey instruments without sufficient illustration of their psychometric properties (*n*=5). The literature describing the potential impact of healthcare experiences upon colorectal cancer survivors' quality of life (*n*=13) was mainly derived from qualitative studies (*n*=7) conducted in the UK (*n*=5). Each of these respective methodological approaches provide useful information. However, there is a need for further research which examines the experiences of broader cohorts of colorectal cancer survivors, recruited from diverse healthcare systems and international backgrounds, to explore the transferability and potential generalisability of these findings.

The literature presented throughout this section largely originates from British and North American settings which operate public or privatised healthcare systems, thereby limiting the generalisability of findings to other cultures and countries with differing healthcare provision models. The absence of literature which considers colorectal cancer survivors' experiences of follow-up care in countries which operate mixed public and private models of healthcare provision represents a gap in the literature. The Irish healthcare system is split into public and private sectors, with survivors able to access diagnostic, screening and treatment services via public and private healthcare services. This model of healthcare provision creates potential disparity in access to diagnostic tests, which may influence survivors' experiences of treatment and follow-up care and warrants investigation to determine the generalisability and transferability of findings presented in this section. Considered together, the empirical, methodological and cultural gaps in the published literature represent an opportunity for a comprehensive exploration of the relationship between healthcare experiences and quality of life outcomes using a mixed methods approach. In the next section of the review, the results of studies conducted in the Irish context are critiqued and presented.

3.6 Colorectal Cancer Survivorship and Quality of Life in Ireland

While it is useful to look at quality of life among cancer survivors in an international context, it is also important to understand it in the context of this study. At the time of this review, two studies by the NCRI explored quality of life outcomes among colorectal cancer survivors in Ireland. The first described the patterns and costs of lost productivity due to colorectal cancer (Hanly *et al.* 2013). The second examined the relationship between colorectal cancer survivors' quality of life and distance from the hospital in which they received cancer-related treatment and follow-up care (Thomas *et al.* 2014). Both studies recruited samples of colorectal cancer survivors between six and 30 months post-diagnosis via the NCRI. However, each study achieved a response rate of 39%, limiting the representativeness and generalisability of results. The authors acknowledged the risk of response bias, as those who have difficulties relevant to the study topic or who were well enough to participate may have been more likely to do so. Indeed, Thomas *et al.* (2014) acknowledge that non-responders tended to be older.

Although not specifically concerned with quality of life outcomes for colorectal cancer survivors, the findings of Hanly *et al.* (2013) have importance for this study, as 37% of 159 participants under the age of 65 left the workforce permanently after diagnosis, while 18% returned on reduced hours. Given the potential impact of employment status on survivors' physical well-being and overall quality of life (Section 3.7.1), that such a large proportion of working-age survivors take early retirement or reduce their working hours have implications for the well-being and care of this cohort. Financial difficulties during diagnosis and treatment may be exacerbated by the potential loss of income and deferral of state pension payments until the survivor reaches pensionable age (66 years). Furthermore, for those who are privately insured, this loss of income may contribute to an inability to continue payment of insurance premiums and may lead to a subsequent loss of coverage in private healthcare settings for some survivors. Though colorectal cancer survivors may subsequently receive care in a public setting, such transfers of care may contribute to a loss of continuity in overall care and relationships with treating healthcare professionals.

Thomas *et al.* (2014) report that greater distance from the treating hospital was related to lower physical and role functioning on the EORTC QLQ-C30, while global health status was associated with surgical treatment, financial difficulty, fatigue, pain, dyspnoea, appetite loss or diarrhoea. The authors make a compelling suggestion that the relationship between further distance and lower quality of life in some domains may be a result of non-compliance with clinical consultation. Thomas *et al.* (2014) propose survivors may take an à la carte approach to appointments to minimise the financial burden which may be created by multiple hospital visits, prioritising attendance at appointments for blood tests, colonoscopy and scans. However, the study lacked evidence to support these claims. An additional issue which this study fails to consider is the fragmented multi-site nature of follow-up for cancer survivors and the potential implications of the frequency of clinical consultations and surveillance, as survivors may have attended one or more hospitals for surgical, radiation oncology and medical oncology follow-up. Nevertheless, the study provides a valuable insight into the impact of remoteness from treating hospital upon survivors' quality of life and the prevalence of a limited number of physical, psychological and social effects among survivors in Ireland (Figure 3.4). An opportunity exists to garner a greater understanding of the physical, psychological and social challenges experienced by colorectal cancer survivors in Ireland.

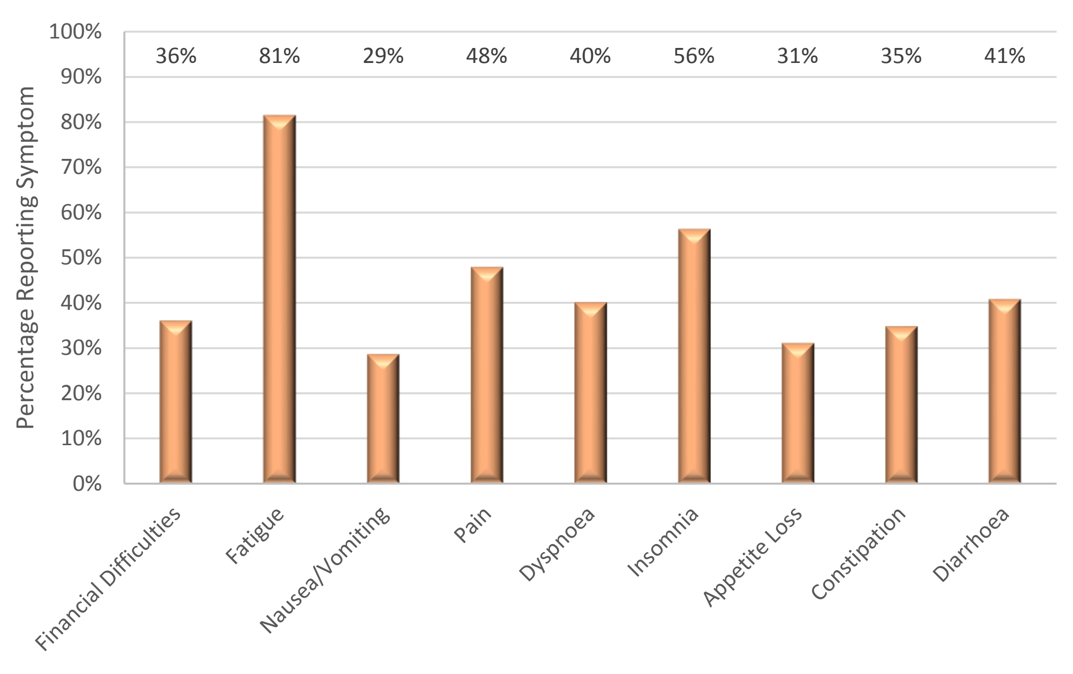


Figure 3.4 Prevalence of disease-related symptoms among colorectal cancer survivors in Ireland (Thomas et al. 2014)

Despite the limitations of Hanly *et al.* (2013) and Thomas *et al.* (2014), these studies advance comprehension of the well-being of colorectal cancer survivors in Ireland. Furthermore, they are strengthened by the availability of registry data, including diagnostic and treatment information for analysis, interpretation of results, and determining the representativeness of the sample. In the next section of the literature review, the factors identified in the literature which may influence colorectal cancer survivors' quality of life are presented in relation to the theoretical framework which guides this study, the Ashing-Giwa (2005) *Contextual Model of Health-Related Quality of Life*.

3.7 Factors Influencing Colorectal Cancer Survivors' Quality of Life

The preceding sections have presented a detailed exploration of the state of the literature regarding colorectal cancer survivors' quality of life and healthcare experiences, identifying specific directions for this research. To conclude this literature review and facilitate the design and selection of dependent variables, this section summarises the factors which influence colorectal cancer survivors' quality of life in the reviewed literature. The results are presented under four broad headings derived from the Ashing-Giwa (2005) *Contextual Model of Health-Related Quality of Life* (Table 2.2): 1) socio-demographic, socio-economic and cultural factors, 2) cancer, co-morbidity and health-related factors, 3) psychological factors, and 4) healthcare factors.

3.7.1 Socio-Demographic, Socio-Economic and Cultural Factors

There is extensive international research to understand the factors which influence colorectal cancer survivors' quality of life. Consistent evidence supports socio-demographic and medical characteristics as predictive factors for more positive quality of life (Table 3.10). Younger colorectal cancer survivors experience better physical, functional and overall quality of life than their older counterparts (Table 3.10). However, older age is associated with better psychological and social well-being (Jansen *et al.* 2011a, Kilic *et al.* 2012, Li *et al.* 2014). Although older colorectal cancer survivors are at greater risk of functional decline following cancer treatment, the process of survivorship occurs parallel to a normal ageing process and may be complicated by co-morbidities (Phipps *et al.* 2008, Ramirez *et al.* 2009, McCaughan *et al.* 2012, Anderson *et al.* 2013, Ronning *et al.* 2014). Consequently, many cancer survivors describe difficulty ascribing the entirety of symptoms experienced following treatment to cancer alone (Schneider *et al.* 2007, Phipps *et al.* 2008, Ramirez *et al.* 2009, McCaughan *et al.* 2012).

Other socio-demographic factors consistently associated with poorer quality of life include female gender, unmarried status and rural dwelling (Table 3.10). More inconsistent evidence from Asia, Europe, the USA and Australia suggest lower education, unemployment, financial difficulty, lack of health insurance and lower socio-economic status negatively impact colorectal cancer survivors' quality of life in all domains (Lundy *et al.* 2009, Steginga *et al.* 2009, Caravati-Jouvenceaux *et al.* 2011, Shun *et al.* 2011, Chambers *et al.* 2012b, Andrykowski *et al.* 2013, Dunn *et al.* 2013a, Abu-Helalah *et al.* 2014, Kim *et al.* 2014, Li *et al.* 2014, Thomas *et al.* 2014). Ethnicity has not been found to relate to any difference in quality of life within the colorectal cancer survivorship literature (Hornbrook *et al.* 2011, Kim *et al.* 2014).

Variable	Physical Well-being	Psychological Well-being	Social Well-being	Functional Well-being	Colorectal Cancer Concerns	Overall Quality of Life
Age	[1-9]	[1, 7, 10, 11]	[7, 10, 11]	[4, 8, 10, 12]	[7]	[7, 8, 13-16]
Gender	[2, 17]	[7, 8, 11]	[7, 14, 16, 18, 19]	[6, 8, 14]	[7, 14]	[14, 20]
Marital Status	[7]	[8]	[7, 8]	[1, 7, 8]	[7]	[7, 8, 21]
Education Level	[3]			[17]	[7]	[1]
Employment Status	[3]					[1]
Socio-Economic Status						[14-16]
Health Insurance			[7]	[7, 19]	[7]	[7, 19]
Area of Residence	[17, 22]					[14, 22]

References:
1: Li *et al.* (2014); **2:** Pucciarelli *et al.* (2008); **3:** Shun *et al.* (2011); **4:** Orsini *et al.* (2013); **5:** Hoerske *et al.* (2010); **6:** Phipps *et al.* (2008); **7:** Steginga *et al.* (2009); **8:** Thong *et al.* (2011a); **9:** Thong *et al.* (2011b); **10:** Jansen *et al.* (2011a); **11:** Kilic *et al.* (2012); **12:** Ronning *et al.* (2014); **13:** Krouse *et al.* (2009); **14:** Dunn *et al.* (2013a); **15:** Hornbrook *et al.* (2011); **16:** Caravati-Jouvenceaux *et al.* (2011); **17:** Abu-Helalah *et al.* (2014); **18:** Ristvedt & Trinkaus (2009); **19:** Chambers *et al.* (2012b); **20:** Gosselink *et al.* (2006); **21:** Lynch *et al.* (2007b); **22:** Thomas *et al.* (2014).

Table 3.10 Socio-demographic factors associated with colorectal cancer survivors' quality of life

Several studies provide contradictory evidence surrounding the effect of gender on social function. Although Dunn *et al.* (2013a) and Kilic *et al.* (2012) suggest females suffer worse social outcomes, Ristvedt & Trinkaus (2009) and Chambers *et al.* (2012b) assert the opposite. All of these studies used cancer-specific measures to assess quality of life; however, cultural considerations may affect results, as samples are drawn from Turkish (Kilic *et al.* 2012), Australian (Chambers *et al.* 2012b, Dunn *et al.* 2013a) and American populations (Ristvedt & Trinkaus 2009). The influence of gender on social well-being is of interest, as male and female survivors are at risk of significant restrictions on social activities arising from unpredictable bowel function (McMullen *et al.* 2008, Krouse *et al.* 2009, Grant *et al.* 2011, Taylor *et al.* 2011, Ramirez *et al.* 2014). Nonetheless, the formation of an ostomy appeared to be more detrimental to men's social well-being than women's in the long-term (Krouse *et al.* 2009). A supportive spouse may enhance psychological and social well-being (Altschuler *et al.* 2009, Thong *et al.* 2011a). However, males are believed to derive greater benefit from such support (Goldzweig *et al.* 2009). On the other hand, females experience better social well-being and receive greater support from friends, which may contribute to a greater sense of social well-being (Goldzweig *et al.* 2009, Chambers *et al.* 2012b).

3.7.2 Cancer, Co-Morbidity, Health and Health Efficacy Factors

Cancer-related factors influence survivors' symptom experience, particularly bowel function, sexual function, and body image (Section 3.4). Moreover, co-morbid health conditions, shorter time since diagnosis, higher tumour stage, treatment with radiotherapy, and the formation of an ostomy each consistently, negatively impact the quality of life of colorectal cancer survivors in all domains (Table 3.11). There is limited evidence to suggest rectal cancer predicts worse quality of life than colon cancer. However, this is an area which requires further clarification (Steginga *et al.* 2009, Caravati-Jouvenceaux *et al.* 2011, Chambers *et al.* 2012b, Sisler *et al.* 2012b, Knowles *et al.* 2013). Although cancer recurrence and metastatic disease have detrimental effects on cancer survivors' physical, functional and overall quality of life, there is no evidence to suggest that survivors in such groups experience greater psychological or social distress than their counterparts who are living in remission (Hornbrook *et al.* 2011, Thong *et al.* 2011a, Thong *et al.* 2011b, Abu-Helalah *et al.* 2014). Much of the colorectal cancer survivorship literature is limited by an under-representation of survivors with recurrence or metastases. Therefore, samples may lack sufficient power to determine association between disease status and psychological or social outcomes (Bouvier *et al.* 2008, Gordon *et al.* 2008, Lynch *et al.* 2008a, Lynch *et al.* 2008c, Chambers *et al.* 2009, Steginga *et al.* 2009, Schlesinger *et al.* 2014).

There is conflicting evidence surrounding the influence of ostomy formation on colorectal cancer survivors' quality of life. Numerous studies suggest that destructive surgery requiring ostomy formation is detrimental to colon and rectal cancer survivors' quality of life (Lynch *et al.* 2007b,

Variable	Physical Well-being	Psychological Well-being	Social Well-being	Functional Well-being	Colorectal Cancer Concerns	Overall Quality of Life
Co-Morbidity	[1-3]	[2, 3]	[1-3]	[1-3]	[2]	[1-5]
Disease Stage	[2, 3, 6, 7]	[2, 6, 7]	[3]	[2, 3, 6, 7]		[2, 3, 7]
Cancer Recurrence	[6]			[1, 6]		[3, 6]
Metastatic Disease	[3]		[3]	[3]		[3, 4]
Time Since Diagnosis or Treatment	[1, 3, 8]	[8, 9]	[8]	[1, 8]	[10]	[11]
Site of Tumour	[5]	[5]	[5, 12]	[5, 12]	[2]	[2, 13]
Presence of a Stoma	[6, 14-16]	[2, 14]	[2, 13, 14, 16, 17]	[2, 16, 17]	[2, 13]	[2, 13, 16, 18]
Type of Treatment	[1, 6, 13]	[1, 2, 8]	[2, 8, 12, 15, 17]	[2, 8, 13]	[2, 13]	[2, 13, 19, 20]
Radiotherapy	[1, 6]	[1]	[12, 15, 17]			[1]
Chemotherapy	[1, 3, 13]		[15, 17]			[13]
Surgery	[6]			[13]	[13]	[20]

References:
1: Thong *et al.* (2011b); **2:** Steginga *et al.* (2009); **3:** Thong *et al.* (2011a); **4:** Hornbrook *et al.* (2011); **5:** Caravati-Jouvenceaux *et al.* (2011); **6:** Abu-Helalah *et al.* (2014); **7:** Dunn *et al.* (2013a); **8:** Kilic *et al.* (2012); **9:** Shun *et al.* (2011); **10:** Ristvedt & Trinkaus (2009); **11:** Serpentini *et al.* (2011); **12:** Knowles *et al.* (2013); **13:** Chambers *et al.* (2012b); **14:** Li *et al.* (2014); **15:** Pucciarelli *et al.* (2008); **16:** Mols *et al.* (2014); **17:** Hoerske *et al.* (2010); **18:** Lynch *et al.* (2007b); **19:** Gosselink *et al.* (2006); **20:** Thomas *et al.* (2014).

Table 3.11 Cancer, morbidity and health-related factors associated with colorectal cancer survivors' quality of life

Fucini *et al.* 2008, Pucciarelli *et al.* 2008, Krouse *et al.* 2009, Steginga *et al.* 2009, Hoerske *et al.* 2010, Thong *et al.* 2011b, Chambers *et al.* 2012b, Kilic *et al.* 2012, Sisler *et al.* 2012b, Milbury *et al.* 2013, Abu-Helalah *et al.* 2014, Li *et al.* 2014, Mols *et al.* 2014). A small number of studies fail to corroborate these findings (Ristvedt & Trinkaus 2009, Knowles *et al.* 2013, Orsini *et al.* 2013). An explanation for these disparate findings may lie in the fact that survivors with ostomies are likely to be older (Mols *et al.* 2014), and as previously discussed, acceptance of declining function among older survivors may be attributed to ageing and greater psychological well-being among this group (Section 3.7.1).

There is an abundance of literature describing the negative impact of ostomy formation, radiotherapy and surgery on colorectal cancer survivors' quality of life (Table 3.11). However, the evidence suggests survivors treated with chemotherapy report more positive physical, functional and overall well-being (Thong *et al.* 2011a, Thong *et al.* 2011b, Chambers *et al.* 2012b). At odds with previously discussed findings of age and physical outcomes, it has been suggested that older colon cancer survivors will experience better physical function following adjuvant chemotherapy (Bouvier *et al.* 2008). However, those who receive chemotherapy tend to be younger (Schneider *et al.* 2007, Jansen *et al.* 2011c, Mols *et al.* 2013). Given these findings, it would be reasonable to assume that older survivors who receive chemotherapy are likely to be those who have fewer comorbidities and better functional status at baseline, who may tolerate chemotherapy as well as younger survivors. There is inconclusive evidence to determine whether treatment with chemotherapy has a positive or negative psychological impact among colorectal cancer survivors. Two studies have suggested survivors treated with chemotherapy report worse social well-being (Pucciarelli *et al.* 2008, Hoerske *et al.* 2010).

Although few studies examine correlations between the severity of symptoms and various aspects of colorectal cancer survivors' quality of life, evidence suggests the enduring symptoms of fatigue, bowel dysfunction, sexual dysfunction and peripheral neuropathy negatively influence quality of life in all domains (Gosselink *et al.* 2006, Lynch *et al.* 2007b, Di Fabio *et al.* 2008, Baldwin *et al.* 2009, Ristvedt & Trinkaus 2009, Steginga *et al.* 2009, Serpentini *et al.* 2011, Chambers *et al.* 2012b, Kilic *et al.* 2012, Milbury *et al.* 2013, Mols *et al.* 2013, Palmer *et al.* 2013, Tofthagen *et al.* 2013a, Abu-Helalah *et al.* 2014, Thomas *et al.* 2014). Health efficacy in the Ashing-Giwa (2005) Model is concerned with colorectal cancer survivors' belief and ability to engage with disease prevention and healthy behaviours. Within the literature, it was evident that a number of these activities could negate the risk of lower quality of life. Physical activity was associated with more positive quality of life (Lynch *et al.* 2007b, Lynch *et al.* 2008a, Lynch *et al.* 2008c, Peddle *et al.* 2008a, Johnson *et al.* 2009, Steginga *et al.* 2009, Grimmett *et al.* 2011, Buffart *et al.* 2012, Husson *et al.* 2014, Lewis *et al.* 2014, Vallance *et al.* 2014). Engaging in healthy dietary behaviours contributed to improved bowel function and demonstrated similar benefits for physical well-being and quality of life (Peddle *et al.* 2008a, Grimmett *et al.* 2011, Buffart *et al.* 2012, Palmer *et al.* 2013, Schlesinger *et al.* 2014). Indeed, increasing the number of healthy behaviours was associated with better quality of life outcomes in all domains, except psychological outcomes, and contributed to less pain, dyspnoea and constipation among colorectal cancer survivors (Bouvier *et al.* 2008, Grimmett *et al.* 2011, Schlesinger *et al.* 2014). Physical activity may have a moderating effect on symptom experience, which indirectly contributes to more positive quality of life outcomes. In a positive finding, colorectal cancer survivors may return to pre-diagnosis levels of physical activity with time (Peddle *et al.* 2008a, Chambers *et al.* 2012b). However, 47-84% of colorectal cancer survivors may fail to achieve recommended levels of physical activity (Lynch *et al.* 2007b, Lynch *et al.* 2008a, Peddle *et al.* 2008a, Grimmett *et al.* 2011, Chambers *et al.* 2012b, Vallance *et al.* 2014).

3.7.3 Psychological Factors

Although colorectal cancer survivors' psychological well-being may eventually surpass that of normative populations, a proportion of long-term survivors may experience psychological morbidities (Section 3.4.2). Depression, anxiety, negative cancer threat appraisal and lower optimism demonstrate negative impacts upon colorectal cancer survivors' quality of life at all stages of survivorship (Ristvedt & Trinkaus 2009, Steginga *et al.* 2009, Hornbrook *et al.* 2011, Shun *et al.* 2011, Chambers *et al.* 2012b, Dunn *et al.* 2013a, Abu-Helalah *et al.* 2014, Husson *et al.* 2014).

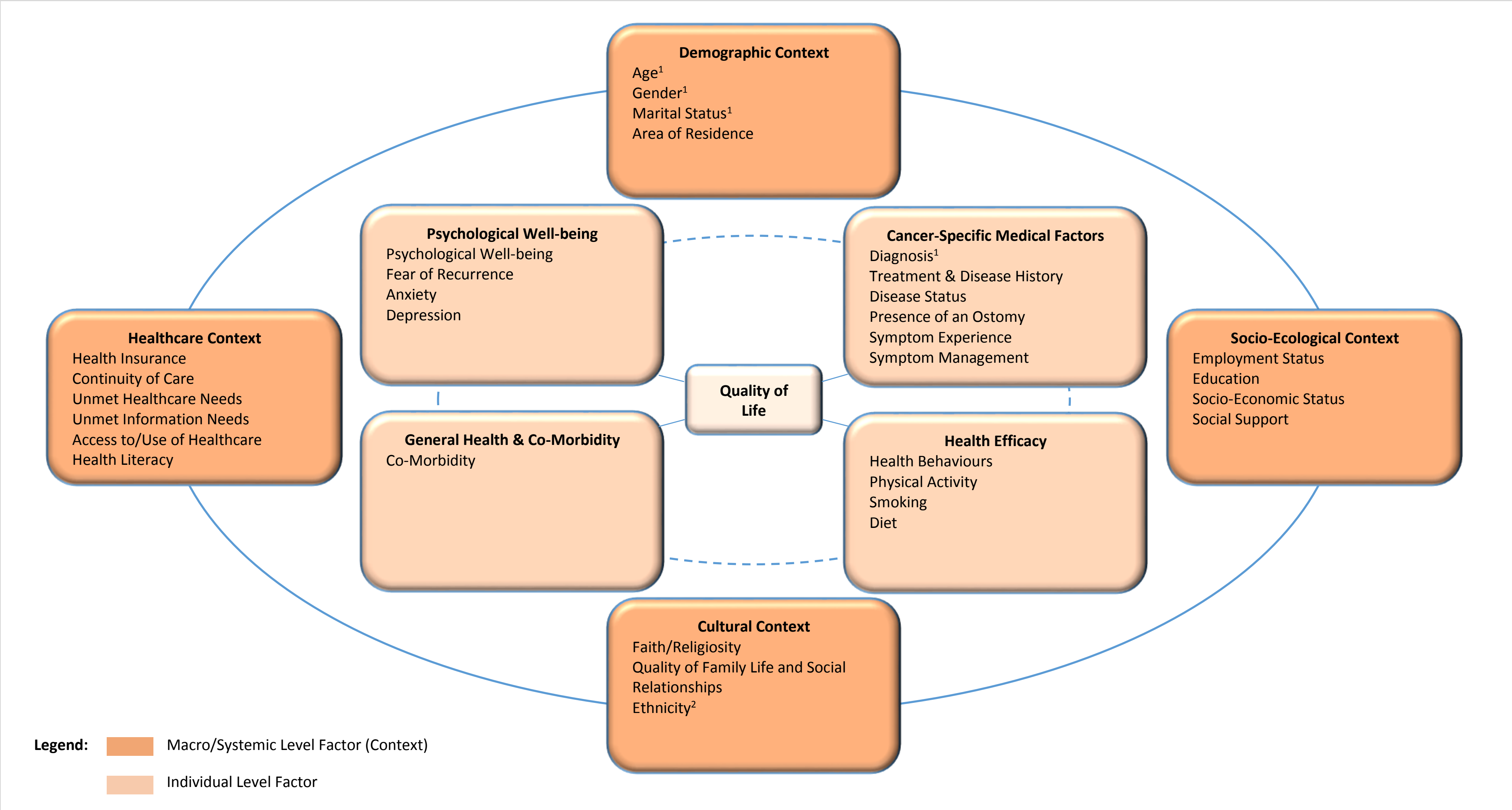
However, Husson *et al.* (2014) discredit the mediating effect of anxiety on quality of life, attributing greater importance to depression in regression analyses.

3.7.4 Healthcare Factors

Much of the evidence suggesting a potential relationship between colorectal cancer survivors' quality of life and experience of healthcare is derived from qualitative research and provide important insights to survivors' experiences and perceptions of the interaction between healthcare experiences and quality of life (Section 3.5.4). Becoming self-sufficient in managing the after-effects of colorectal cancer and regaining a sense of normality were important goals for survivors' recovery and well-being (DeSnoo & Faithfull 2006, Grant *et al.* 2011, Beech *et al.* 2012, McCaughan *et al.* 2012, Appleton *et al.* 2013). Unmet healthcare and information needs are substantial barriers to these goals being realised, causing survivors distress and confusion (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Ramirez *et al.* 2009, Beech *et al.* 2012, Bennett *et al.* 2012, Anderson *et al.* 2013, Appleton *et al.* 2013, Johansson *et al.* 2014, Sun *et al.* 2014). Even in the presence of a supportive network of healthcare professionals, late-effects of treatment may continue to adversely affect survivors' quality of life up to five years after treatment (Fucini *et al.* 2008). As already discussed, a single quantitative study indicates lower quality of life and male gender are predictive of poorer continuity of care (Section 3.5.4) (Sisler *et al.* 2012b). Another study illustrates the detrimental effects of low health literacy on survivors' quality of life overall and in physical, emotional and social domains (Husson *et al.* 2014). Finally, Thomas *et al.* (2014) identified a relationship between greater distance from the treating hospital and poorer physical and functional well-being (Section 3.6).

3.7.5 Summary: Factors Influencing Colorectal Cancer Survivors' Quality of Life

The current section has highlighted a range of factors which influence colorectal cancer survivors' quality of life, in keeping with the *Contextual Model of Health-Related Quality of Life* (Ashing-Giwa 2005) (Figure 3.5). However, there are several factors which demonstrate inconsistency or insufficiency of evidence which require further investigation. For example, age and gender have demonstrated an inconsistent effect upon quality of life among colorectal cancer survivors. Sections 2.2 and 3.4 have highlighted the competing effect of age-related physical and functional decline, and the possibility that older survivors may possess greater coping mechanisms and greater capacity for post-traumatic growth, which may partially explain these inconsistencies. Furthermore, Section 3.4.3 illustrates gendered differences in social well-being, return to social activities and differences in sources of support following colorectal cancer. As described extensively throughout Section 3.4, the inconsistency of instruments used to measure quality of life outcomes within the colorectal cancer survivorship literature may also be a contributory factor to the conflicting results.



Source adapted from Ashing-Giwa (2005) The Contextual Model of HRQoL: A Paradigm for Expanding the HRQoL Framework. *Quality of Life Research* **14**(2), p.298.
[1]Inconsistent evidence available to determine the effect of the variable; [2]Variable not significantly associated with quality of life outcomes.

Figure 3.5 Factors identified from the literature which may influence the quality of life of colorectal cancer survivors in physical, psychological or social domains, categorised within the theoretical framework of the Ashing-Giwa (2005) Contextual Model of Health-Related Quality of Life

Therefore, these issues were considered in the design of the data collection instruments (Section 4.4.3).

3.8 Implications of the Literature Review

This section considers the overarching implications of this literature review for this study. Within this section, summaries of the methodological limitations of the reviewed studies (Section 3.8.1), and the overarching results of the literature review and gaps for further study are presented (Section 3.8.2). This section concludes with a description of the adapted Ashing-Giwa (2005) Model which was used to guide this study.

3.8.1 Methodological Critique of Studies Included in the Literature Review

While there is a broad body of literature describing colorectal cancer survivors' quality of life and symptom experiences, the results of this literature review should be considered within the context of the limitations of the reviewed studies. Firstly, studies are consistently limited by younger, ethnically homogeneous samples, with earlier stages of disease (Schneider *et al.* 2007, Bouvier *et al.* 2008, Gordon *et al.* 2008, Lynch *et al.* 2008a, Lynch *et al.* 2008c, Chambers *et al.* 2009, Ristvedt & Trinkaus 2009, Steginga *et al.* 2009, Caravati-Jouvenceaux *et al.* 2011, Jansen *et al.* 2011a, Thong *et al.* 2011a, Buffart *et al.* 2012, Den Oudsten *et al.* 2012, Mols *et al.* 2012a, Knowles *et al.* 2013, Thong *et al.* 2013, Mols *et al.* 2014, Schlesinger *et al.* 2014, Thomas *et al.* 2014). Secondly, the post-diagnosis timelines examined in colorectal cancer survivorship research vary, with mixed samples of survivors in acute, extended and permanent stages of survivorship, thereby failing to investigate the distinct concerns of survivors at each stage. Thirdly, there is little consideration of the potential impact of acute treatment toxicities which may continue for up to six months after treatment, which may also partially explain the wide variance in reported prevalence of physical, psychological and social concerns described in Section 3.4. Di Fabio *et al.* (2008) is the only paper which transparently acknowledges this risk and attempts to reduce bias by excluding survivors who are less than one year post-surgery. Finally, and most notably, the variety of instruments used to assess quality of life and symptom experience among colorectal cancer survivors may account for the variance in symptom prevalence rates within this literature (Section 3.4.5).

Section 3.5 illustrated growing attention to survivors' experiences and interactions with the healthcare system since the publication of *From Cancer Patient to Cancer Survivor* (IoM 2006). However, much of the literature in this growing field is driven by analysis of healthcare metrics, rather than description of survivors' experiences of the healthcare system. Furthermore, this literature is limited by the overwhelming use of original survey instruments without sufficient discussion of their psychometric properties. Section 3.5.4 highlights a limited body of evidence which demonstrates survivors' experiences of healthcare and how it may impact upon quality of life. Of 127 studies which met the PEOS criteria for inclusion in this review, just 13 provided insight into this relationship. These studies are predominantly qualitative (*n*=8), with results derived from the UK (*n*=5) and North American (*n*=4) settings which operate predominantly universal or privatised healthcare systems. Thus, transferability and generalisability of these results to an Irish context may be limited, as the healthcare systems in which the research was conducted do not reflect the unique challenges associated with the dualistic healthcare delivery model used in Ireland.

Although there are a number of large-scale longitudinal studies of quality of life in colorectal cancer, these are limited by multiple reports from single datasets and unclear reporting of recruitment, retention and response rates (Lynch *et al.* 2007b, Gordon *et al.* 2008, Lynch *et al.* 2008a, Lynch *et al.* 2008b, Lynch *et al.* 2008c, Chambers *et al.* 2009, Salsman *et al.* 2009, Steginga *et al.* 2009, Kunitake *et al.* 2010, Jansen *et al.* 2011a, Lynch *et al.* 2011, Thong *et al.* 2011a, Thong *et al.* 2011b, Buffart *et al.* 2012, Chambers *et al.* 2012b, Den Oudsten *et al.* 2012, Mols *et al.* 2012a, Andrykowski *et al.* 2013, Dunn *et al.* 2013a, Dunn *et al.* 2013b, Mols *et al.* 2013, Orsini *et al.* 2013, Thong *et al.* 2013, Tofthagen *et al.* 2013b, Husson *et al.* 2014, Mols *et al.* 2014). This lack of clarity may result in an inaccurate evaluation of the available literature, particularly as many longitudinal studies employ registry-based recruitment strategies, which have lower response rates and a greater risk of response bias as survivors who experience concerns particular to the study topic may be more likely to respond.

The diversity of methodologies used in quality of life research for colorectal cancer survivors is dominated by quantitative approaches, with some qualitative work, and a small number of mixed methods approaches. The mixed methods study conducted by the Kaiser-Permanente healthcare system in the USA is a well-designed programme of research involving ostomates who are more than five years following diagnosis. However, there is a failure to integrate the findings of this study, as quantitative and qualitative results are reported separately without due consideration of their relationship to results drawn from the alternative method (McMullen *et al.* 2008, Krouse *et al.* 2009, Ramirez *et al.* 2009, McMullen *et al.* 2011, McMullen *et al.* 2014, Ramirez *et al.* 2014). Grant *et al.* (2011), Sun *et al.* (2013), and Sun *et al.* (2014) attempt integration of mixed methods, reporting the results of focus groups stratified by participants' quality of life (high/low) obtained via surveys.

3.8.2 Summary of Literature Review Findings and Opportunities for Further Research

This chapter reported the results of a literature review to describe the quality of life and healthcare experiences of colorectal cancer survivors. Colorectal cancer survivors have been the focus of many quality of life studies. Although colorectal cancer survivors' quality of life may improve with increasing time from diagnosis, many will continue to experience a range of physical, psychological and social challenges and may positively reframe their expectations of quality of life to accommodate these challenges. Given the inconsistencies in the prevalence of symptoms experienced by colorectal cancer survivors and the limited literature available in the Irish context, it is of importance that these concerns are evaluated among survivors in the present study to provide context for the potential relationship between quality of life and healthcare experiences.

The burgeoning literature examining aspects of colorectal cancer survivors' interactions with the healthcare system indicates largely favourable evaluations of care from survivors. However, some qualitative studies have suggested that survivors may feel neglected by the healthcare system following treatment as the frequency of consultations with healthcare professionals reduces. As a result, some survivors may feel insufficiently prepared and unsupported to manage persistent disease-related symptoms and may contribute to physical, psychological and social distress among survivors. Indeed, access to and understanding of information and support from healthcare professionals, and the relative priority of symptom management in follow-up care have been described as important factors which may facilitate or hinder follow-up for survivors and consequently impact upon survivors' symptom experience and their quality of life. A significant gap in the knowledge is the predominantly British and North American origin of research describing survivors' healthcare experiences. Given the discrepancy between universal or private models of healthcare provision in these regions and the two-tier system in Ireland where each of these models of care are loosely replicated and intermingled, the generalisability or transferability of results from these studies may be limited, representing a significant cultural knowledge gap in the field.

Continuity of care is an emerging concept in the colorectal cancer survivorship literature. Three studies have described potential consequences of poorer continuity of care, including difficulties with healthcare navigation, healthcare professionals' insensitivity to survivors' needs and survivors' sense of abandonment or isolation from the support of healthcare professionals (McMullen *et al.* 2008, Johansson *et al.* 2014, Sun *et al.* 2014). A single study has described the potential predictive importance of quality of life in determining survivors' perceptions of continuity of care in primary care follow-up (Sisler *et al.* 2012b). Despite the already discussed limitations, this study provides an important insight into the potential relationship between quality of life and healthcare experiences in primary care. The nature of this interaction is an area which warrants further investigation in specialist oncology-led follow-up models of care. Therefore, this study will examine how continuity of care and unmet needs may influence colorectal cancer survivors' quality of life in tertiary follow-up care settings in Ireland up to five years after diagnosis.

3.8.3 Theoretical Implications of the Literature Review for the Current Study

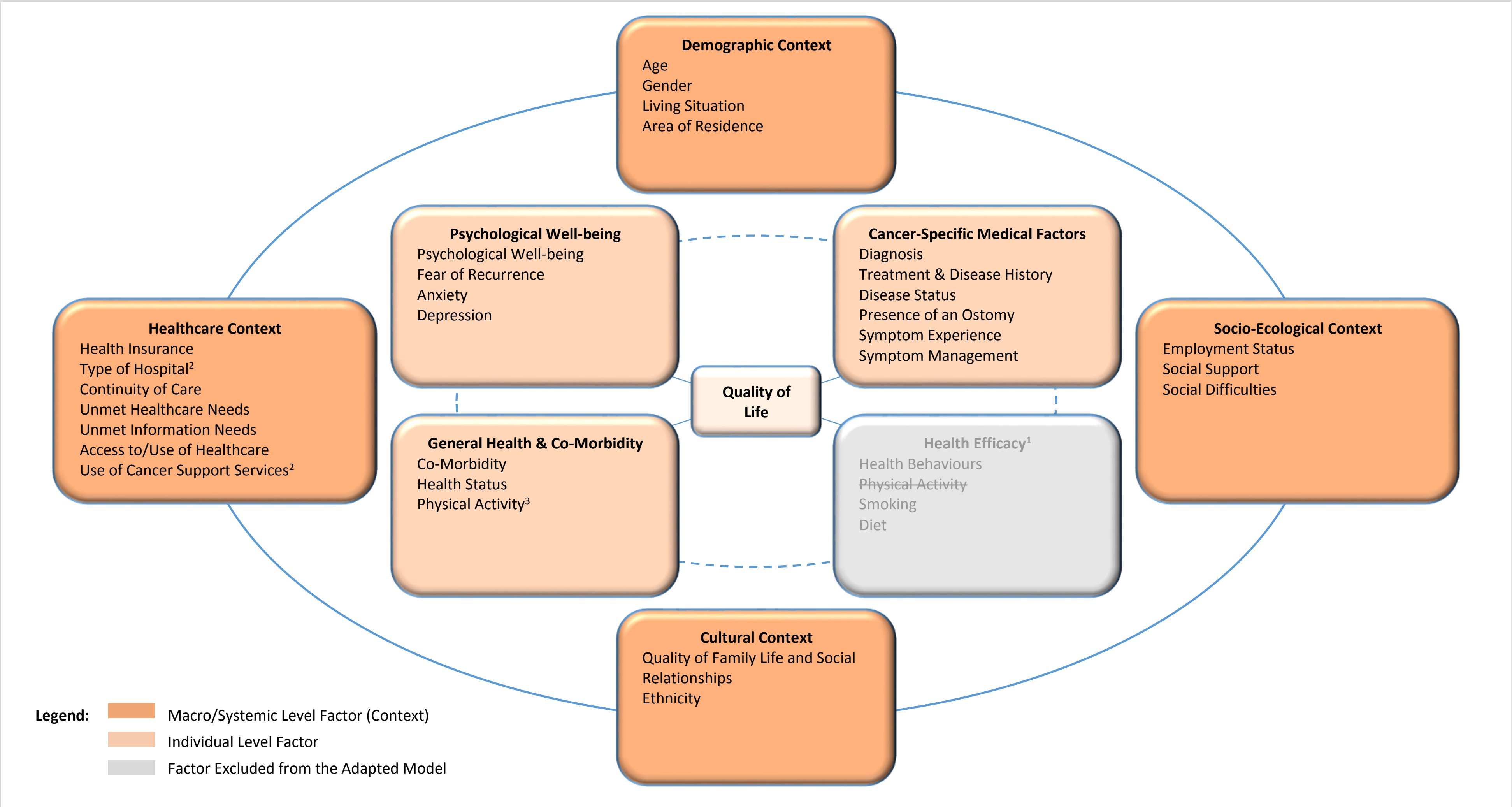
This literature review has presented clear evidence to support the use of *The Contextual Model of Health-Related Quality of Life* to frame this study. A variety of socio-demographic, socio-economic, cultural, psychological and health and cancer-related issues may impact survivors' quality of life

(Figure 3.5). However, the relationship between the healthcare context and quality of life is a neglected area of research within the colorectal cancer survivorship literature (Section 3.5.4). Therefore, the current exploratory study aims to generate further evidence in this field and will focus on the impact of variables within the *Healthcare Context* of the Ashing-Giwa (2005) Model.

As described in Section 2.3.4, the Ashing-Giwa (2005) Model was presented as an evolving work in progress, which has been predominantly used to assess quality of life among ethnically and culturally diverse samples of female cancer survivors. Therefore, the Model has been adapted conceptually to reflect the findings of the literature review, and practically to reflect the culture and model of healthcare provision in Ireland (Figure 3.6). Given the complexity of the Ashing-Giwa (2005) Model, aspects of the model have been rationalised to provide an evidence-based framework which guides quality of life research with an explicit focus upon colorectal cancer survivors' experiences within the Irish healthcare context.

Decisions regarding adaptations to the model were made based on the contextual (Chapter One), conceptual (Chapter Two) and empirical (Chapter Three) background to this study. The first, and most notable adaptation to the model concern the exclusion of the *Health Efficacy* component of the model. Section 3.7.2 outlined several studies demonstrating the importance of survivors' belief and ability to engage in healthier lifestyle and prevention behaviours for their quality of life. *Health Efficacy* represents an ever-evolving area of enquiry; given the exploratory nature of this study, it was considered beyond its scope to include this component in the theoretical framework. However, survivors' engagement in physical activity is considered within the *General Health and Comorbidity* component of the Model. A second considerable amendment to the model involves the exclusion of significant aspects of the *Cultural Context* which forms a central basis for the ethnically and culturally diverse research which has informed the development of the Ashing-Giwa (2005) Model. Although there has been a growth in the population of ethnic minority groups residing in Ireland, the ethnic profile of the country remains relatively homogeneous. At the time of the 2011 census, 94% of the population were of White ethnic background and 85% of Roman Catholic faith (Central Statistics Office 2012). Given these considerations, it was deemed appropriate to exclude some cultural aspects of the model. Nevertheless, the adapted model explicitly considers how family life, social relationships and sources of support may impact colorectal cancer survivors' quality of life, in keeping with the original model (Table 2.2). It was anticipated that survivors might describe issues relevant to *Health Efficacy* and the *Cultural Context* of the model during follow-up interviews.

Finally, the *Healthcare Context* of the model adapted for this study has undergone minor adaptations to reflect the literature review findings and the context of follow-up care in Ireland. In keeping with the Ashing-Giwa (2005) Model, aspects concerning access to healthcare (health insurance), quality of care (continuity of care, access to/use of healthcare, unmet healthcare and information needs) and relationships with healthcare professionals are retained in the model.



Source adapted from Ashing-Giwa (2005) The Contextual Model of HRQoL: A Paradigm for Expanding the HRQoL Framework. *Quality of Life Research* **14**(2), p.298.
[1] Component excluded from the adapted model; [2] New variable added to adapted model; [3] Variable rearranged into an alternative context within the adapted model.

Figure 3.6 The Ashing-Giwa (2005) Contextual Model of Health-Related Quality of Life, adapted for the Cost of Survival Study

However, the Model has been adapted to reflect the critical importance of advocacy-based cancer support services for the delivery of psychosocial care to cancer survivors in Ireland, and the impact of these services on survivors' quality of life. The complete adapted model is presented in Figure 3.6.

3.9 Chapter Summary

Healthcare experiences are increasingly recognised as a factor which may influence colorectal cancer survivors' quality of life, amongst an array of socio-demographic, socio-economic, cultural, psychological, health- and cancer-related factors. This literature review highlights a burgeoning evidence-base describing colorectal cancer survivors' experiences of healthcare following treatment. However, a limited understanding of the effect of healthcare experiences upon colorectal cancer survivors' quality of life remains. This study will examine how continuity of care and unmet needs influence colorectal cancer survivors' quality of life in tertiary follow-up for colorectal cancer in Ireland. Given the methodological critique of the literature to date (Section 3.8.1), this study will be guided by a mixed methods approach, allowing comparison of the quality of life outcomes of this sample to the large body of international quantitative research, while responding to the scarcity of qualitative research in the field. The qualitative component will offer a deeper understanding survivors' quality of life following treatment and provide further insight into the potential impact of the Irish healthcare setting on quality of life outcomes. The next chapter will describe the philosophical and methodological considerations of the mixed methods research design implemented within this study.

Chapter Four – Methodology

4.1 Introduction

Research is defined as a way of *"knowing or understanding … a process of systematic inquiry … designed to collect, analyse, interpret, and use data"* (Mertens 2015, p.2). However, research methods may take the central role of research discussion, replacing the role of the theoretical framework, philosophical beliefs, worldview or paradigm in guiding the research process. The paradigm sets down the intent, motivation and expectations for the research (Mackenzie & Knipe 2006). The preceding chapters have illuminated the aims and objectives of this study, and the limited empirical knowledge describing the relationship between healthcare experiences and quality of life in cancer survivorship. Therefore, the current chapter outlines and justifies the methodological and philosophical assumptions considered in the design and conduct of this study. The chapter opens with a definition of mixed methods research (Section 4.2). This is followed by a discussion of the pertinent philosophical (Section 4.3) and methodological (Section 4.4) considerations in mixed methods research. Finally, the chapter closes with a discussion of the application of a sequential explanatory mixed methods design in the current study (Section 4.5).

4.2 Mixed Methods Research

Creswell & Plano Clarke (2011) encourage mixed methods research definitions clarifying the core characteristics of the research approach, philosophy, design and methods. As a research methodology, mixed methods is underpinned by philosophical assumptions guiding the quantitative and qualitative approaches to the research process. However, divergence in the ontological and epistemological stances associated with quantitative and qualitative research approaches are a considerable source of division among social and behavioural researchers. Quantitative research is guided by positivist or post-positivist philosophy, striving for objective, replicable observation of phenomena, driven by a singular reality influenced by natural causes (Cohen 2006, Morgan 2014, Polit & Beck 2014). On the other hand, the constructivist worldview emerged as a counter-movement to positivism, advocating for an understanding of the context of human experience, fostering a reality that is multiple, subjective and heavily influenced by environment and culture (Cohen 2006, Morgan 2014).

Mixed methods research calls for rigourous collection, analysis and interpretation of quantitative and qualitative data concurrently or sequentially within a single study, with priority allocated to one or both forms of data (Leech & Onwuegbuzie 2009, Creswell & Plano Clarke 2011). Mixed methods research is contingent upon the mixing or integration of quantitative and qualitative methods of inquiry at one or more points of a single research study, including design, sampling, data collection, data analysis or interpretation of findings (Creswell & Plano Clarke 2011). The products of integration are the meta-inferences drawn from the combination of quantitative and qualitative results, which may provide a more comprehensive understanding of a research problem than quantitative or qualitative approaches alone (Ivankova *et al.* 2006, Creswell & Plano Clarke 2011). In the current study, a mixed methods research approach provides a unique opportunity to fully evaluate the scope and meaning of quality of life issues and the implications of the healthcare context upon these outcomes, providing an in-depth and coherent image of the experiences of cancer survivors.

4.3 Philosophical Concerns

A fundamental challenge in justifying the use of mixed methods research lies in the union of the conflicting ontologies and epistemologies of quantitative and qualitative research. Biesta (2010) argues that the concerns raised by advocates of quantitative and qualitative research approaches are not fundamentally related to the nature of the data used, but to the philosophical issues underpinning the nature of reality and limits of knowledge. Pragmatism provides a middle ground, disrupting the reliance on metaphysical concerns, resolving issues of mixing methods by prioritising the research problem. As a result, appropriate mixed methods data collection and analysis techniques may be selected, mixed and logically justified in their ability to respond to the research question (Johnson & Onwuegbuzie 2004, Morgan 2014).

Pragmatism offers a pluralist and compatibilist approach to research endeavours, emphasising abductive-intersubjective-transferable aspects of research (Johnson & Onwuegbuzie 2004, Morgan 2007). Abductive reasoning promotes a more comprehensive approach to inquiry than top-down or bottom-up privileging of ontological assumptions and facilitates a logical connection between data and theory, as the researcher moves back and forth between inductive and deductive research methods, thereby furthering the process of inquiry (Morgan 2007, Feilzer 2010). The recognition of singular and multiple realities within an intersubjective frame of reference allows the pragmatic researcher to adopt a reflexive approach to research, rather than being forced into an objective or subjective worldview, maximising the potential shared understanding which can be achieved in mixed methods research (Morgan 2007, Creswell 2014). Finally, pragmatists believe knowledge is acquired through action, consequence and reflection upon the reality we experience (Johnson & Onwuegbuzie 2004, Morgan 2007). This tenet has positive and negative implications, as the utility of research is prioritised over the most accurate representation of reality. The researcher has the freedom to study a phenomenon in the manner most likely to achieve the purpose of the study (Maxcy 2003). However, pragmatic researchers must be practical, flexible, open to the emergence of unexpected data and accept the fallibility of conclusions, as they are rarely, if ever, certain or absolute (Johnson & Onwuegbuzie 2004, Feilzer 2010). Truth is verifiable in the correspondence of events with the accounts and beliefs of those researched, ascribing to objective and subjective aspects of truth (Howell 2013). Therefore, the researcher seeks to ascertain the transferability of results, rather than assuming results are context-bound or generalisable.

Pragmatism offers the most practical underpinning for this mixed methods study, as it supports a plurality of research methods which prioritise answering the research question and the practical outcome-driven consequences of research. Undertaking an evaluation of complex, multi-factorial phenomena such as quality of life and healthcare experiences using mono-method designs deprives the results of the context which could be provided by the alternative methodological approach, be it prevalence in quantitative research or human experience in qualitative research. Pragmatic beliefs permit a needs or contingency-based approach to support this study, which is likely to produce results with greater breadth and depth of meaning than a mono-method research strategy.

4.4 Methodological Considerations

A principle of mixed methods research is to identify and justify the reasons for mixing quantitative and qualitative research methods within a study (Creswell & Plano Clarke 2011). In considering the utility of mixed methods research, Feilzer (2010) calls for reflexivity on the beneficiaries and stakeholders in the research endeavour as well as method selection. Mixed methods research responds to the diverse needs of healthcare planners, clinicians and patients. The results of both quantitative and qualitative research methods provide evidence for change in healthcare practice and policy. In instances where quantitative and qualitative methods are merged, the strengths of each method may be exploited, enabling a complete investigation, thereby enhancing the utility of the research findings (Pluye & Hong 2014). The pragmatic mixing of methods provides the bridge to explore multi-layered phenomena. In this study, quantitative data provide statistical data about colorectal cancer survivors' quality of life and experiences of continuity, access and support within the healthcare system, enabling exploration of the frequencies and relationships between these variables. The qualitative data offers rich description and understanding of the survivor's experiences and interpretations of the potential impact of healthcare experiences on their quality of life outcomes. The information derived from the qualitative investigation enhanced and complemented the quantitative results, offering a greater richness and depth of findings, as well as contextual information to aid the interpretation of statistically and clinically significant quantitative findings. The purpose of combining quantitative and qualitative methods in this study was to provide greater insight into the complexity and individuality of colorectal cancer survivorship experiences, which cannot be measured or explained solely by quantitative or qualitative methods alone.

4.5 Mixed Methods Research Design

Research designs are the procedures of inquiry steering the study from inception through planning and implementation, to generate evidence and answer the research questions posed while controlling for factors which could interfere with the validity of findings insofar as possible (Burns & Grove 2009, Gorard 2010). Well-designed research produces rigourous, high-quality results, therefore, researchers should endeavour to choose a specific research design to frame their study (Creswell & Plano Clarke 2011). There are more than 40 frameworks classifying mixed methods research designs (Creswell *et al.* 2003). Creswell & Plano Clarke (2011) proposed six major prototypical versions of mixed methods designs with variation between designs based on the interaction, priority, timing and sequence of quantitative and qualitative research strands in a mixed methods research design. Although mixed methods designs differ in their emphasis, they share many commonalities, in particular, the '*what works*' approach to answering research questions (Creswell & Plano Clarke 2011). Critical decisions in selecting a mixed methods design are 1) the level of interaction between the strands, 2) the relative priority of the strands, 3) the timing of the strands and 4) the procedures for integrating the strands (Creswell & Plano Clarke 2011).

The Creswell & Plano Clarke (2011) sequential explanatory design was considered the most appropriate framework to achieve the objectives of the present study (Figure 4.1). Decisions of interaction, priority, timing and integration were made at the outset of the study with due consideration to the research problem and questions. The limited understanding of the relationship between colorectal cancer survivors' quality of life and healthcare experiences in tertiary follow-up care settings suggested that qualitative inquiry should be dependent on and guided by the findings of the first quantitative phase. When prioritised, the quantitative investigation acquires essential PROMs data to ascertain survivors' quality of life, symptom burden, healthcare experience and unmet needs and the relationships between these variables. The subsequent qualitative inquiry

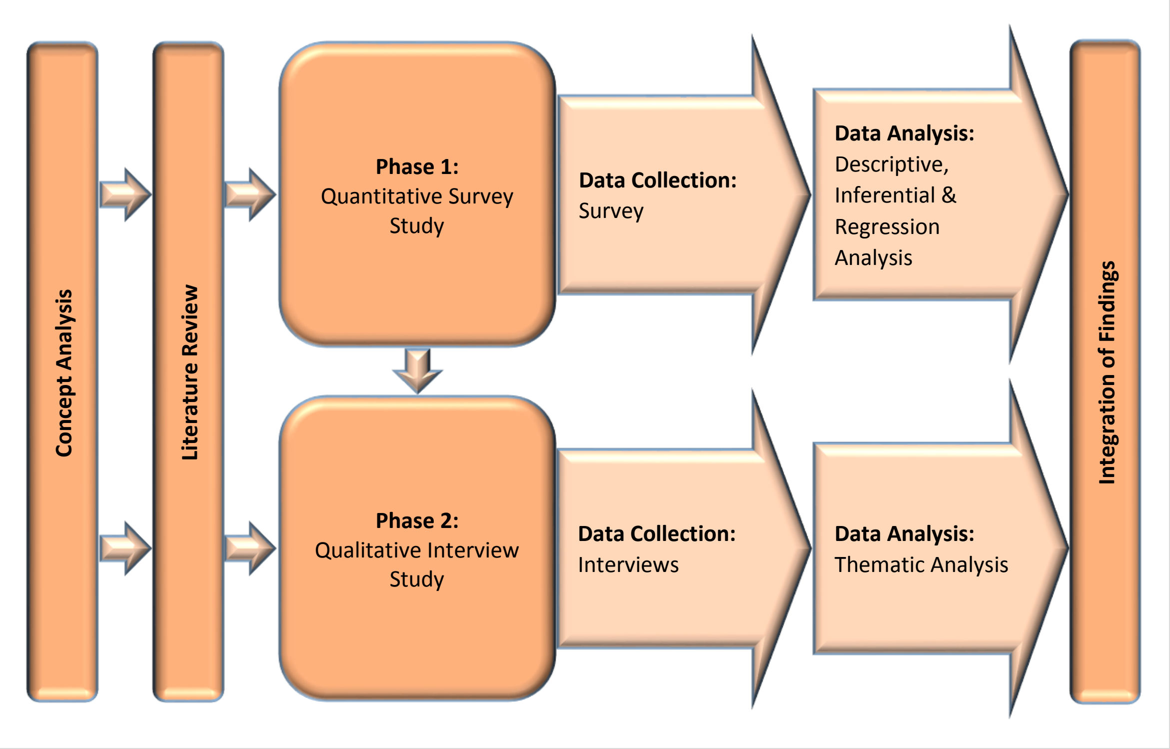


Figure 4.1 The mixed methods sequential explanatory design adapted for the Cost of Survival Study

explores the quantitative findings further, to provide context and facilitate interpretation of the quantitative results, helping to refine, explain, clarify and enhance the depth of understanding about the predominant issues experienced by colorectal survivors (Creswell & Plano Clarke 2011). Sequential implementation of quantitative and qualitative research methods lent itself to these objectives, allowing flexibility to adapt the qualitative phase to address the quantitative findings (Feilzer 2010). The researcher sought to achieve a high level of integration between quantitative and qualitative strands, therefore approaches to integration were explored at sampling, data collection and analysis stages of design (Section 5.2.3). While the sequential explanatory design is considered the most straightforward of the mixed methods designs, challenges may arise due to 1) the time and financial resources required to implement a two-phase design, 2) difficulties associated with obtaining funding, 3) ethical approval for emergent qualitative phases of the research study, and 4) decisions around results and participants to follow-up in the subsequent qualitative inquiry (Creswell & Plano Clarke 2011). These are discussed further in Chapters Five and Eight.

4.6 Chapter Summary

The philosophical and methodological background to this mixed methods examination of the relationship between quality of life and healthcare experiences of colorectal cancer survivors in tertiary-led models of oncology follow-up have been outlined in this chapter. The philosophical concerns associated with the mixing of quantitative and qualitative research methods were outlined. A mixed methods sequential explanatory design, underpinned by pragmatist philosophy was selected to guide this study, as it facilitates a comprehensive understanding of the healthcare factors and experiences which may influence colorectal cancer survivors' quality of life during follow-up care for colorectal cancer in tertiary oncology healthcare settings. Objective survey data will provide evidence surrounding the healthcare factors which may influence quality of life outcomes, including continuity of care and unmet information and supportive care needs. Narrative interview data will provide greater insight into survivors' complex and individual experiences of quality of life in relation to their physical, psychological and social well-being and their understanding of how healthcare experiences may affect their quality of life in the aftermath of colorectal cancer. The next chapter will describe the research methods and ethical considerations of this study.

Chapter Five – Research Methods

5.1 Introduction

This mixed methods study aims to explore the impact of healthcare experiences upon the quality of life of colorectal cancer survivors between six months and five years following diagnosis who are receiving follow-up care in tertiary oncology healthcare settings in Ireland. This chapter will discuss and justify the research methods used to address the aims and objectives of this study. The quantitative and qualitative approaches of this mixed method study are described and justified (Section 5.2). The population of interest and sampling technique are explained in Section 5.3. The selection and development of the respective quantitative and qualitative data collection instruments and procedures of recruitment are outlined in Sections 5.4 and 5.5. This is followed by an evaluation of the issues of quality and rigour (Section 5.6) and ethics (Section 5.8) of relevance to this study.

5.2 Study Design

As outlined in Chapter Four, a two-phase mixed methods sequential explanatory design was used. Quantitative methods were prioritised; therefore, survey data were collected and analysed in the first phase of the study to ascertain colorectal cancer survivors' quality of life outcomes, symptom experience and the potential impact of healthcare experiences, including continuity of care, information and supportive care needs upon these outcomes. The subsequent qualitative phase was designed to build upon the quantitative phase, exploring the impact of physical and psychosocial survivorship issues to elicit a deeper understanding of survivors' healthcare experiences and interpretations of how these experiences might influence their quality of life. Thus, the qualitative phase provides context and rich descriptions of colorectal cancer survivors' experiences which facilitated interpretation, explanation and enhanced understanding of the knowledge garnered from the quantitative phase (Creswell & Plano Clarke 2011).

5.2.1 Phase 1: Descriptive Correlational Survey Study

For the quantitative phase of the study, a descriptive correlational study design was used, which is a non-experimental approach conceived to gain more information and examine relationships between two or more variables of interest through observation and description (LoBiondo-Wood & Haber 2006, Wood & Ross-Kerr 2011). Descriptive correlational research permits the researcher to examine the strength of the relationship between the variables of interest, without an obligation to specify hypotheses regarding the direction of relationships between variables (Wood & Ross-Kerr 2011). Due to the non-experimental nature of correlational research designs, causality cannot be inferred from study results (Polit & Beck 2006). However, the results of descriptive correlational research may form the basis for the design of experimental studies which provide stronger evidence about causality (Wood & Ross-Kerr 2011). In keeping with the rationale for the sequential explanatory design, the descriptive correlational survey design is suitable to establish reliable estimates of colorectal cancer survivors' quality of life and the proportion of survivors who are experiencing long-term physical or psychosocial side-effects or unmet need in Ireland. The results of the survey provide information about areas requiring further exploration in the qualitative phase.

5.2.2 Phase 2: Descriptive Qualitative Interview Study

A descriptive qualitative research design was utilised in the second phase of the study, a form of generic qualitative inquiry that adopts an eclectic approach to research. Descriptive qualitative research aims to understand and describe an experience, event or phenomena and provide answers to questions of interest to stakeholders, practitioners and policymakers (Sandelowski 2000, Caelli *et al.* 2003, Neergaard *et al.* 2009, Sandelowski 2010). Descriptive qualitative research has received much criticism for its lack of explicit theoretical and philosophic assumptions (Caelli *et al.* 2003, Milne & Oberle 2005, Kahlke 2014). However, descriptive qualitative research adopts an epistemology which acknowledges pre-existing knowledge derived from research or clinical interpretation (Neergaard *et al.* 2009, Grypdonck *et al.* 2013, Stanley 2015). Therefore, its use in this pragmatic mixed methods sequential explanatory study is justifiable. In this study, the qualitative phase was theoretically framed by the Ashing-Giwa (2005) model and the results of the quantitative phase.

Descriptive qualitative research has received further criticism due to lack of clarity about what constitutes a rigourous qualitative study (Sandelowski 2000, Caelli *et al.* 2003, Milne & Oberle 2005, Neergaard *et al.* 2009, Parahoo 2014, Stanley 2015). Descriptive qualitative designs may be influenced by '*hues, tones and textures*' from phenomenological, grounded theory, ethnographic and narrative studies (Sandelowski 2000, p.337). However, this may lead to slurring of methods which threaten the validity of conclusions, as incompatible research methods are blended (Caelli *et al.* 2003, Kahlke 2014). In keeping with the pragmatic rationale for research decisions, decisions surrounding methodology and methods were guided by the research problem and are explicitly discussed and rationalised throughout this chapter. A descriptive qualitative study complemented the quantitative strand of this study, as it permitted further exploration of key survey findings, providing a deeper understanding of the natural context in which colorectal cancer survivors experience quality of life and healthcare (Sandelowski 2000, Neergaard *et al.* 2009, Stanley 2015).

5.2.3 Integration

Mixed methods studies have an advantage over quantitative or qualitative research in its potential to produce knowledge that is unavailable in either method alone. However, there is often a failure to adequately integrate the findings of mixed methods research to realise its full potential (Bryman 2007, O'Cathain *et al.* 2007). Creswell & Plano Clarke's mixed methods designs have been criticised for distinguishing between quantitative and qualitative approaches (Biesta 2010). Integration remains a core principle of the prototypical designs proposed by Creswell & Plano Clarke (2011). Integration refers to the points where quantitative and qualitative phases intersect and may occur at one or more points of the planning, design, sampling, data collection, data analysis, interpretation and reporting stages of research (Creswell & Plano Clarke 2011). Within the current study, a strong emphasis was placed on achieving multiple levels of integration throughout (Table 5.1). As data were collected sequentially, the results of each phase of the study are presented logically, in a sequential manner (Chapter Six; Chapter Seven). The results are then integrated in Chapter Eight to address the mixed methods objectives of this study (Section 2.4.1) and identify confirmatory, explanatory or discordant results in line with recommendations of Creswell & Plano Clarke (2011) and Fetters *et al.* (2013).

Points of Integration in the Mixed Methods Cost of Survival Study

- Integrated research objectives derived from gaps in the literature drove this study (Section 2.4.1).
- Quantitative findings informed the development of the qualitative interview schedule (Section 5.5 and 5.6).
- An integrated nested sampling strategy was used, inviting a subsample of survey participants to take part in follow-up interviews (Section 5.3.3).
- Quantitative results informed the development of the maximum variation sampling strategy used to identify interview participants (Section 5.3.3.2).
- An integrated discussion of findings responding to the mixed methods objectives is presented, identifying convergence and divergence of results between quantitative and qualitative phases (Sections 8.3-8.8).
- The integrated results of this study inform the development of a conceptual model to demonstrate the impact of healthcare, socio-ecological and cultural contexts of the Ashing-Giwa (2005) *Contextual Model of Health-Related Quality of Life* upon colorectal cancer survivors' quality of life (Section 8.9). The integrated results are presented in a joint display (Figure 8.2) (Guetterman *et al.* 2015).
- Meta-inferences drawn from the integration of quantitative and qualitative findings are summarised (Section 9.2).
- Further integration of findings from this study will be achieved in future research through the development of an intervention to improve an aspect of colorectal cancer survivors' experience of healthcare which is amenable to intervention.

Table 5.1 Points of integration in this mixed methods study

5.3 Population and Sample

5.3.1 Population

A colorectal cancer survivor is defined as any individual who has received a diagnosis of colorectal cancer of any diagnostic stage (Reuben 2004). The target population of this study are colorectal cancer survivors who have completed primary treatments including radiotherapy, chemotherapy and surgery between six months and five years prior to the study. This group were selected to ensure the experiences of cancer survivors engaged in processes of surveillance and follow up were represented.

5.3.2 Projected Sample Size

Descriptive correlational designs require large representative samples to determine variability in the variable of interest and the existence of relationships between dependent and independent variables (Wood & Ross-Kerr 2011). Choosing the sample size is equally as important as the choice of sampling scheme, as it determines the extent of statistical and analytical generalisations (Onwuegbuzie & Collins 2007). According to NCRI (2014a), 66% (*n*=7,223) of those diagnosed with colorectal cancer in Ireland in the five years preceding December 31st, 2012 were still alive. To obtain a nationally representative sample of colorectal cancer survivors, a sample size of 363 participants was required for a precision confidence interval of ±5% at a confidence level of 95%. Sample sizes were calculated to determine the sample size required to estimate mean scores (*n*=304) and proportions (*n*=383) within the population (Table 5.2).

<table>
<tr><th>(a) Sample size calculation for confidence interval precision for prevalence (Naing <i>et al.</i> 2006)</th><th>(b) Sample Size Calculation for Estimating a Mean (Sullivan 2008)</th><th>(c) Sample Size Calculation for Estimating a Proportion (Sullivan 2008)</th></tr>
<tr><td>
<table>
<tr><th>Confidence Interval Precision</th><th>Sample Required</th></tr>
<tr><td>±0.04</td><td>555</td></tr>
<tr><td>±0.05</td><td>365</td></tr>
<tr><td>±0.06</td><td>267</td></tr>
</table>
</td><td>$N = \left(\frac{Z\partial}{E}\right)^2$
$N = \left(\frac{(1.96)(22.25)}{2.5}\right)^2$
$N = \left(\frac{43.61}{2.5}\right)^2$
$N = (17.444)^2$
$N = 304.2931$</td><td>$N = p(1-p)\left(\frac{Z}{E}\right)^2$
$N = 48(1-48)\left(\frac{1.96}{5}\right)^2$
$N = 48(52)(0.392)^2$
$N = (2496)(0.1537)$
$N = 383.64$</td></tr>
<tr><td><i>Where:</i>
Proportion=49%
Population=7,223</td><td><i>Where:</i>
<i>N</i>=Sample Size
<i>Z</i>=1.96
σ (FACT-C)=22.25
Margin of Error (<i>E</i>)=2.5</td><td><i>Where:</i>
<i>N</i>=Sample Size
Proportion (<i>p</i>)=48%
<i>Z</i>=1.96
Margin of Error (<i>E</i>)=5</td></tr>
</table>

Table 5.2 Sample size calculations

5.3.3 Sampling

Sampling decisions impact upon the quality of the researcher's inferences and the generalisability or transferability of research findings (Onwuegbuzie & Collins 2007, Collins 2010). Nested sampling strategies are commonly used in sequential explanatory designs, inviting a subsample of survey participants to participate in follow-up interviews (Figure 5.1) (Onwuegbuzie & Collins 2007, Teddlie & Yu 2007). Figure 5.2 provides a visual representation of the sampling strategy and procedures conducted within this study. The inclusion and exclusion criteria for the study are presented in Table 5.3. Eligible participants may have been disease-free or living with advanced colorectal at the time of recruitment to the study.

Inclusion Criteria	Exclusion Criteria
Survivors were eligible to participate if they: • had been diagnosed with colon or rectal carcinoma within the last five years, • were over 18 years of age, • were able to speak, read and write in English, and • were able to provide written, informed consent.	Survivors were not eligible to participate if they: • had been diagnosed with colon or rectal cancer more than five years ago, • were still receiving primary treatment for colon or rectal cancer, • were not resident in Ireland, or • had received treatment for colon or rectal cancer in another country.

Table 5.3 Study inclusion and exclusion criteria

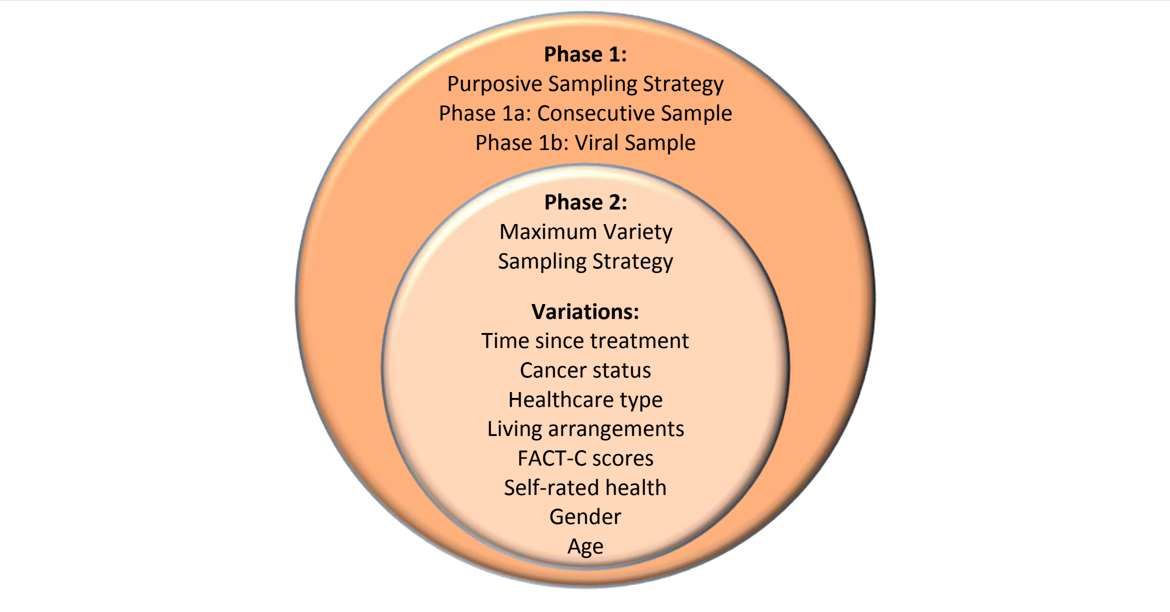


Figure 5.1 Nested sampling strategy

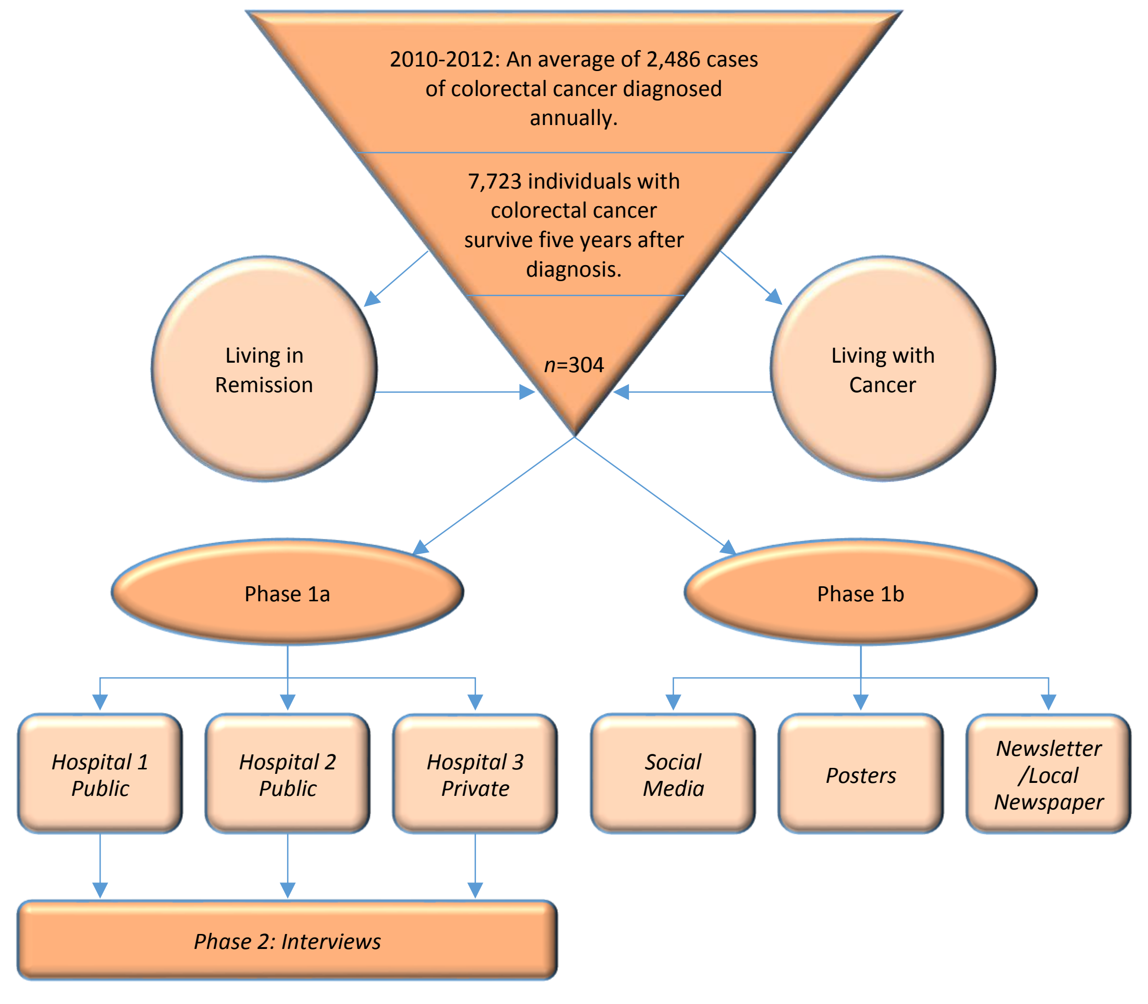


Figure 5.2 Visual representation of sampling procedures

5.3.3.1 Quantitative Sampling Strategies

Data collection in Phase 1 was divided into two sub-phases. In Phase 1a, a postal questionnaire was used to collect data from participants recruited via surgical and medical oncology clinics in three hospitals. In Phase 1b, an online questionnaire was used to gather data from participants who volunteered in response to online and print advertisements of the study. The decision to conduct an online survey emerged in response to issues that arose during data collection in Phase 1a. Delays in obtaining ethical approval and discrepancies in the gatekeeping and recruitment procedures at the private hospital site resulted in much lower rates of recruitment than expected. Both Gorard (2010) and Creswell & Plano Clarke (2011) assert that research designs may *'emerge'* or *'evolve'* as a research study progresses, either due to issues that arise during the study, or as the researcher's knowledge develops.

During Phase 1a, a consecutive sample of colorectal cancer survivors attending surgical and medical-oncology follow-up clinics in three hospitals were recruited over a 12-month period. Use of a consecutive sampling strategy in Phase 1 minimised potential bias that may arise due to seasonal or other time-related fluctuations (Polit & Beck 2012). The three hospitals were located in the HSE Dublin Mid-Leinster Region (Table 5.4). These hospitals reflect the healthcare environments where colorectal cancer survivorship follow-up care take place in Ireland. Furthermore, the catchment areas of each of these sites serve urban and rural populations and with varying socio-economic circumstances.

Site	Funding/Status	Oncology Services	Model of Follow-up Care
Hospital 1	Public hospital & cancer centre of excellence	Medical Surgical Radiation	Nurse-led surgical follow-up Consultant-led medical oncology follow-up Consultant-led radiation oncology follow-up
Hospital 2	Public regional hospital	Medical Surgical	Nurse-led surgical follow-up Consultant-led medical oncology follow-up
Hospital 3	Private hospital	Medical Surgical Radiation	Consultant-led surgical follow-up Consultant-led medical oncology follow-up Consultant-led radiation oncology follow-up

Table 5.4 Characteristics of Phase 1a recruitment sites

Participants of the Phase 1b online survey were recruited through viral sampling approaches (Palys & Atchison 2012). Study advertisements were shared in print and via social media accounts managed by 13 cancer support groups and centres in the HSE Dublin Mid-Leinster region including newsletters, email bulletins, Facebook and Twitter. In total, 21 affiliated cancer support services and organisations distributed the study advertisement on Facebook and Twitter as a result of the viral approach to sampling.

5.3.3.2 Qualitative Sampling Strategy

Maximum variation sampling permits the selection of diverse participants. It is useful in determining the scope of a phenomenon, capturing the complexity of shared and unique patterns of survivors' experiences as they emerge (Creswell & Plano Clarke 2011, Polit & Beck 2014). The maximum variation sampling strategy in this study was drawn from the sampling frame of Phase 1a participants who consented to follow-up interview (*n*=238, 92.2%). This sampling strategy was designed to select information-rich cases, representing relevant, pre-selected phenomenal and demographic variables identified during statistical analysis, as well as typical or outlying cases (Sandelowski 1995, Coyne 1997, Sandelowski 2000). The sampling strategy sought to achieve phenomenal variation by insurance status, disease response, continuity of care, use of cancer support services, level of social difficulty and quality of life. Other socio-demographic and cancer-related factors considered in the sampling strategy included age, gender, living arrangements, diagnosis, time since diagnosis and history of an ostomy. Consideration of these variables enabled the collection of information-rich descriptive data (Table 5.5). Determining a sufficient sample size in qualitative research relies on judgement and experience to evaluate the quality of data and its utility in answering the research question (Sandelowski 1995). Sandelowski (1995, p.179) criticised the acceptance of "*small is beautiful*" in qualitative research sampling, warning it may undermine the credibility of findings. However, Sandelowski (1995), Coyne (1997) and Creswell & Plano Clarke (2011) suggest an in-depth understanding of a few cases could provide a new and richly textured understanding of experience. A priori, 15-20 interviews were planned to achieve information saturation within the aims of the present study.

Variable	Variations		
Age Group	<50	50-65 years	>65 years
Gender	Male	Female	
Diagnosis	Colon	Rectum	
Time Since Diagnosis	0-2 years	3-5 years	
Living Arrangement	Alone	With Family/Friends	
Presence of an Ostomy	Ostomy	None	Reversed
Insurance Status	Private	Medical Card/Public	
Disease Status	In Remission	Active Disease	
Continuity of Care	Satisfied	Dissatisfied	
Use of Cancer Support	No	Yes	
Social Difficulties	No	Yes	
FACT-C	Higher	Lower	
Regression Model Fit	Yes	No	

Table 5.5 Maximum variation sampling stratifications for Phase 2 interviews

5.4 Phase 1: Quantitative Data Collection

Selection of data collection instruments in mixed methods research must follow examination and consideration of all potential options to determine which sources can best answer the research questions and provide a complete picture of the research problem (Andrew & Halcomb 2009, Creswell & Plano Clarke 2011). In this study, a questionnaire incorporating close-ended survey items and open-ended questions was used in the first phase of data collection, while a semi-structured interview was conducted in the second phase.

5.4.1 The Patient-Reported Outcome Measures Living with and Beyond Colorectal/Gastro-Intestinal Cancer Questionnaire

The quantitative phase of this study used an amended version of the PROMs Living with and Beyond Colorectal/Gastro-Intestinal Cancer Questionnaire for data collection (DoHUK 2012) (Appendix 5.1). This questionnaire contains 72 items and was used in a study of quality of life for cancer survivors in England by DoHUK (2012). The questionnaire was designed through literature review, expert reviews, consultation with patient groups, cancer charities and expert advisory groups (Glaser *et al.* 2013). Items include the Colorectal Cancer Subscale (CCS) of the FACT-C questionnaire (Ward *et al.* 1999), the Social Difficulties Inventory (SDI) (Wright *et al.* 2005) and the EuroQol 5D-5L questionnaire (Herdman *et al.* 2011). The colorectal/gastrointestinal cancer arm of the study achieved a reasonable response rate of 66% with relatively low levels of missing data (DoHUK 2012). The PROMs Questionnaire demonstrated face and content validity according to a panel of health and social care professionals; core components of the questionnaire were deemed reliable during an independent review (Glaser *et al.* 2013).

5.4.2 Refining the Questionnaire

There is an abundance of measurement scales which capture information about health outcomes, and physical, psychological and social functioning across a variety of populations, with significant overlap in the content of these measures (Bowling 2009). Instruments designed to measure generic health status have broad applicability across a range of population and patient groups but are limited in their ability to measure the intricacies of disease-specific quality of life and concerns. On the other hand, several cancer-related quality of life questionnaires have emerged to address the limitations of generic instruments, with further cancer site-specific concern subscales developed to complement these questionnaires.

The PROMs Questionnaire (DoHUK 2012) measured quality of life using the EuroQol 5D-5L questionnaire and the CCS subscale of the FACT-C. However, Ward *et al.* (1999) caution the CCS Subscale was designed to be used in conjunction with the FACT-General (FACT-G) questionnaire to assess colorectal cancer patients' quality of life comprehensively. To ensure that a full picture of colorectal cancer survivors' quality of life, symptom and healthcare experience were captured with minimal overlap, a content analysis of commonly used instruments was undertaken (Table 5.6). The Cost of Survival questionnaire surveys and items were selected based on the literature review findings, the researcher's clinical experience as an oncology nurse and consultation with a panel of oncology healthcare professionals. Following the analysis and consultation, all subscales of the FACT-C, the Patient Continuity of Care Questionnaire (PCCQ) and items to assess symptoms and

Questionnaire Genre	Questionnaire
Generic Instruments	MOS SF-36
	EuroQol 5D-5L
Cancer-Specific Instruments	Functional Assessment of Cancer Therapy-General (FACT-G)
	EORTC QLQ-C30
Colorectal Cancer-Specific Instruments	Functional Assessment of Cancer Therapy-Colorectal Cancer Subscale (CCS)
	EORTC QLQ-CR29/EORTC QLQ-CR38
Cancer Symptom Instrument	National Cancer Institute Common Terminology Criteria for Adverse Events V4.03

Table 5.6 List of quality of life instruments included in the content analysis

PROMs Living with and Beyond Colorectal/Gastro-Intestinal Cancer Questionnaire (DoHUK 2012)	The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life Questionnaire	
Your Health Today		
Self-Reported Response to Treatment and Disease Status	Self-Reported Response to Treatment and Disease Status	
EuroQol 5D-5L	EuroQol 5D-5L	
	EuroQol Visual Analogue Scale*	
Your Health and Well-being in the Last Seven Days		
	Functional Assessment of Cancer Therapy-General*	FACT-C
Colorectal Cancer Subscale	Colorectal Cancer Subscale	
	Symptom Experience* (Incorporating PROMs Fear of Recurrence and Dying and Psychological Issues Items)	
Physical Activity	Physical Activity	
Your Health and Well-being in the Last Month		
Social Difficulties Inventory	Social Difficulties Inventory	
Fear of Recurrence and Dying Items		
Psychological Issues Items		
Overall Support and Care		
	Patient Continuity of Care Questionnaire*	
Experience of Care	Experience of Care	
	Experience of Cancer Support Services*	
About You		
Demographic Questions	Demographic Questions	
Open-ended comments about living with and beyond cancer	Open-ended item to express any issues which were not addressed by the questionnaire	
*New items/scales added to The Cost of Survival Questionnaire following the content analysis of quality of life, symptom experience and continuity of care instruments		

Table 5.7 Amendments to the Patient-Reported Outcome Measures Living with and Beyond Colorectal/Gastro-Intestinal Cancer Questionnaire for The Cost of Survival Study

comorbidities not included in the PROMs Questionnaire were included in Cost of Survival questionnaire. The components of the Cost of Survival and PROMS questionnaires are compared in Table 5.7.

5.4.3 Finalised Questionnaire

Permission to use a modified version of the PROMs Living with and Beyond Colorectal/Gastro-Intestinal Cancer Questionnaire, the FACT-C, SDI and EuroQol 5D-5L and PCCQ questionnaires were granted by the relevant authors (Appendix 5.2).

5.4.3.1 EuroQol 5D-5L

The EuroQol ED-5L is a generic self-report questionnaire to describe and value health (Brooks 1996). The EuroQol 5D-5L defines health in five dimensions: Mobility, Self-Care, Usual Activities, Pain/Discomfort and Anxiety/Depression. Each item is measured at five levels of severity: *no problems*; *slight problems*, *moderate problems*, *severe problems* and *extreme problems*. The EuroQol 5D-5L records the respondent's self-rated health on a 20cm vertical visual analogue scale (VAS) ranging from 0, "*the worst health you can imagine*" to 100, "*the best health you can imagine*".

The EuroQol 5D-5L was designed to complement other quality of life measures across a range of health interventions (Brooks 1996). However, concerns were raised regarding ceiling effects and its ability to detect small changes in health in general populations and milder conditions, which stimulated a desire to improve the measure (Herdman *et al.* 2011). The five dimensions of the EuroQol 5D-5L questionnaire were based on the existing EuroQol 5D-3L questionnaire (The EuroQol Group 1990). The five response levels of the EuroQol 5D-5L were identified through response scaling methods, with labels derived from a literature review and existing health-related quality of life instruments. Extensive psychometric testing of the EuroQol 5D-5L has been conducted internationally. The instrument has demonstrated face and content validity and showed strong reliability among English speaking cancer patients with an intraclass correlation coefficient of 0.81 for the EuroQol 5D utility index and 0.83 for the VAS (Herdman *et al.* 2011, Lee *et al.* 2013).

5.4.3.2 Functional Assessment of Chronic Illness Therapy–Colorectal

The Functional Assessment of Chronic Illness Therapy–Colorectal (FACT-C) is a 36-item self-report instrument to assess colorectal cancer patients' quality of life in the past week. The FACT-C questionnaire is suitable for use with colorectal cancer patients of any disease stage and may be used in clinical or research settings to 1) assess treatment effectiveness, 2) compare quality of life with other cancer groups (FACT-G subscales), 3) identify concerns specific to colorectal cancer patients (CCS subscale) and 4) assess sensitivity of quality of life to treatment effects and worsening physical condition (Ward *et al.* 1999).

The questionnaire contains four subscales of the core FACT-G Questionnaire; Physical Well-being (PWB, 7 items), Social Well-being (SWB, 7 items), Emotional Well-being (EWB, 6 items), Functional Well-being (FWB, 7 items) and the Colorectal Cancer Subscale (CCS, 7 items). FACT-C items are assessed using a Likert-scale format, with item scores ranging from 0, *not at all* to 4, *very much* (Table 5.8). The FACT-C score is calculated from the sum of all five subscales and has a possible range of 0-136, with higher scores reflecting better quality of life (Ward *et al.* 1999). The FACT-C subscale has undergone significant psychometric testing and has demonstrated internal consistency in English-speaking samples of colorectal cancer patients with advanced disease (Cronbach's α=0.91) (Cella *et al.* 1993, Ward *et al.* 1999).

Subscale	Items	Subscale Score Range
Physical Well-being (PWB)	7 items	0-28
Social Well-being (SWB)	7 items	0-28
Emotional Well-being (EWB)	6 items	0-24
Functional Well-being (FWB)	7 items	0-28
Colorectal Cancer Subscale (CCS)	7 items	0-28
FACT-C	34 items	0-136

Table 5.8 Functional Assessment of Cancer Therapy-Colorectal Cancer (FACT-C) subscales

5.4.3.3 Social Difficulties Inventory

The Social Difficulties Inventory (SDI) is a self-report questionnaire designed to assess social difficulties experienced by cancer patients in the past month (Smith *et al.* 2007). The SDI may be used in clinical practice to identify social difficulties to be discussed with the patient or to calculate an overall social distress score to identify cancer patients with multiple problems requiring assessment (Wright *et al.* 2007). The SDI is suitable for use with cancer patients across various age groups, gender, stages of disease, disease sites and levels of deprivation (Smith *et al.* 2007).

The SDI consists of 21 Likert scale items with responses ranging from 0, *no difficulty* to 3, *very much* (Table 5.9) (Smith *et al.* 2007). It contains subscales to assess social difficulties in three domains; 1) Everyday Living (EDL), 2) Money Matters (MM) and 3) Self and Others (SO). The SDI also has a group of miscellaneous items, which evaluate additional social difficulties including family planning and living conditions. An overall Social Distress score (SD-16) may be calculated from the sum of these subscales (16 items, range 0-44) (Wright *et al.* 2011). An SD-16 score of ≥10 is indicative of social distress (Wright *et al.* 2007). Psychometric testing of the SDI subscales was undertaken with an English-speaking sample of 271 oncology patients in the UK (Cronbach's α=0.73-0.86).

Subscale	Items	Subscale Score Range
Everyday Living (EDL)	6 items	0-16
Money Matters (MM)	5 items	0-13
Self and Others (SO)	5 items	0-15
Social Distress (SD-16)	16 items	0-44

Table 5.9 Social Difficulties Inventory (SDI) subscales

5.4.3.4 Patient Continuity of Care Questionnaire

Participants' experiences of continuity of care were captured using the Patient Continuity of Care Questionnaire (PCCQ). The PCCQ is a 25-item self-report questionnaire which may be used to identify negative perceptions interfering with relational, informational and management continuity in healthcare (Hadjistavropoulos *et al.* 2008). The PCCQ consists of six subscales rated on a five-point Likert Scale from 1, *strongly disagree*, to 5, *strongly agree* (Table 5.10). The Relationships in Hospital subscale addresses participants' experiences as an in-patient. As the current study aimed to explore follow-up experiences of colorectal cancer survivors up to five years after treatment, this scale was excluded from the questionnaire. This amended version of the PCCQ has demonstrated

Subscale	Items	Subscale Score Range
Relationships in Hospital	7 items	1-5
Information Transfer	5 items	1-5
Relationships with Healthcare Providers	4 items	1-5
Management of Forms	3 items	1-5
Management of Follow-up	3 items	1-5
Management of Communication Among Providers	3 items	1-5
Continuity of Care	25 items	1-5
Continuity of Care (Excluding Relationships in Hospital)	18 items	1-5

Table 5.10 Patient Continuity of Care (PCCQ) subscales

reasonable reliability, with alpha coefficients of 0.78-0.83 with English-speaking oncology patients (Sisler *et al.* 2012b).

5.4.3.5 Miscellaneous Items

Demographic and treatment-related items used in the PROMs Questionnaire were adapted from the National Cancer Patient Experience Survey, collecting information including age, gender and diagnostic information (site, timing, treatment, disease response) (DoHUK 2010). The PROMs Questionnaire includes items relating to the experience of care adapted from the National Cancer Patient Experience Survey; these were retained (DoHUK 2010). Cancer support and advocacy service experience questions were generated for this study, based on the experience of care items adapted from the National Cancer Patient Experience Survey. Several symptom and supportive care experience items were generated from the National Cancer Institute Common Terminology Criteria for Adverse Events V4.03 (National Cancer Institute 2010) that were not addressed by the PROMs, EuroQol 5D-5L, FACT-C or SDI questionnaires. Generated symptom items included constipation, peripheral neuropathy, cognitive changes and fear of recurrence. The PROMs Questionnaire co-morbidity item was a list of long-term conditions used in DoHUK surveys. Additional comorbidity items were included in the Cost of Survival questionnaire following the questionnaire content analysis, including high cholesterol, osteoporosis, skin conditions, stomach ulcer, stroke and any other previous cancer diagnosis. In the current study, the physical activity item is interpreted in relation to the Get Ireland Active (2009) guidelines which recommend a minimum of 30 minutes of moderate exercise per day on five days per week.

5.4.4 Phase 1: Participant Recruitment

At the Phase 1a recruitment sites, a gatekeeper identified suitable candidates and invited them to participate in the study (Table 5.11). Each participant received a pack containing the questionnaire, a letter of invitation (Appendix 5.3) and the participant information leaflet and consent form (Appendix 5.4). Phase 1a recruitment took place between October 2014 and September 2015.

In Phase 1b, participants were invited to participate via poster and social media advertisement from cancer support centres (Appendix 5.5). Potential participants were provided with the study website address and the researcher’s contact details to obtain further information about the study.

Recruitment Method 1 Surgical Clinics: Sites 1 and 2 Medical Oncology Clinics: Site 2	Recruitment Method 2 Surgical Clinics: Site 3 Medical Oncology Clinics: Site 1 and 3
1. Gatekeeper invited suitable candidates to receive information about the study.	1. Gatekeeper invited suitable candidates to receive information about the study.
2. Researcher provided written and verbal information about the study.	2. Gatekeeper provided written and verbal information about the study.
3. If the candidate agreed to participate, a participant ID was assigned, and recruitment consent completed.	3. Gatekeeper invited the candidate to contact the researcher for further information about the study if required.
4. Participant given a questionnaire pack and asked to return the completed questionnaire in the prepaid envelope within one month.	4. If the participant agreed to participate, they were given a questionnaire pack (ID code pre-assigned).
5. If the questionnaire was not returned, a reminder letter was sent after three weeks.	5. Participants were asked to return the completed questionnaire and recruitment consent form in the prepaid envelope within one month.

Table 5.11 Recruitment protocol for Phase 1a participants

Participants were invited to complete an online or print version of the questionnaire. The Phase 1b questionnaire was identical to the Phase 1a questionnaire, aside from two additional items to determine the county of residence and type of hospital attended for cancer follow-up. Participants who requested a print version of the questionnaire received an information pack containing the questionnaire, a letter of invitation and the participant information leaflet. Recruitment to Phase 1b commenced in October 2015 and was completed in January 2016.

5.5 Phase 2: Qualitative Data Collection

5.5.1 Semi-structured Interviews

For the qualitative phase of this study, data were collected via cross-sectional semi-structured interviews between February 2016 and June 2016 with a purposive sample of Phase 1a participants, selected using maximum variation sampling techniques. Interviews are an extremely personal form of data collection, in this study, colorectal cancer survivors are sharing information about their experience of illness and recovery (Kvale & Brinkmann 2009). Semi-structured face-to-face interviews were selected to collect data as they allow the researcher to retain control of the interview, yet permit flexibility to respond to unexpected issues which arise in the course of the interview (Britten 1995). Colorectal cancer survivorship is an emotive topic; participants' emotional responses to questions must be handled sensitively by the researcher. Face-to-face interviews allow the researcher to observe the participant's body language, maintain eye contact and interpret and appropriately respond to participants' emotion, anxiety or distress (Kvale & Brinkmann 2009).

5.5.2 Developing the Interview Guide

Preliminary analysis of Phase 1 survey data collected between October 2014 and May 2015 was conducted in June 2015 to inform development of the Phase 2 interview schedule (n=207), forming a point of integration at design level. The analysis highlighted areas for further investigation in the qualitative phase, particularly survivors' information and support needs. This led to the development of the interview schedule which included two central questions:

1. Could you please tell me about your experiences of living with/after colon/rectal cancer?
2. Could you tell me about the healthcare you have received since your treatment for colon/rectal cancer?

Several probing questions were developed, addressing aspects of quality of life, symptom experience, follow-up care and unmet needs to probe these topics of concern, if necessary. There is a risk of bias in semi-structured interview schedules as they may address only the researcher's preconceived ideas, omitting other important aspects of the participant's experience (Britten 1995, Cronin *et al.* 2015). To avoid this, the central interview questions were purposively broad, while probing questions were designed to allow flexibility, facilitate participant reflection and elicit more in-depth responses about the findings of Phase 1 and relevant issues identified by participants. A detailed interview schedule is presented in Appendix 5.6.

5.5.3 Access to Interview Participants

As outlined in Section 5.3.3, interview participants were selected from the sampling frame of Phase 1a participants who consented to be contacted. Twenty-two participants were selected according to the maximum variation sampling procedures of this study. Potential participants were sent a letter of invitation (Appendix 5.7) and an information leaflet and consent form (Appendix 5.8) specific to Phase 2 of the study. The information leaflet outlined the purpose of the study, the procedures of the interview and the potential benefits and risks of the study. Two weeks after the information pack was posted, participants were contacted by phone regarding participation. If the individual agreed to volunteer for an interview, a convenient time and place for the interview was arranged.

5.5.4 Interview Procedures

Interviews commenced once quantitative data collection ceased in January 2016. Interviews were conducted over a six-month period between February and July 2016. By the time of the first interview, 17 months had elapsed since quantitative data collection had begun. Consequently, between nine and 20 months had passed since interviewees had returned their questionnaires. However, this did not appear to impact upon survivors' engagement with the interviews, as many described very vivid recollections of their experiences of diagnosis and treatment several years before; most discussed ongoing survivorship issues in detail.

Interviews were arranged in places of mutual convenience. To put participants at ease, all were offered the option of having the interview conducted in their home or a place of their choosing. All but one interview was conducted in participant's homes. One participant suggested it would be more convenient to meet in the university, and the interview was conducted in a private meeting room in the researcher's department. Interviews lasted an average of 62 minutes (range: 35-110 minutes). Interviews were recorded using a digital voice recorder with the participant's permission, facilitating verbatim transcription of the interview discussion.

For an interview to be successful, the researcher must build trust and rapport with the participant (Kvale & Brinkmann 2009). Although I am a novice qualitative researcher, I possess strong interpersonal skills as a result of my experience as a clinical nurse. Throughout the interviews, I endeavoured to be congenial, non-judgemental and empathetic to the participant's perspective, using nonverbal communication to convey concern and interest in the participant's story (Polit & Beck 2012, Cronin *et al.* 2015). I opened each interview by introducing myself, thanking the participant for agreeing to be interviewed, describing the study and responding to any questions raised. I assured participants they could stop the interview or withdraw from the study at any time and could seek clarification of any questions asked during the interview. Each interview was opened with an ice-breaker question to ease the participant into the interview, more sensitive questions about quality of life and healthcare experiences were reserved for later in the interview. Central questions were deliberately broad, with probing and prompting questions used to provide direction to the interview when appropriate. In two interviews, it was necessary to temporarily pause, as participants were overcome with distress during reflections upon their diagnosis, treatment and care. However, two others declined the offer of pausing the interview when they became distressed. Emotional responses may be cathartic for the participant and may be an opportunity to collect data on a sensitive and upsetting experience of value to the study (Tod 2010, Polit & Beck 2012). No matter the outcome, I endeavoured to create an atmosphere of caring and concern for participants who became emotional during interviews.

As I am an oncology nurse, there was a risk I could enter interviews with pre-conceived ideas about the topic or slip into the role of nurse rather than interviewer (Britten 1995, Tod 2010). Each of these could have potentially compromised my ability to collect meaningful and trustworthy data. To overcome these challenges, I engaged with an experienced qualitative researcher to discuss my concerns and identify strategies to prevent their interference with the interview. During interviews, I strived to create a supportive environment for the participant but refrained from intervening to resolve problems. Where survivors requested assistance with ongoing psychosocial issues, I provided contact information for local cancer support centres which offered group support and individual counselling services. Throughout the data collection process, I remained reflexive, engaging in critical reflection about my role and involvement in the study through journaling.

5.6 Evaluation of Mixed Methods Research

There is much literature discussing issues of quality or rigour in quantitative and qualitative research. As an evolving field, there is a growing discourse surrounding quality appraisal in mixed methods research. Curry (2015) drew together the works of Lincoln & Guba (1985), Miles & Huberman (1994), Bradley (1997), Sale & Brazil (2004) and Polit & Beck (2010) to define appraisal criteria for mixed methods studies. Curry (2015) proposed the concepts of veracity, consistency, applicability and neutrality to respond to equivalent quantitative and qualitative concepts (Table 5.12).

Quantitative Appraisal Criteria	Mixed Methods Criteria	Qualitative Appraisal Criteria
Internal Validity	Veracity	Credibility
Reliability	Consistency	Dependency
Generalisability	Applicability	Transferability
Objectivity	Neutrality	Confirmability
Source adapted from Curry L. (2015) *Mixed Methods in Health Sciences Research: A Practical Primer.* Sage Publications Ltd., London, p.167.		

Table 5.12 Common standards of quality appraisal for quantitative, qualitative and mixed methods research (Curry 2015)

5.6.1 Veracity

Veracity is concerned with the degree to which results accurately and precisely represent the phenomenon under study and refers to the internal validity of quantitative research and the credibility of qualitative research (Curry 2015). In non-experimental research, greater focus is placed on achieving external validity, rather than causation, as variables are examined in their natural, real-world settings (Gravetter & Forzano 2016). Credibility in qualitative research describes confidence that the findings of research are a true representation of the participants' experiences (Polit & Beck 2012).

5.6.1.1 Internal Validity

A clinical expert panel and service user panel was assembled to establish face validity of the questionnaire. The clinical expert panel consisted of healthcare professionals and academics specialising in colorectal cancer and cancer survivorship (Table 5.13). A key concern raised by members of the clinical expert panel was the length and time required to complete the questionnaire (Appendix 5.9). A decision was made to allow the stakeholder group to assess this issue and provide feedback. Two new questions were added following feedback from the expert panel; an open-ended question was developed to provide insight into the support resources used by colorectal cancer survivors (Question 38) and a question to clarify survivors' insurance status (Question 45).

The decision to engage service users was an important consideration, as it ensures research becomes more patient-centred, yielding valuable and trustworthy results (Minogue 2009). Several attempts were made to recruit colorectal cancer service users to the stakeholder panel through hospital and charitable organisations in Ireland. However, difficulties including a lack of understanding of the ethical implications of engaging service users in such a panel necessitated consultation with a pre-existing group from the UK. One colorectal cancer survivor was recruited

Member	Professional Title
1	Consultant Medical Oncologist
2	Consultant Colorectal Cancer Surgeon
3	Consultant Colorectal Cancer Surgeon
4	Consultant Radiation Oncologist
5	Colorectal Cancer Nurse Co-Ordinator
6	Colorectal Cancer Nurse Co-Ordinator
7	Radiation Oncology Advanced Nurse Practitioner Candidate
8	Pelvic Radiation Oncology Clinical Nurse Specialist
9	Academic with Expertise in Cancer Survivorship Research

Table 5.13 The professional disciplines of members of the clinical expert panel

through a charitable organisation in Ireland. The remaining members were palliative care research partners from Lancaster University, a group of lay service users who live with chronic illness or who care for individuals with chronic illnesses. It is notable that all stakeholder group members came from well-educated backgrounds; three were professional educators. Feedback from the stakeholder panel is detailed in Appendix 5.10. Similar to the clinical expert panel feedback, stakeholders supported the inclusion of Question 38 to ensure the variety of support services used by post-treatment colorectal cancer survivors were captured.

Several factors pose threats to internal validity in this study including history, maturation, mortality and selection bias (LoBiondo-Wood 2014). Up to 20 months elapsed between survivors' participation in the survey and interview. In this time, a small number of survivors experienced recurrent disease; one was receiving palliative treatment for terminal disease, which naturally affected their quality of life and interactions with the healthcare service. Further threats to validity include selection bias. It was evident during recruitment for Phase 1a that a small number of survivors did not believe themselves eligible to participate in the study as they did not suffer chronic effects arising from their disease. However, once the inclusion criteria and rationale for the study were explained, most of these survivors agreed to participate.

5.6.1.2 Credibility

Credibility is verified in the plausibility of findings, consistency with prior knowledge, consideration of alternative interpretations of the phenomenon and conformity between the researcher and participant's representation of the experience (Curry *et al.* 2009). In the current study, credibility may be demonstrated in the convergence and corroboration of quantitative and qualitative data collected in each phase (Curry 2015). Prolonged engagement recommended by Lincoln & Guba (1985), builds trust between the researcher and participant. To facilitate this, I endeavoured to meet each participant at the point of recruitment to Phase 1a. Each participant selected for follow-up was contacted by post and then by phone to discuss participation in the interview. Participants meeting the maximum variation sampling criteria were selected randomly, minimising researcher bias and providing assurance that those selected were representative of the larger group (Shenton

2004). Throughout the interviews, I maintained detailed field notes, audiotaped interviews, composed verbatim transcripts of the interviews and confirmed the accuracy of interview data via member checking (Curry *et al.* 2009, Polit & Beck 2012).

From the outset, I was cognisant of my prior experience conducting clinical interviews with cancer survivors as an oncology nurse and my lack of experience in the conduct of research interviews. Clinical interviews are intrinsically problem-focused, controlled by the clinician. In contrast, research interviews are purposively broad and designed to understand meanings from the participant's viewpoint. To overcome my inexperience, I drew upon the extensive knowledge and skill of my supervision team and participated in qualitative research training. Reflexive journaling and debriefing with my research supervision team facilitated ongoing critical evaluation of data collection activities, analytical processes and my development as a qualitative researcher (Shenton 2004, Polit & Beck 2014).

5.6.2 Consistency

Consistency is underpinned by the reliability of quantitative research and the dependability of qualitative research (Curry 2015). Reliability denotes the precision, consistency and comparability of an instrument's measures with repeated use (Burns & Grove 2009). Dependability is similarly concerned with the reliability of data over time with similar participants and context (Polit & Beck 2014). Consistency and veracity are inherently linked in mixed methods research, as unreliable quantitative instruments compromise the validity of the research, while credibility is reliant on the dependability of data (Lacey 2010).

5.6.2.1 Reliability

Control in correlational research is concerned with ensuring the reliability of data collection instruments and sample selection procedures (Wood & Ross-Kerr 2011). The study used questionnaires with established validity and reliability (Section 5.4.3). Each instrument was assessed for internal consistency with the current sample using Cronbach α for the subscales of each instrument, achieving acceptable levels of $\alpha \geq 0.7$ (Table 5.14) (Streiner 2015). The current study used an amended version of the PCCQ instrument, excluding the Relationships in Hospital subscale. This amended instrument was used to operationalise Continuity of Care among colorectal cancer survivors in a previous study by Sisler *et al.* (2012); the PCCQ subscales demonstrated acceptable internal reliability (α=0.78-0.83).

5.6.2.2 Dependability

The naturalistic nature of interviews permits the emergence of unexpected or potentially relevant variables. This raises concerns about the repeatability of the study and potential variability of the phenomenon (Curry 2015). Shenton (2004) calls for transparency in reporting the study processes to enable assessment of research practices and provide a prototype for future replications of the

Questionnaire	**Scale**	**The Cost of Survival Study**			**Previous Studies**		
		Cronbach Alpha	***Number of Items***	***N***	***Cronbach Alpha***	***Number of Items***	***N***
Functional Assessment of Cancer Therapy - Colorectal (FACT-C)[1]	*PWB*	0.85	7	235	0.80	7	60
	SWB	0.84	7	135	0.71	7	60
	EWB	0.74	6	260	0.75	6	60
	FWB	0.89	7	250	0.79	7	60
	CCS	0.75	7	257	0.76	7	60
	FACT-G	0.94	27	111	0.88	27	60
	FACT-C	0.94	34	105	0.91	34	60
Social Difficulties Inventory (SDI)[2]	*EDL*	0.85	6	269	0.82	6	652
	MM	0.82	5	261	0.74	5	652
	SO	0.80	5	267	0.72	5	652
	SD-16	0.89	16	247	N/A	16	652
Patient Continuity of Care Questionnaire (PCCQ)[3]	*Information Transfer*	0.92	5	254	0.82	5	204
	Relationships with Healthcare Providers	0.98	4	225	0.85	4	204
	Management of Forms	0.96	3	237	0.76	3	204
	Management of Follow-up	0.94	3	277	0.71	3	204
	Management of Communication	0.83	3	231	0.68	3	204
	CC-18	0.96	18	184	N/A	N/A	N/A

[1] Internal consistency: Sample A (colorectal cancer patients with advanced disease) (Ward *et al.* 1999)

[2] Internal consistency: A sample of cancer patients with mixed tumour types and stages (Wright *et al.* 2011)

[3] Internal consistency: A sample of 204 patients discharged from orthopaedics and family medicine units (Hadjistavropoulos *et al.* 2008)

Table 5.14 Cronbach α coefficients for internal consistency of The Cost of Survival Study survey instruments

study. In keeping with Shenton (2004), detailed discussions of the research design, study implementation and data collection processes have been provided in this chapter, and a reflective appraisal of the study strengths and limitations are presented in Section 9.5. Curry (2015) describes the merits of an independent audit of the research results to evaluate the trustworthiness of findings. As this was not possible for the present study, I exercised attention to potential biases through reflexive journaling and engaged with my supervision team throughout the research process. These strategies allowed me to consider multiple perspectives and interpretations of subjective data (Curry *et al.* 2009). A systematic audit trail was maintained, detailing decisions made during qualitative data analysis using the coding, memo and annotation functions of NVivo 10 (Rodgers 2008, Curry *et al.* 2009).

5.6.3 Applicability

Applicability of mixed methods research is essential to progressing the knowledge of a field. Applicability describes the potential for study results to translate to a different settings or populations and may be judged by the generalisability of quantitative research and transferability of qualitative research (Curry 2015). Generalisability refers to the extent the results of a study might hold true for different populations, conditions and settings beyond the sample used in the study

(Polit & Beck 2014). Similar to generalisability, transferability is the benchmark by which the usefulness of the data beyond the study sample and context may be assessed (Shenton 2004).

5.6.3.1 External Validity

The multisite nature of the current study increases the generalisability of the results in Ireland, as study procedures were replicated at three hospital sites (Grove *et al.* 2015). Participants of the current study are drawn from several sites with different designations (centre of excellence vs regional vs private), varying sources of funding (public vs private healthcare) and diverse approaches to healthcare (nurse-led vs consultant-led). Each hospital site accommodates patients from varying geographical regions, including urban and rural areas and various socio-economic circumstances. Due to replication of the study at several sites, the researcher may assess whether the overarching results are duplicated in each subgroup, indicating whether results are generalisable beyond this study (Polit & Beck 2014). However, as discussed in Section 1.5, the Irish healthcare setting is unique in that it operates a duality of public and private healthcare provision models, and private patients can access care within public hospitals. This may limit the generalisability of findings to countries where healthcare is funded via singularly universal or privatised models.

Internal sources of bias may also affect the generalisability of results, including retention and selection bias which may lead to homogeneity within the sample (LoBiondo-Wood 2014). A Hawthorne effect may occur as participants react to involvement in a research study (LoBiondo-Wood 2014). Colorectal cancer survivors may have developed an awareness of information needs or the effects of cancer treatments following survey participation and may have actively sought information or support regarding these issues. This is a concern in the period preceding follow-up interviews. However, the results of the quantitative and qualitative phases appeared to converge (Chapter Eight), suggesting the quantitative survey may not have spurred survivors to seek additional information or support during the intervening period.

5.6.3.2 Transferability

Transferability refers to the likelihood that qualitative research findings will be meaningful to individuals experiencing similar phenomena (Streubert 2011). To assist readers to establish the transferability of findings and understand the complexity of the fieldwork and participants, rich, detailed descriptions of the study context, time, place and culture are required (Shenton 2004, Streubert 2011). Shenton (2004) recommends researchers should strive to achieve ecological validity rather than becoming preoccupied with transferability, and seek to understand the results of the study within the context of the organisation and geographical area where the fieldwork was conducted. To this end, detailed discussions have been provided about the evolution of oncology services and policies in Ireland (Sections 1.4-1.6), the conceptual evolution of colorectal cancer survivorship (Section 2.2) and the current knowledge surrounding quality of life among colorectal cancer survivors in Ireland (Section 3.6). Furthermore, a scoping study to understand the range of charitable and advocacy-led support services available to cancer survivors within the HSE Dublin Mid-Leinster Region was undertaken (Section 1.6).

5.6.4 Neutrality

Neutrality focuses on the assumptions which may bias the implementation of a study or the interpretation of results. Neutrality is evaluated in the objectivity of quantitative research and the confirmability of qualitative research (Curry 2015). Objective research minimises the researcher's judgement and influence (Mertens 2015). Confirmability is concerned with ensuring the data, and its interpretations are not fabricated or invented by the researcher (Mertens 2015). Confirmability allows an independent researcher to establish the accuracy, relevance and meaning of the data (Polit & Beck 2014).

5.6.4.1 Objectivity

Aspirations to achieve total objectivity in quantitative research is now recognised as an impractical goal; rather, post-positivist philosophy urges researchers to remain as impartial as possible in the collection and analysis of data (Polit & Beck 2014). Although procedures of quantitative research are designed to minimise bias, vulnerability may transpire in design and analysis decisions (Curry 2015). Transparency in the reporting of quantitative methods and analytic decisions is of utmost importance in mixed method studies to ensure objectivity may be adequately assessed by readers (Curry 2015). The issue of transparency is addressed throughout this thesis, as decisions relating to the topic selection, research questions, methodology, methods and analysis are discussed and justified in detail.

5.6.4.2 Confirmability

Unlike quantitative research, subjectivity, theoretical sensitivity and prior experience or knowledge of phenomenon are valued in qualitative research describing human experience (Burns & Grove 2009). Similar to objectivity, confirmability seeks to corroborate the findings of a study with the contributions of participants, ensuring the interpretations and conclusions were not influenced by the researcher's bias, motivations or interests (Polit & Beck 2014, Curry 2015). Of key importance to the concept of confirmability is the ability to track qualitative data to their source and explicitly identify the logic which brought about the researcher's conclusions (Mertens 2015). Several strategies may be used to enhance confirmability of research findings. Reflexive journaling allowed me to reflect on my influence during each step of the research process (Curry 2015). NVivo 10 allowed me to document analysis decisions, facilitating a systematic and transparent audit trail to establish confirmability and dependability (Rodgers 2008). Finally, the use of participant quotations illustrate and support the analysis and interpretation of the qualitative data in Chapter Six (Sutton & Austin 2015).

5.7 Pilot Study

A pilot study was conducted to determine the feasibility of recruitment methods, the clarity of the letter of invitation and participant information leaflet and ease of use of the questionnaire. The pilot study took place over a three-week period in September 2014. The pilot study was designed to simulate the recruitment and data collection conditions proposed for Phase 1a. Participants were conveniently recruited during their attendance at surgical or medical oncology follow-up clinics at two of the three hospitals proposed for the main study.

Twelve questionnaires were returned within the timeframe for inclusion in the pilot study (response rate: 50%). Therefore, the anticipated response rate of 40% was considered acceptable for the main study. The challenges encountered and amendments to the study protocol arising from the pilot study are detailed in Appendix 5.11. Concerns raised by the clinical expert panel and stakeholder group regarding the length of the questionnaire were allayed, as all participants completed the questionnaire, apart from missing data on two adjacent pages in four cases (p.8-9 [*n*=2]; p.14-15 [*n*=2]). The pattern was thought to be related to the quality of paper. Therefore, questionnaires for the main study were printed on higher quality paper, and this issue did not reoccur.

For the second phase of the study, the qualitative data collection protocol was piloted during the first three interviews. The interview transcripts were reviewed by the researcher and supervision team to assess the interview schedule and technique. Following this review, no changes to the interview schedule were deemed necessary.

5.8 Ethical Considerations

Ethical issues may arise throughout the research process from design and data collection, through to analysis and interpretation. As this was a multi-site mixed methods study, ethical approval was obtained from the research ethics committees representing each of the hospital sites (Phase 1a and Phase 2) and the School of Nursing and Midwifery, Trinity College Dublin (Phase 1b) (Appendix 5.12). Further approval was obtained from the Patient Advocacy Committee at one hospital and local permissions from the Chief Executive Officer, the heads of department for Colorectal Surgery and Oncology at each site and the consultants responsible for the care of patients with a diagnosis of colorectal cancer at each site.

Throughout this study, the researcher was guided by 1) the *Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives* (Nursing and Midwifery Board of Ireland 2014), 2) *Guidance to Nurses and Midwives Regarding Ethical Conduct of Nursing and Midwifery Research*

(An Bord Altranais 2007), 3) *The Declaration of Helsinki* (World Medical Association 2013) and 4) the *Trinity College Dublin Lone Worker Guidelines* (Faculty of Health Sciences Trinity College Dublin 2015). An ethical protocol was devised for this study, outlining how the ethical principles of autonomy, beneficence, non-maleficence, justice, veracity, fidelity and confidentiality were upheld throughout the study.

5.8.1 Respect for Persons/Autonomy

Respect for persons requires the researcher to respect the individual's capacity to make decisions and their right to full disclosure (An Bord Altranais 2007). The principle of respect for persons compels the researcher to treat the individual as an autonomous person with capacity for self-determination and protect individuals whose capability to deliberate personal choices is diminished (Tappen 2011). To ensure participants' autonomy and ability to provide informed consent was preserved, all participants were comprehensively informed about the study via participant information leaflets. All participants were offered the opportunity to obtain further information from the researcher via face-to-face meetings, post, phone or e-mail. Participants were assured of the voluntary nature of the study and their right to withdraw from the study at any time without repercussion. The gatekeeper played an important role safeguarding potential participants, providing the initial invitation to receive information about the study and ensure those who were unable to provide informed consent were not enrolled in the study. A small number of participants (*n*=3) declined continuing participation in the study following the survey due to recurrent disease or time constraints. In each of these cases, all personal information was removed from the database, and no further contact was made. To avoid coercion of participants during recruitment for follow-up interviews, a decision was made to accept three deferrals of an interview as reluctance to participate, and they did not receive further correspondence regarding interviews.

5.8.2 Informed Consent

Autonomy is inherently linked to participants' ability to provide informed consent. Informed consent requires competent and voluntary consent to participate following full disclosure and comprehension of information by the participant (Grove & Burns 2013). Before participation in the survey, Phase 1a participants were asked to read the participant information leaflet and return a completed consent form, indicating their consent to participate and willingness to be contacted about future questionnaires or interviews relating to this study. Phase 1a participants completed an anonymous survey and were informed in the participant information leaflet that their consent to participate in the study was inferred by the submission of a survey.

As previously discussed, interview participants were selected from the sampling frame of consenting Phase 1a participants. Selected participants were invited to participate via letter and received a participant information leaflet specific to the interview phase of the study. The voluntary nature of the study was emphasised in the correspondence. Participants were advised that the researcher would contact them via phone within two weeks of the postal correspondence to ascertain their interest in participating in the study. The researcher's contact information was included in this correspondence, in the event participants required further information or wished to disclose their decision to accept or decline the study invitation in advance of the researcher's call. In the researcher's follow-up phone call, participants were informed again of the purpose, topics and process of the interview. Participants' questions were addressed during the phone call. Where participants agreed to be interviewed, verbal consent was obtained over the phone, and the interview was arranged at a time and place of mutual convenience. Participants provided written consent to be interviewed at the time of the interview.

5.8.3 Beneficence and Non-Maleficence

The ethical principles of beneficence and non-maleficence are intertwined, centred upon the researcher's duty to maximise the benefits of the research and minimise the risk of harm to participants (An Bord Altranais 2007). Sensitive questions are inherent in quality of life research. Questions about physical, psychological or social difficulties may be distressing to some participants. Although the potential psychological and life-limiting implications of a cancer diagnosis means some participants may be vulnerable, their involvement in the study is justifiable, as the study aims to understand and improve the experiences of cancer survivors in general. At all stages of the study, participants' well-being was prioritised. At enrolment to each phase of the study, the nature of topics examined in the questionnaire and interview were discussed. Participants were provided with information about national and local cancer support services before participation in the study. Participants were encouraged to contact these services and their healthcare provider should they feel they required additional psychological support.

An interview protocol was developed to identify the steps to follow in the event a participant became distressed. As discussed in Section 5.5.4, four participants became distressed during interviews. In all cases, the participants were invited to pause the interview. However, only two accepted this offer, discussing their distress off-tape. In each of these four cases, information about local cancer support centres was provided after the interview and participants were encouraged to discuss the sources of their ongoing distress with the healthcare professional responsible for their follow-up or their general practitioner. A further risk of distress existed for participants and their family members, as a proportion of survey participants may develop recurrent or metastatic disease or die in the period between survey and interview. In all cases where I became aware that a participant was no longer suitable for follow-up, I ensured this was noted in the participant database, and no further correspondence was sent to these individuals.

5.8.4 Justice

Justice refers to the ethical obligation of the researcher to treat participants with fairness and equality before, during and after a research study (Tappen 2011). Justice is concerned with equitable distribution of research burden and research benefit (Polit & Beck 2014). This research study recruited participants who are considered vulnerable due to the life-limiting nature of their disease (DePoy 2011). The ethical principle of justice places an obligation on the researcher to protect those who are at risk of exploitation and ensure they reap the benefits of any research conducted (Tappen 2011, Polit & Beck 2014). Terminally-ill participants may be at greater risk of harm or exploitation, as they lack the opportunity to benefit from research, may feel coerced into participation and may provide biased evaluations of care due to their reliance on the healthcare system (Addington-Hall 2002). However, these issues are not unique to end of life research. Therefore, survivors with all stages of disease who held the capacity to consent and participate were invited to take part. Gatekeeping arrangements were put in place to ensure protection of participants who are at risk of exploitation or coercion. Participants were informed of the voluntary nature of the study and their right to withdraw from the study at any time without consequence.

5.8.5 Veracity

The researcher is bound to be truthful with all potential participants, providing full disclosure about the potential risks and benefits of the study and respecting the participant's autonomy (Moule 2014, Parahoo 2014). Comprehensive and truthful information about the study was disclosed to the participant via the participant information leaflet and other study communications. The researcher's contact details were included in all correspondence and requests for information were responded to promptly and respectfully. All participants were advised of the intent to publish the study findings in the form of a thesis and peer-reviewed papers.

5.8.6 Fidelity

Fidelity is concerned with building trust with the participant. This trust necessitates a commitment from the researcher to protect participants (Parahoo 2014). All potential risks and benefits related to the study were disclosed in the participant information leaflet. If a participant experienced excessive distress arising from participation in this study, the study would have been suspended and steps taken to resolve the cause of distress. However, this did not occur.

5.8.7 Confidentiality

Anonymity and privacy of participants was a priority for this research study, and every endeavour was made to ensure these standards were maintained. Varying levels of anonymity were possible at different phases of the study. All information collected during this study will remain confidential, managed in accordance with The Data Protection Acts (Government of Ireland 1988, 2003).

Phase 1 participants were afforded varying levels of anonymity depending on whether they participated in the postal or online survey and provided consent to be contacted about follow-up questionnaires or interviews. Postal survey participants consenting to follow-up correspondence provided contact information and were assigned an ID code allowing the researcher to link questionnaire and interview data. All personal information relating to the participant ID code was encrypted and stored securely on a participant database separate to study data. Participants' personal information was only accessible by the researcher. Participants of the online and postal surveys who declined participation in subsequent phases of data collection were afforded complete anonymity. These participants were informed that it would not be possible to withdraw from the study once they had returned a questionnaire due to the anonymous nature of responses.

The survey did not collect identifying information and all data collected was treated confidentially. Data from the paper and online surveys were entered into SPSS, saved on an encrypted password-protected hard drive which was accessible only by the researcher and stored in a locked cabinet in the researcher's office when not in use. Paper questionnaires were stored in the same manner. Access to anonymised coded data was limited to the researcher and her academic supervisors. All members of the research team who had access to coded data received training regarding data protection and maintaining the confidentiality of participants.

Interviews were recorded on a digital recorder. Interview recordings were uploaded onto an encrypted password-protected hard drive and transcribed as soon as possible after each interview. Identifying information was removed from each interview transcript. Transcripts were assigned the same unique ID code as the participant's survey. The interview recordings and transcripts were stored on an encrypted password-protected hard drive in the same manner as the survey data. All data collected in the course of the study will be stored for five years following completion of analysis and dissemination, in keeping with the Faculty of Health Sciences Trinity College Dublin (2015) guidelines.

5.9 Data Analysis

In this study, the quantitative and qualitative data were analysed sequentially and reported separately using appropriate analytic techniques for each dataset in keeping with the sequential explanatory design guidelines. Once quantitative and qualitative analysis was complete, the researcher analysed the results of the quantitative and qualitative phases to address the mixed methods objectives of this study (Section 2.4.1) and identify confirmatory, explanatory or discordant results between the phases (Creswell & Plano Clarke 2011, Fetters *et al.* 2013, Guetterman *et al.* 2015). The integrated results are outlined and discussed in Chapter Eight, informing each of the mixed methods study objectives, supported by a graphic joint display (Figure 8.2). The meta-inferences derived from the integration of the quantitative and qualitative approaches are then summarised in Section 9.2. The current section will outline the data analysis strategies for the quantitative and qualitative phases of this study.

5.9.1 Quantitative Data Management and Analysis

Quantitative data analysis employed a descriptive, exploratory approach to understand the prevalence and factors influencing colorectal cancer survivors' quality of life issues. Responses to each standardised survey were coded according to the instructions of the corresponding author (Section 5.4.3). Questionnaire data were manually entered to SPSS v23.0 according to the codebook guidelines to ensure consistency of data entry. Data entry was double-checked to confirm accuracy. Once the SPSS database was prepared, variables were descriptively analysed to screen for errors. Detected errors were corrected in consultation with the participant's questionnaire responses. Open-ended responses were screened, and potentially identifiable information was removed, including the names of places, organisations and healthcare professionals. Apart from questionnaire comments, open-ended item responses were descriptively analysed, categorised and recoded into existing or new variables. After data cleaning, subscale and total scores were calculated for the FACT-C, SDI and PCCQ questionnaires, per the instrument scoring instructions. Participants' age, time since diagnosis and number of treatments and unmet needs were summed to calculate continuous variables. Co-morbidity items were categorised into system disorders for ease of presentation.

Several open-ended items were included in the questionnaire to allow participants to provide additional information or expand upon close-ended question responses. The supplemental nature of this textual data lent itself to descriptive rather than interpretive analysis. Participants' ID codes and responses were transcribed into Microsoft Excel worksheets created for each question and analysed according to the principles of content analysis discussed by Kipping (1996). Responses for each open-ended question were categorised based on themes emerging from the data. Data were quantified through the creation of new quantitative variables based on the themes identified. The new variable responses were entered in a yes/no manner to reflect the responses of the participant and were imported to the primary SPSS database for analysis.

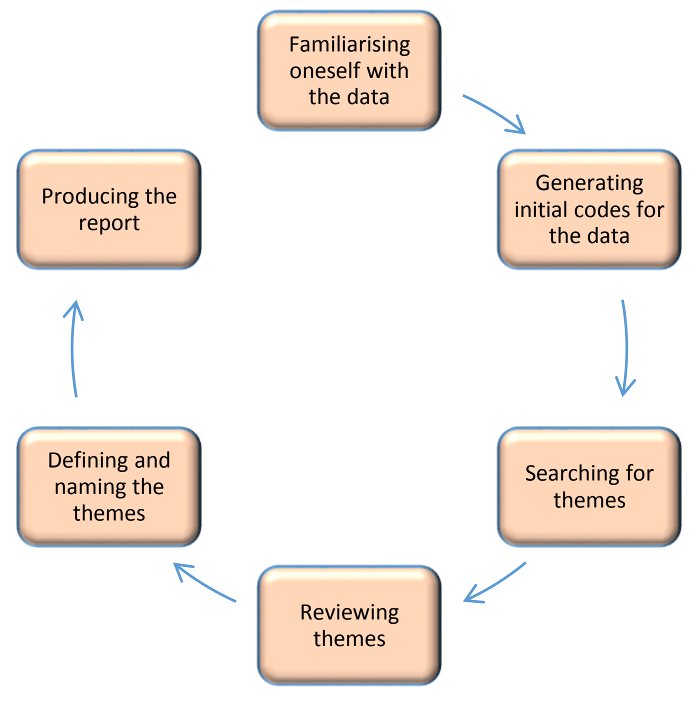
All returned questionnaires were included in the study database. In instances where data were missing due to partially incomplete or illegible responses, cases were excluded from analysis on a test-by-test basis. The sample size eligible for analysis is reported for each analysis procedure, and valid proportions are presented. For continuous data derived from the FACT-C, SDI and PCCQ surveys, prorated scores were calculated for each participant where ≥80% of scale items are completed. The FACT-C subscales permit proration of scores where ≥50% of items are complete (FACIT.org 2010).

Univariate descriptive frequencies were generated to summarise categorical data, facilitating description, comparison and characterisation of relationships within the data (Pallant 2010, Polit 2010, Pallant 2013). Descriptive statistics included percentages, means or medians, range and standard deviations as appropriate to the variables. Parametric and nonparametric inferential statistics were used to characterise the significance of differences in quality of life scores between subgroups within the sample. Nonparametric tests included Mann-Whitney *U* and the Kruskal-Wallis *H* Tests; parametric tests included *t*-tests and one-way analysis of variance (one-way ANOVA). Logistic regression analysis was used to examine and elicit the relative influences of multiple variables on colorectal cancer survivors' quality of life, as quality of life scores were not normally distributed. All statistical tests were assessed for significance at the $\alpha \leq 0.05$ level of confidence unless otherwise stated. Greater detail regarding the management of data, statistical analysis and the assumptions underpinning each statistical technique are discussed in Chapter Six.

5.9.2 Qualitative Data Management and Analysis

Qualitative data were analysed using thematic analysis, guided by Braun & Clarke's Analytical Framework (2006) and supported by NVivo 10. Qualitative data analysed included responses to open-ended items within the survey, survey margin comments, field notes and interview transcripts. Although open-ended or unsolicited margin comments may suggest a validity issue in the questionnaire (Morse 2003), these comments often provide a rationale for survivors' responses to survey items and offer further insight into the concerns raised by survey items (Feilzer 2010). The merging of open-ended survey data and interview data is justifiable in the pragmatic approach to research, particularly as the themes emerging from solicited and unsolicited comments within the survey were reflective of those of emerging from the interview data. In preparation for analysis, all qualitative data were cleaned to remove personal identifiers and efforts were made to ensure illustrative quotes selected to support analysis did not compromise the anonymity of participants.

Thematic analysis supports the identification, analysis and reporting of patterns in qualitative data (Figure 5.3) (Braun & Clarke 2006). I was familiar with the data from the outset, as I conducted interviews, participated in the transcription of interviews and cleaned the data. This familiarity was consolidated through listening to interview recordings and multiple reads of transcripts. Listening to the interview recordings provided context and reminders of the nuances of each interview, as the emotion and tone which provided a greater depth of meaning in survivors' narratives did not translate to interview transcripts. An example of this arose in one survivor's use of dark humour to rationalise the limitations of her peripheral neuropathy, as she simultaneously cried and laughed about her experience. During this stage of analysis, the reflexive diary became a valuable tool to document emerging thoughts, comments and ideas.



Source adapted from Braun V. & Clarke V. (2006) Using Thematic Analysis in Psychology. *Qualitative Research in Psychology* **3**(2), 77-101.

Figure 5.3 Braun & Clarke's Thematic Analysis Framework (2006)

Thematic analysis may be approached in an inductive data-driven way, or a deductive theory-driven manner (Fereday & Muir-Cochrane 2008). Initial codes were generated in a data-driven manner, reducing the data into manageable units to identify patterns. Given the mixed method nature of this study, analysis required a hybrid approach. In the third phase of analysis, qualitative data were analysed with cognisance of themes emerging from the quantitative data (deductive) and more openly for themes emerging from the interviews themselves (inductive) (Fereday & Muir-Cochrane 2008). Initial codes were highly descriptive, with roots reflecting the physical, psychological and social symptoms affecting survivors' quality of life and examples of healthcare-related events which contributed to positive or negative quality of life. Consequently, the third phase of analysis encompassed much greater attention to the context in which survivors described their quality of life. Transcripts were re-examined, and the NVivo annotation function was used to make notes about the stage of survivorship to which the survivor referred and include information from relevant field notes regarding the survivor's body language. During this analysis, initial codes were organised and reorganised into broader themes until comprehensive themes began to emerge describing participants' experiences and views as closely as possible.

The fourth phase of analysis seeks to ensure that implied and contextual meanings within each interview are respected. I reviewed the themes generated during the third stage of analysis, evaluating them first, against the coded abstracts and secondly, against the original data sources to ensure the accuracy of analysis and interpretation to ensure no potential themes were overlooked. A thematic map was then generated to describe the relationships between the themes. In the fifth phase of analysis, the titles of each theme were developed to reflect narratives which substantiated each theme. The specifics of each theme were refined to ensure the story emerging from the analysis was appropriately relayed. In the final stage of analysis, the story of colorectal cancer survivors' quality of life was composed. To ensure an in-depth account of colorectal cancer survivors' quality of life and experiences of healthcare are reported, direct quotes from survivors' interviews and survey responses were presented in italics, accompanied by the participant's ID code. Vivid, compelling quotes were selected from participants' transcripts or survey comments to illustrate and support the analysis and relate the analysis to the research questions and literature explored.

5.10 Chapter Summary

There is concern that mixed methods research has become fashionable and the rationale for mixing methods may not be entirely thought through, which can impact upon the quality of a research study if it is not justified with a clear sense of purpose (Bryman 2007). Chapters Three, Four and Five have provided empirical and methodological justifications for a mixed methods research approach to explore the impact of healthcare experiences upon the quality of life of colorectal cancer survivors receiving follow-up care in tertiary oncology healthcare settings in Ireland. This chapter has described the specific junctures of integration in this mixed methods study, defending decisions regarding the design and execution of the study. Chapter Five has presented a comprehensive discussion of the quantitative and qualitative approaches within this study, including sampling, data collection and data analysis and offers an appraisal of quality and ethical issues relevant to the study. The next chapters will present the results of analysis of the quantitative (Chapter Six) and qualitative (Chapter Seven) data.

Chapter Six – Phase 1 Survey Findings

6.1 Introduction

This chapter presents the findings from the quantitative phase of this mixed method sequential explanatory design study. The specific aims of the quantitative phase of the study were:

1. To understand colorectal cancer survivors' physical, psychological and social outcomes,
2. To ascertain colorectal cancer survivors' ratings of continuity of care and support from healthcare professionals and services during post-treatment follow-up,
3. To identify the unmet information and supportive care needs of colorectal cancer survivors, and
4. To devise a model of the healthcare-related factors which influence colorectal cancer survivors' quality of life outcomes in the five years following diagnosis.

The chapter begins with an analysis of the distribution of continuous variables within the study and an outline of the transformations undertaken to achieve normal distributions for parametric statistical analysis (Section 6.2). This is followed by a summary of the demographic and cancer-related characteristics of the sample (Section 6.3). Section 6.4 describes the response frequencies for quality of life and healthcare experience items. Section 6.5 reports the result of parametric and nonparametric statistical analysis conducted to ascertain the differences between colorectal cancer survivors' quality of life, based on demographic, cancer-related and healthcare outcomes variables. This section will interpret the factors independently associated with quality of life outcomes from the relevant analysis. Finally, the results of Section 6.5 inform the development of a backward stepwise logistic regression model (Section 6.6).

6.2 Data Distribution

To facilitate the selection of appropriate statistical tests, the distribution of data on the scales and subscales of the EuroQol 5D-5L, the EuroQol Visual Analogue Scale (VAS), the Functional Assessment of Cancer Therapy-Colorectal (FACT-C), the Social Difficulties Inventory (SDI) and the Patient Continuity of Care Questionnaire (PCCQ) were assessed for normality. Histograms were prepared from the data for each scale and overlaid with a normal distribution curve. Normality of the distribution curves were evaluated in consultation with normal and de-trended Q-Q plots and box plots. Skewness, kurtosis, Kolmogorov-Smirnov and Shapiro-Wilks values were computed and checked for continuous variables derived from the standardised data collection instruments.

The FACT-C, EuroQol 5D-5L and PCCQ scales and subscales were each moderately negatively skewed. The SDI scale was positively skewed. In an effort to normalise the data on each scale, each variable was transformed using a square root transformation. Negatively distributed data were reflected prior to transformation (Pallant 2013, Tabachnick & Fidell 2013). Tests of normality were repeated on the newly transformed variables to evaluate the distribution of responses. With the exception of the transformed FACT-C score, all transformed variables continued to violate the assumptions of normality.

The numeric and visual data representations used to evaluate the normality of the original FACT-C and transformed FACT-C data distributions are presented in Table 6.1 and Figure 6.1. Skewness and Kurtosis values improved following transformation, achieving positive values approaching zero. Although the kurtosis values are negative, they are each less than one. Skewness and Kurtosis do not have a substantial effect on analysis, as it is assumed that larger samples reflect a normal distribution, reducing the risk of underestimation of variance (Field 2013, Tabachnick & Fidell 2013). The Shapiro-Wilk results suggest the distribution violates the assumption of normality. However, Pallant (2013) state this is a common occurrence in larger samples and recommends visual inspection of the distribution (Figure 6.1). The histogram in Figure 6.1(i) follows a relatively normal distribution for the transformed FACT-C data. The Normal Probability Plot (Q-Q plot) plots the observed value for each participant against the expected value drawn from the normal distribution, and follows a relatively straight line, suggesting an approximately normal distribution for the transformed FACT-C data (Figure 6.1ii). The Detrended Normal Q-Q Plot shows an equal variance of scores on each side of the line indicating normal distribution (Figure 6.1iii). Finally, the transformation has yielded a boxplot which does not demonstrate any outliers (Figure 6.1iv). There are debates surrounding the use of transformations on continuous data to achieve a normal distribution, as it increases the difficulty of interpretation and understanding (Osborne 2005, Tabachnick & Fidell 2013). Due to the lack of consensus on the use of data transformations, and to ease the interpretation of analysis on transformed variables, parametric tests were conducted on the transformed FACT-C data and nonparametric tests on the original FACT-C data, where appropriate.

FACT-C Scale	**Mean**	**Standard Deviation**	**5% Trimmed Mean**	**Skewness**	**Kurtosis**	**Kolmogorov-Smirnov**	**Shapiro-Wilk**
Original	111.9	1.2	113.4	-1.11 (0.15)	1.05 (0.31)	≤ 0.001	≤ 0.001
Transformed	4.7	0.1	4.6	0.26 (0.15)	-0.43 (0.31)	0.200	0.016

Table 6.1 Results of the tests of normality on the original and transformed Functional Assessment of Cancer Therapy-Colorectal (FACT-C) scores

6.3 Sample Characteristics

A total of 435 colorectal cancer survivors were deemed eligible to participate in Phase 1a and Phase 1b during the study period September 2014-January 2015. In Phase 1a, 368 questionnaire packs were distributed, of which 270 were returned (response rate 73.4%). A total of 34 colorectal cancer survivors responded to the study advertisements of Phase 1b. In total, 304 questionnaires were returned, resulting in a raw response rate of 75.6%. A summary of the response rates is shown in

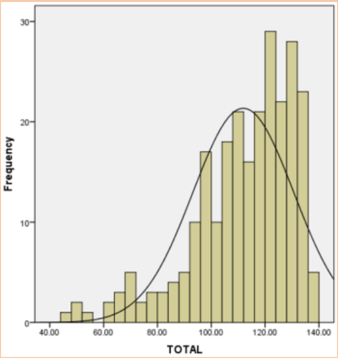
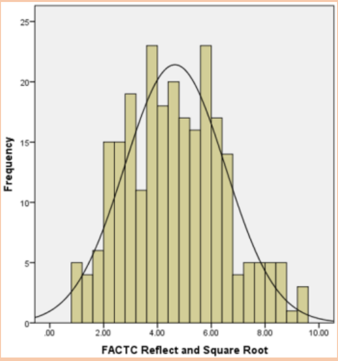
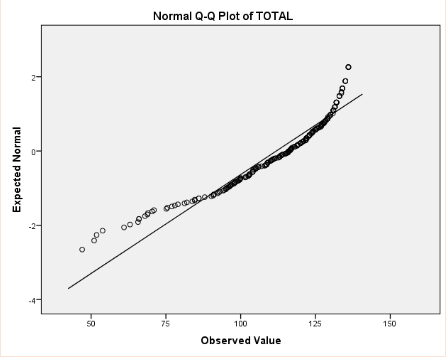
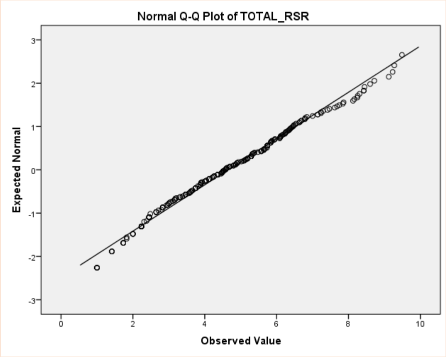
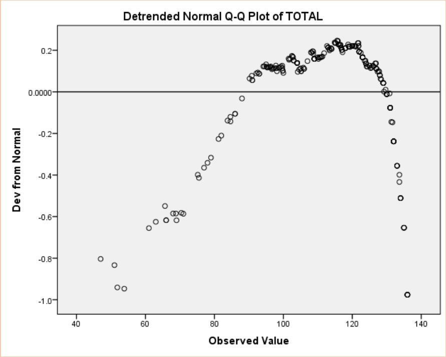
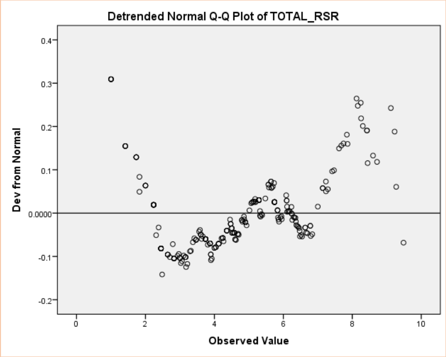
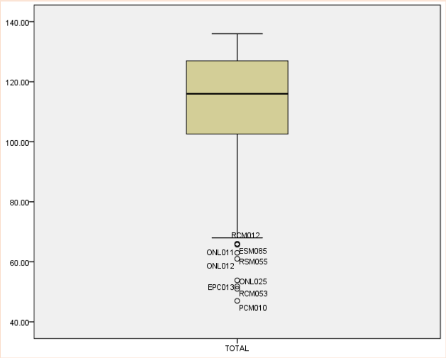
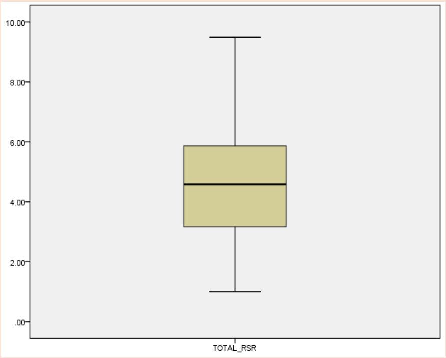
	(a) Original FACT-C Data	(b) Reflect and Square Root Transformed FACT-C Data
(i)	 Mean $(\bar{\chi})$=111.9; Standard Deviation (*SD*)=18.8; Sample Size (*N*)=251	 Mean $(\bar{\chi})$=4.9; Standard Deviation (*SD*)=1.9; Sample Size (*N*)=251
(ii)		
(iii)		
(iv)		

Figure 6.1 (i) Histograms overlaid with the normal distribution curve, (ii) Normal Q-Q Plots, (iii) Detrended Normal Q-Q Plots, and (iv) Boxplots of original and transformed FACT-C data

Table 6.2. Due to differences in recruitment processes at the sites in Phase 1a, it was not possible to ascertain how many participants were missed or declined participation before distribution of the questionnaire at Site 3 and in Phase 1b. However, of 361 eligible participants identified at Sites 1 and 2, 22 were not approached (6.1%) due to survivors' time constraints, administrative error or the researcher being on leave. Eleven declined participation at the point of recruitment (3.0%), citing reasons including a lack of interest or time, fears about triggering anxiety relating to their cancer or feeling that participation would be too burdensome.

Phase	Site	Dispatched	Returned	Response Rate (%)
Phase 1a	*Site 1 Surgical Clinic*	186	148	79.6
	Site 1 Medical Oncology Clinic	12	5	41.6
	Site 1 Total	*198*	*153*	*77.3*
	Site 2 Surgical Clinic	73	55	75.3
	Site 2 Medical Oncology Clinic	57	41	71.9
	Site 2 Total	*130*	*96*	*73.8*
	Site 3 Medical Oncology Clinic	40	21	52.5
	Site 3 Total	*40*	*21*	*52.5*
	Phase 1a Total Response	368	270	73.4
Phase 1b	***Phase 1b Total Response***	34	34	100.0
Total Response	***Total Response***	**402**	**304**	**75.6**

Table 6.2 Questionnaire response rates by research site and phase

Table 6.3 describes the socio-demographic characteristics of the sample. The average age of Phase 1 participants was 67.2 years (*SD*=11.4, *N*=283). One hundred and fifty-nine were male (55.8%), and the majority were of White Irish ethnicity (95.5%, *n*=274). Most lived with a partner, spouse, family or friend (79.9%, *n*=227), and 53 lived alone (18.7%). Over three-quarters lived in an urban environment (76.5%, *n*=215). Almost half held private health insurance (47.6%, *n*=136), and nearly two-thirds held a medical card (62.6%, *n*=179). Less than 10% had neither health insurance nor a medical card (5.9%, *n*=17). The majority were retired at the time of diagnosis (39.2%, *n*=112). However, this proportion increased to 48.2% (*n*=137) after treatment. Of those who were employed at the time of diagnosis (38.5%, *n*=110), two-fifths left the workforce due to retirement, illness or other reasons by the time of the survey (38.2%, *n*=42), and one-third were working fewer hours than before their illness (31.1%, *n*=23). Of those who had disengaged from the workforce between diagnosis and participation in the survey (16.2%, *n*=46), almost half were below the standard retirement age of 65 (47.8%, *n*=22, $\bar{x}$=62.2 years, *SD*=11.7). Of those who were employed at the time of the survey (25.0%, *n*=71), more than one-third indicated they were working less hours than before their illness (37.3%, *n*=25).

Table 6.4 outlines the cancer-related characteristics of the sample. One hundred and ninety-one survivors (64.1%) had a diagnosis of colon cancer, 69 had rectal cancer (23.2%). The remainder indicated that they had another form of colorectal cancer, represented as '*bowel cancer*', or a description of the location of metastatic disease (12.7%, *n*=38). The average time since diagnosis

Characteristic (*N*)	Response	*n*	%
Age (N=283)	*0-54 years*	35	12.4
	55-65 years	58	20.5
	66-75 years	121	42.8
	Over 75 years	69	24.4
Gender (N=285)	*Male*	159	55.8
	Female	126	44.2
Living Arrangements (N=284)	*With Partner/Spouse/Family/Friends*	227	79.9
	Alone	53	18.7
	Other	4	1.4
Area of Residence (N=281)	*Urban*	215	76.5
	Rural	66	23.5
Health Insurance Status (N=286)	*Medical Card*	179	62.6
	Private Health Insurance	136	47.6
	None	17	5.9
	Other	9	3.1
Ethnicity (N=287)	*White Irish*	274	95.5
	Any Other White Background	10	3.5
	Other – Including Mixed Background	3	1.0
Current Employment Status (N=284)	*Engaged with Labour Force*	71	25.0
	Not Engaged with Labour Force by Choice	190	66.9
	Unable to Engage with Labour Force	23	8.1
Pre-Diagnosis Employment Status (N=286)	*Engaged with Labour Force*	110	38.5
	Not Engaged with Labour Force by Choice	162	56.6
	Unable to Engage with Labour Force	14	4.9
Change in Employment Status (N=284)	*Remained/Became Engaged with Labour Force*	71	25.0
	Remained Disengaged with Labour Force	167	58.8
	Became Disengaged from the Labour Force	46	16.2

Table 6.3 Socio-demographic characteristics of Phase 1 participants

was three years ($\bar{x}$=3.1, *SD*=1.4, *N*=278). More than four-fifths of the sample indicated they were in remission at the time of the study (82.9%, *n*=228). Participants had received an average of 1.8 previous treatments for colorectal cancer (*SD*=0.8, *N*=299). Almost all survivors underwent surgical excision of their colorectal cancer (91.3%, *n*=273), either alone (35.1%, *n*=105) or in combination with chemotherapy (32.8%, *n*=98), or chemotherapy and radiotherapy (19.7%, *n*=59). At the time of the study, 33 participants were receiving treatment for their colorectal cancer (11.4%). Most of this group reported metastatic (*n*=12, 36.3%) or recurrent disease (*n*=4, 12.1%). However, five were uncertain about the status of their disease (15.2%), six reported remission (18.2%), and the remaining six declined to divulge the status of their disease (18.2%).

This sample had 1.9 co-morbidities on average (*SD*=1.8, *N*=280; Table 6.5). Over three-quarters (77.9%, *n*=218) reported a long-standing health condition other than colorectal cancer, most commonly hypertension (29.6%, *n*=83), hypercholesterolemia (23.2%, *n*=65), arthritis (19.6%, *n*=55), a cardiac condition (16.8%, *n*=47) or diabetes (11.1%, *n*=31). Other primary sites of cancer included skin (1.4%, *n*=4), breast (1.8%, *n*=5), and prostate (2.9%, *n*=8). Seven participants (2.5%) indicated they had received a diagnosis of metastatic cancer.

Characteristic (*N*)	Response	*n*	%
Diagnosis (N=298)	*Colon*	191	64.1
	Rectum	69	23.2
	Other	38	12.7
Time Since Diagnosis (N=278)	*6-12 months*	43	15.5
	1-2 years	67	24.1
	2-3 years	60	21.6
	3-4 years	43	15.5
	4-5 years	65	23.4
Treatment History (N=299)	*Surgery*	273	91.3
	Chemotherapy	175	58.5
	Radiotherapy	71	23.7
	Other	6	2.0
	None	9	3.0
Current Treatment (N=291)	*None*	251	88.3
	Chemotherapy	20	6.9
	Other	3	1.0
	Surgery	10	3.4
	Monoclonal Antibody	1	0.3
	Radiotherapy	1	0.3
	Awaiting Treatment	6	2.0
Disease Status (N=275)	*Remission*	228	82.9
	Treated, but still present	17	6.2
	Uncertain	16	5.8
	Not Treated	10	3.6
	Cancer Recurrence Since Treatment	4	1.5
Stoma (N=286)	*None*	153	53.5
	Reversed	78	27.3
	Present	55	19.2
Hospital Type (N=288)	*Centre of Excellence*	164	56.9
	Regional/Other	100	34.7
	Private	24	8.3

Table 6.4 Cancer-related characteristics of Phase 1 participants

Response (*N*=280)	*n*	%
Cardiovascular System Disorder	131	46.8
Musculoskeletal System Disorder	85	30.4
Another Form of Cancer	40	14.3
Endocrine System Disorder	37	13.2
Respiratory System Disorder	25	8.9
Hearing Impairment	22	7.9
Dermatological Disorder	21	7.5
Digestive System Disorder	16	5.7
Genito-Urinary System Disorder	14	5.0
Visual Impairment	11	3.9
Neurological System Disorder	8	2.9
Hepatic System Disorder	7	2.5
Mental Health Disorder	6	2.1
Other Disorder	7	2.5

Table 6.5 Co-morbidities reported by colorectal cancer survivors

6.4 Descriptive Analysis

The following section presents a summary of descriptive survey data, including numerical data derived from responses to the standardised data collection instruments and categorised responses to open-ended questions. Univariate descriptive statistics were used to summarise categorical data, means ($\bar{x}$), standard deviations (*SD*), and medians ($\tilde{x}$) are used to summarise continuous variables. 95% confidence intervals (CI) are presented to estimate 1) the proportion of the population experiencing physical, psychological or social side-effects, and 2) the population mean scores for continuous variables. Results are presented in table format and supported visually with bar and pie charts.

6.4.1 Colorectal Cancer Survivors' Quality of Life

6.4.1.1 EuroQol 5D-5L

Colorectal cancer survivors were asked to indicate their level of difficulty with five tasks on the day they completed the questionnaire (Figure 6.2). Although more than one-quarter reported difficulties with *Mobility* (28.8%, *n*=85), *Usual Care* (36.7%, *n*=108), *Pain/Discomfort* (33.7%, *n*=98) and *Anxiety/Depression* (29.9%, *n*=88), only 6.1% reported issues with *Self-Care* (*n*=18). Few reported *severe* or *extreme* difficulties with *Mobility* (3.4%, *n*=10), *Usual Care* (3.4%, *n*=10), *Pain/Discomfort* (1.7%, *n*=5) or *Anxiety/Depression* (1%, *n*=3). On the EuroQol VAS, participants' ratings of their health on the day of the survey were reasonable, with an average score of 81 ($\bar{x}$=81.2, *SD*=16.1, $\tilde{x}$=85.0, range=20.0-100.0, *N*=287; data not shown).

6.4.1.2 Functional Assessment of Chronic Illness Therapy–Colorectal

Quality of life in the past seven days was assessed overall (FACT-C score), and in five domains: 1) Physical Well-being (PWB), 2) Social/Family Well-being (SWB), 3) Emotional Well-being (EWB), 4) Functional Well-being (FWB), and 5) Colorectal Cancer Subscale (CCS). FACT-C items were positively worded and negatively worded. Positively worded items are scored such that the response *very much* reflects a more positive response (e.g. *I Get Emotional Support from my Family*; range of responses: *not at all* to *very much*). Negatively worded items are scored such that the response *not at all* reflects a more positive response (e.g. *I Worry About Dying*; range of responses: *not at all* to *very much*). Throughout this subsection, the proportion of the sample who indicated difficulty (i.e. a negative response) with each item are presented in bar charts.

Figure 6.3 illustrates boxplots of the score distribution and average scores for the FACT-C subscales and scale. This sample achieved relatively high overall scores for PWB, SWB, and EWB, however, FWB and CCS mean scores ranked slightly lower on their respective subscales. Despite this, the sample achieved reasonably positive quality of life scores, and the FACT-C results are negatively skewed to reflect this (Figure 6.1). The mean FACT-C score indicates the sample experienced

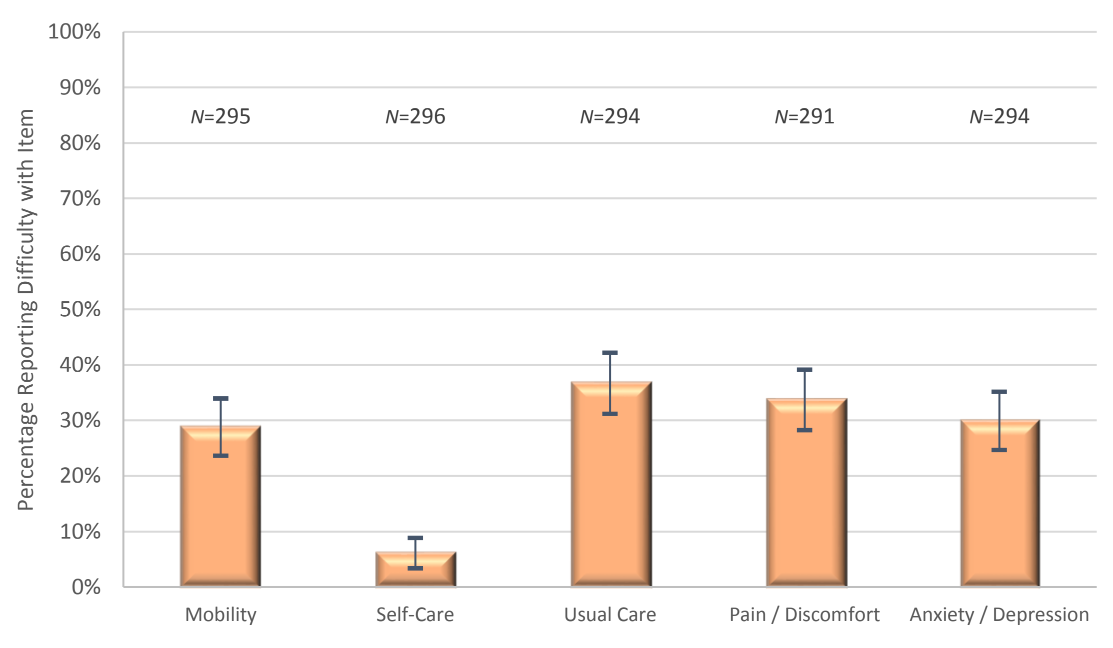
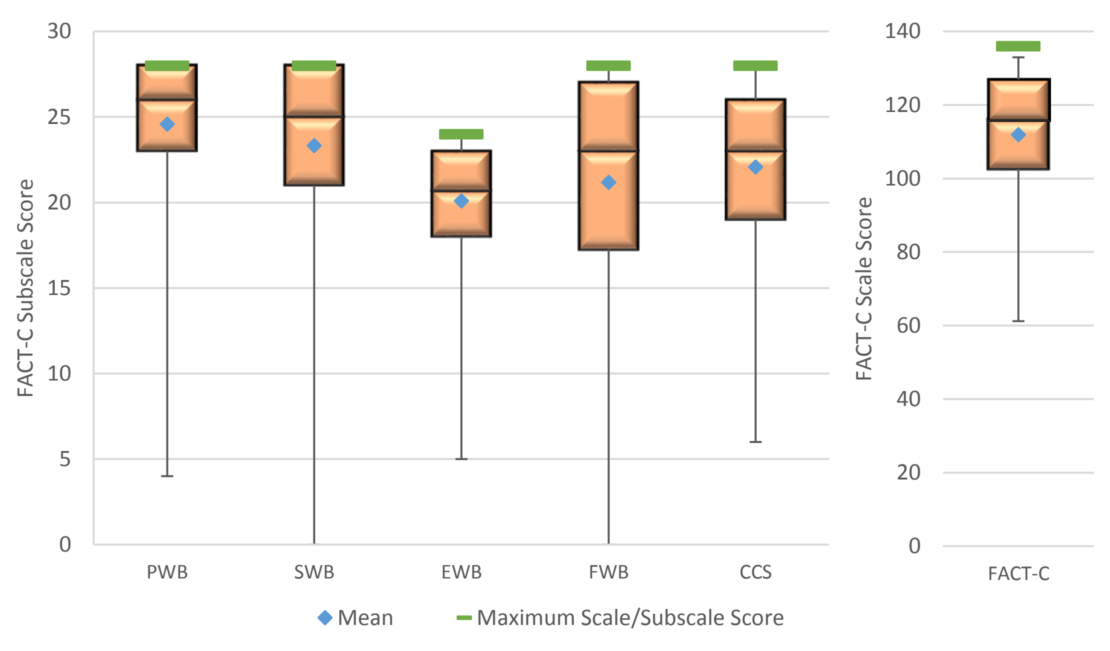


Figure 6.2 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with EuroQol 5D-5L items on the day of the survey



FACT-C Subscale	Physical Well-being (PWB)	Social/ Family Well-being (SWB)	Emotional Well-being (EWB)	Functional Well-being (FWB)	Colorectal Cancer Subscale (CCS)	Functional Assessment of Cancer Therapy (FACT-C)
N	264	278	276	283	283	251
Mean	24.6	23.3	20.1	21.2	22.1	111.9
SD	4.3	5.4	3.9	6.6	5.0	18.8
Median	26.0	25.0	20.7	23.0	23.0	116.0
Min	4.0	0.0	5.0	0.0	6.0	47.0
Max	28.0	28.0	24.0	28.0	28.0	136.0

Figure 6.3 Box plot and table depicting the distribution of colorectal cancer survivors' scores on the Functional Assessment of Cancer Therapy (FACT-C) scale and associated subscales

relatively positive quality of life overall ($\bar{x}$=111.9, *SD*=18.8, $\tilde{x}$=116.0, range=47.0-136.0, *N*=251; Figure 6.3).

Overall, the sample achieved very positive PWB scores ($\bar{x}$=24.6, *SD*=4.3, $\tilde{x}$=26.0, range=4.0-28.0, *N*=264; Figure 6.3). However, a substantial proportion indicated that lack of energy had affected them in the seven days before the survey (68.4%, *n*=197). More than one-tenth reported a lack of energy *quite a bit* or *very much* (12.9%, *n*=37). Over one-third were bothered by the side-effects of their treatment (34.6%, *n*=91), of whom 29.7% were bothered *quite a bit* or *very much* (*n*=27). Of those who reported pain in the past week (30.3%, *n*=79), most reported it was *a little* or *somewhat* problematic (87.3%, *n*=69). Apart from a lack of energy and being bed bound, less than one-fifth of those who reported difficulty with each respective symptom on the PWB scale rated each at the most negative levels (*quite a bit* or *very much*) (Figure 6.4).

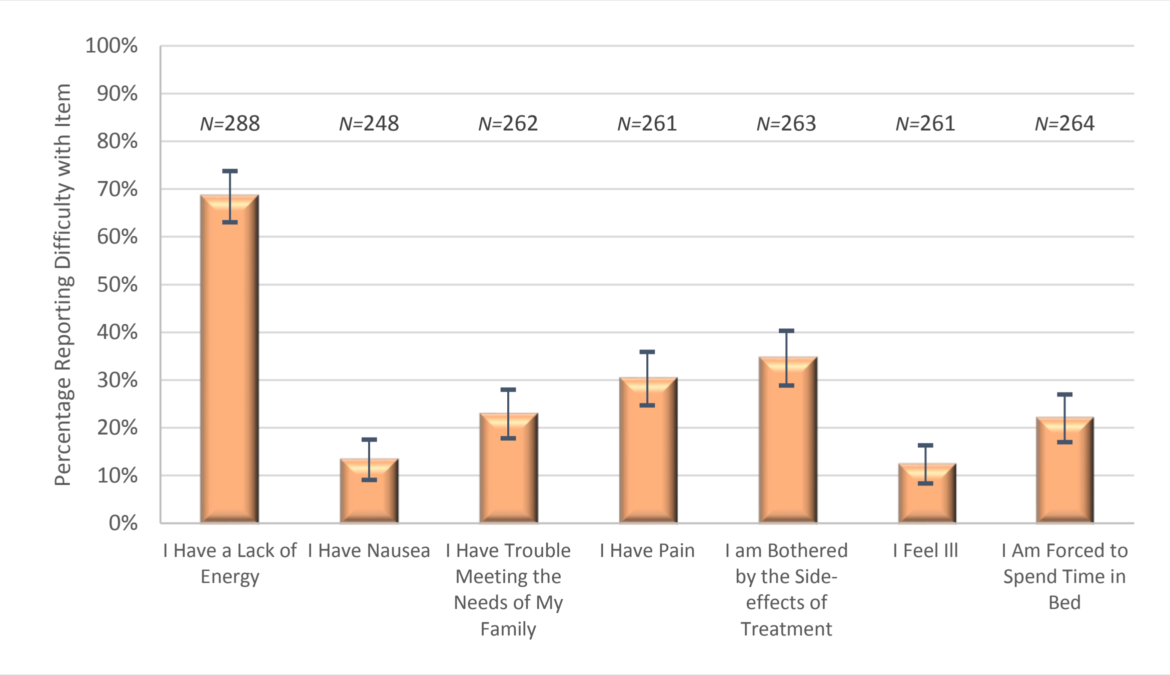
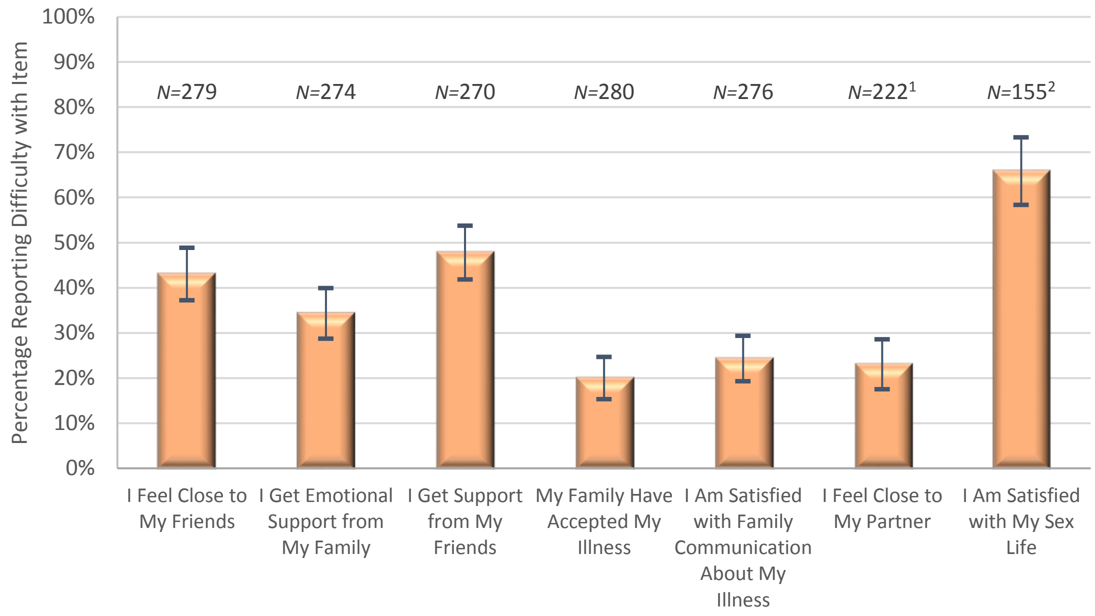


Figure 6.4 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with Physical Well-being (PWB) subscale items in the past week

Figure 6.5 depicts responses to the FACT-C SWB scale. Dissatisfaction with sexual activities was the most prominent difficulty on the SWB scale in this sample (65.8%, *n*=102). However, 111 participants opted not to answer the item *I Am Satisfied with my Sex Life* (36.5%). Those who opted not to answer this question were more likely to be living alone (χ^2(2)=22.251, *p*≤0.0005) or over the age of 65 (χ^2(1)=31.654, *p*≤0.0005). No differences were observed between those who answered, and those who did not, for gender (*p*=0.114) or diagnosis (*p*=0.139). Almost half of the survivors reporting dissatisfaction with sexual activities did so at the most negative levels (*not at all* or *a little*; 48.0%, *n*=49).

Apart from one item, less than one-quarter of colorectal cancer survivors expressed negative responses to family-related items on the SWB scale (Figure 6.5). For the most part, survivors' family



[1] *n*=30 indicated the "*I Feel Close to My Partner*" item was not applicable, *n*=52 were missing/spoilt

[2] *n*=111 indicated the "*I Am Satisfied with My Sex Life*" item was not applicable, *n*=38 were missing/spoilt

Figure 6.5 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with Social/Family Well-being (SWB) subscale items in the past week

members *very much* accepted their illness (80%, *n*=224) and appeared to communicate well (75.7%, *n*=209). However, more than one-third of participants negatively evaluated the emotional support from their family (34.3%, *n*=94); yet, most of this group felt supported by their families *quite a bit* (67.0%, *n*=63). Overall, most participants felt close to their partner (77.0%, *n*=171). In contrast, more than two-fifths did not feel close to their friends (43.0%, *n*=120), and almost half felt they did not receive support from their friends (47.8%, *n*=129). One-quarter of those who did not feel close to (25%, *n*=30) or did not receive support from friends (17.8%, *n*=23) reported these challenges at the highest levels (*a little bit* or *not at all*). Despite the high proportions of colorectal cancer survivors who reported adverse responses to SWB items, mean scores on the scale were relatively high ($\bar{x}$=23.3, *SD*=5.4, $\tilde{x}$=25.0, range=0.0-28.0, *N*=278; Figure 6.3).

Responses to EWB subscale items are illustrated in Figure 6.6. One of the most striking findings on this subscale was that 92.4% (*n*=254) were *not at all* losing hope. Yet, more than two-fifths indicated unfavourable responses to the remaining EWB items, including sadness (42.0%, *n*=116), coping with illness (43.8%, *n*=126), feeling nervous (40.1%, *n*=110), worry about dying (43.7%, *n*=121) and worry about their condition deteriorating (51.3%, *n*=143). Substantial proportions of those who reported problems with coping (31.7%, *n*=40) and worry about dying (21.5%, *n*=26) did so *quite a bit* or *very much*. However, few of those who reported difficulty with sadness (15.5%, *n*=18), feeling nervous (13.6%, *n*=15) or worrying about their condition deteriorating (17.4%, *n*=25) did so *quite a bit* or *very much*. The low ranking applied to these symptoms goes some way to explain the reasonably

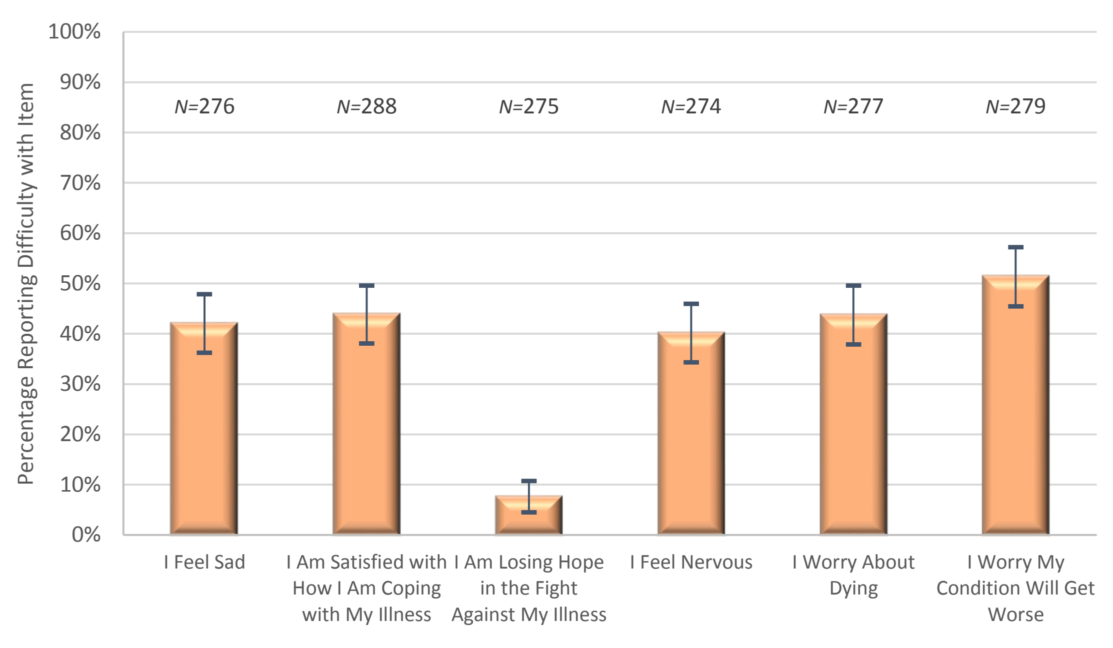


Figure 6.6 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with Emotional Well-being (EWB) subscale items in the past week

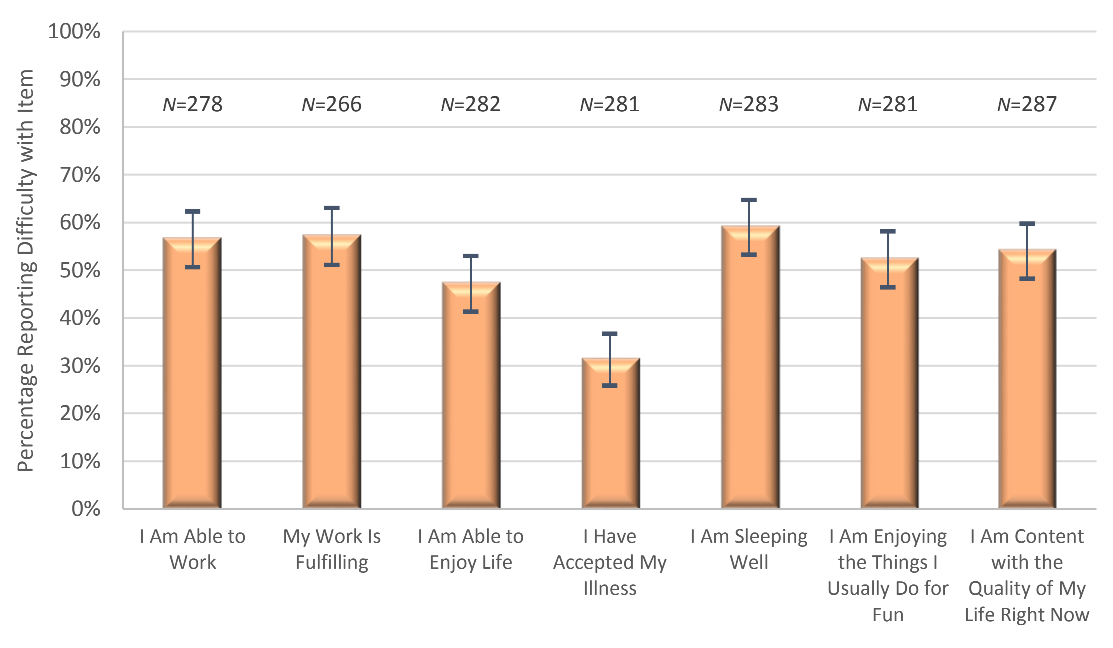


Figure 6.7 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with Functional Well-being (FWB) subscale items in the past week

positive mean scores achieved on the EWB subscale ($\bar{x}$=20.1, *SD*=3.9, $\tilde{x}$=20.7, range=5.0-24.0, *N*=276; Figure 6.3).

Of all the FACT-C subscales, the FWB subscale achieved the lowest average score but also had the greatest variance ($\bar{x}$=21.2, *SD*=6.6, $\tilde{x}$=23.0, range=0.0-28.0, *N*=283; Figure 6.3). The frequency of responses to FWB subscale items are demonstrated in Figure 6.7. Less than one-third of the sample had difficulty accepting their illness (31.3%, *n*=88). However, more than half were dissatisfied with the quality of their life in the week preceding the survey (54%, *n*=155); of these, 55% (*n*=85) were *somewhat*, *quite a bit* or *very much* dissatisfied. Furthermore, of those who had trouble sleeping (59%, *n*=167), almost 15% selected the most negative responses (*not at all* or *a little bit*; 14.5%, *n*=41). More than half of the sample reported difficulties hindering their ability to work (56.5%, *n*=157) and find fulfilment in their work (57.1%, *n*=152); of these, approximately 55% reported moderate or high difficulties with these items (*not at all*, *a little bit*, *somewhat*; *n*=87 and *n*=86, respectively). However, of those who reported difficulties enjoying life (47.2%, *n*=133), more than half indicated they enjoyed life *quite a bit* (52.6%, *n*=70). Similarly, of those who had difficulty enjoying the things they usually did for fun (52.3%, *n*=147), more than two-fifths indicated they enjoyed such activities *quite a bit* (42.8%, *n*=63).

The average scores for the CCS subscale within this sample were the second-lowest ranked of the FACT-C subscales after FWB ($\bar{x}$=22.1, *SD*=5.0, $\tilde{x}$=23.0, range=6.0-28.0, *N*=283; Figure 6.3). A particularly high proportion of colorectal cancer survivors indicated concerns about their body image (73.7%, *n*=202; Figure 6.8). Of these, more than one-quarter responded to the statement *I Like the Appearance of my Body*, *not at all* or *a little bit* (27.2%, *n*=55). Bowel-related symptoms were reported by a considerable proportion of the sample. Two-fifths reported diarrhoea in the past seven days (40.9%, *n*=115), of whom 20% indicated it was a problem *quite a bit* or *very much* (*n*=23). More than one-fifth of the total sample ranked difficulty with bowel control at the most negative levels (*not at all* or *a little bit;* 21.4%, *n*=60). In addition, almost one-third of the sample had abdominal swelling or cramps (28.2%, *n*=79); however, most of this group indicated this symptom affected them only *a little bit* (51.9%, *n*=41). Most colorectal cancer survivors did not report a disturbance in their appetite (61.1%, *n*=174) and could digest their food well (55.5%, *n*=156). Less than a quarter of those who provided negative responses about their appetite or

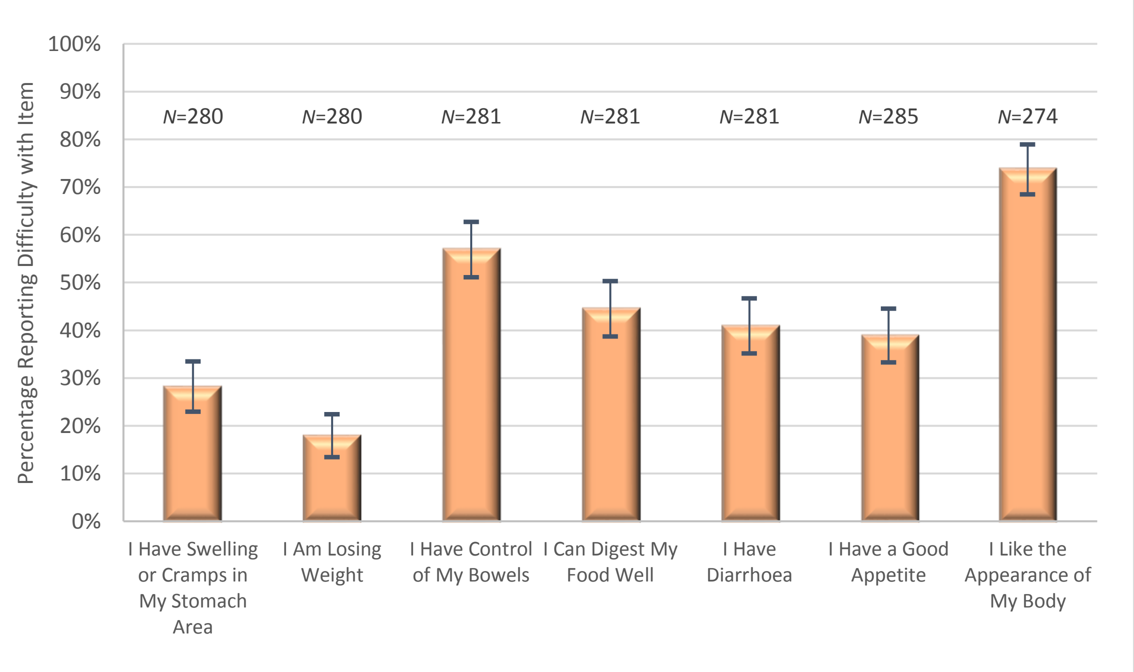


Figure 6.8 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with Colorectal Cancer Subscale (CCS) items in the past week

digestion did so at the highest level (*not at all* or *a little bit*; 24.3%, *n*=27 and 24.8%, *n*=31, respectively). This is reflected in the relatively small group who reported they were losing weight over the week preceding the survey (17.9%, *n*=50).

Although large proportions of the sample reported more frequent urination (49.6%, *n*=139) and urinary incontinence (33.8%, *n*=94), comparatively few indicated difficulty urinating (17.6%, *n*=49; Figure 6.9). Furthermore, the majority of those who had urinary frequency indicated it was problematic *a little bit* or *somewhat* in the past week (69.8%, *n*=97), while more than four-fifths of the sample indicated similar responses to the urinary leakage item (*a little bit*, *somewhat*; 81.9%, *n*=77).

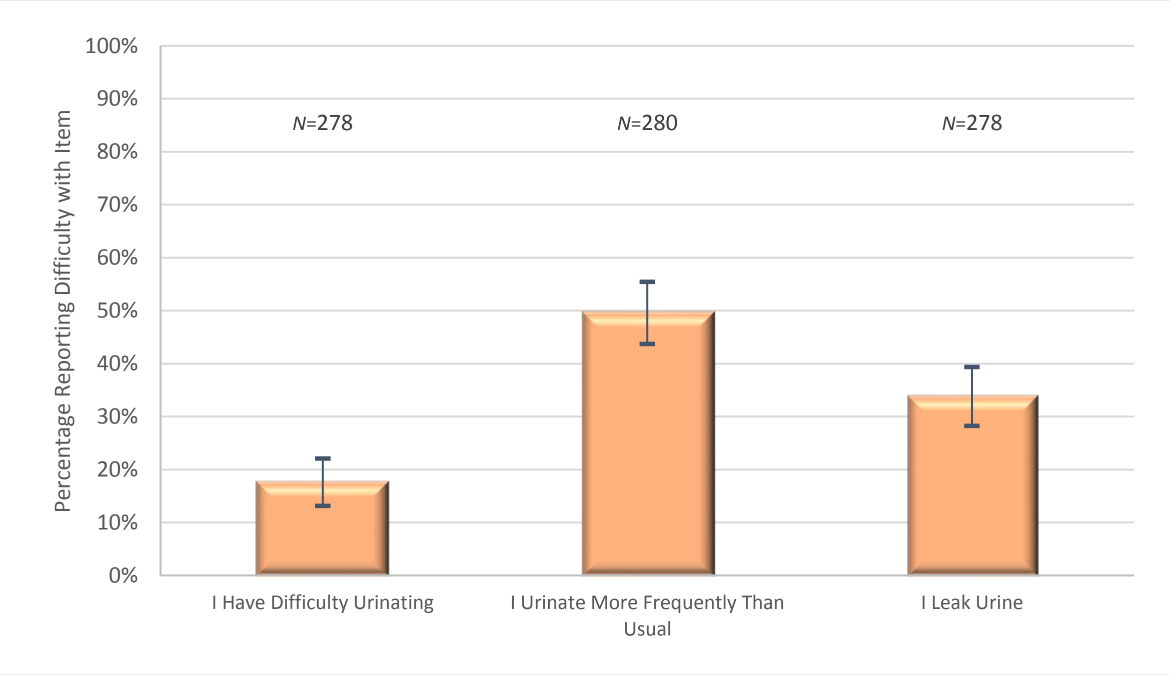


Figure 6.9 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with Urinary Concerns items in the past week

Figure 6.10 demonstrates the range of responses to the FACT-C ostomy and bowel control items. A total of 19.2% (*n*=55) reported having a stoma at the time of the survey. Of this group, 58.3% (*n*=28) reported feeling some level of embarrassment relating to their ostomy appliance or stoma (Figure 6.10i), and 44% (*n*=22) had difficulty caring for their ostomy appliance or stoma (Figure 6.10ii). However, in both cases, the majority of those who reported a negative response did so at the lowest possible level (*a little bit*; 53.3%, *n*=32 and 75.0%, *n*=18, respectively). Overall, 56.9% (*n*=160) of participants reported having control of bowel function on the five-level FACT-C questionnaire item (Figure 6.8), yet only 24.7% (*n*=70) indicated a problem with bowel control on the dichotomous variable (data not shown). Of the group who indicated problems on the dichotomous bowel control variable, the majority reported variability in the frequency of difficulties with bowel control (61.4%, *n*=43), while almost two-fifths had difficulty on a weekly basis (18.2%, *n*=12; Figure 6.10iii).

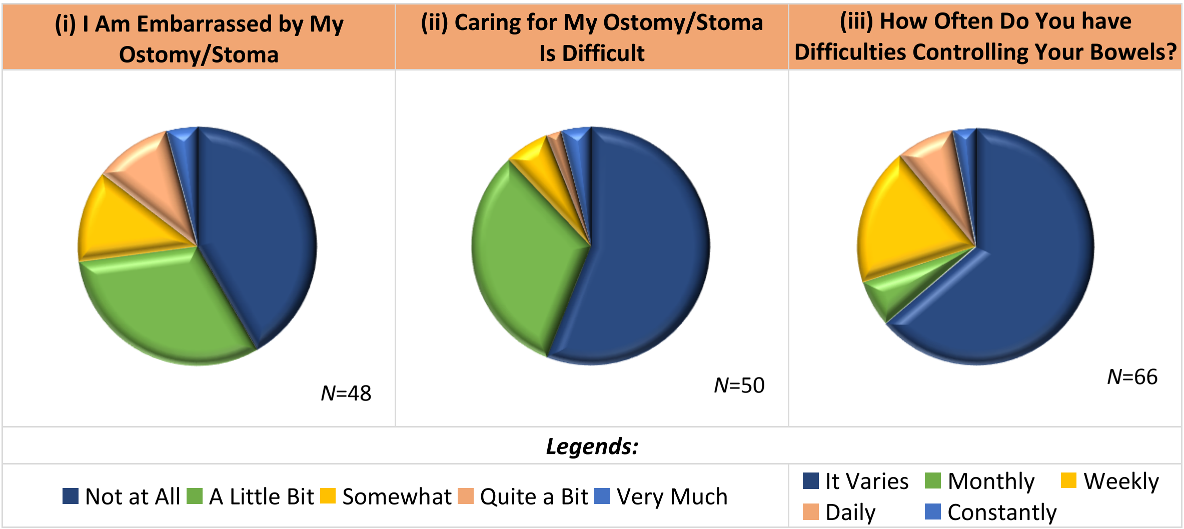


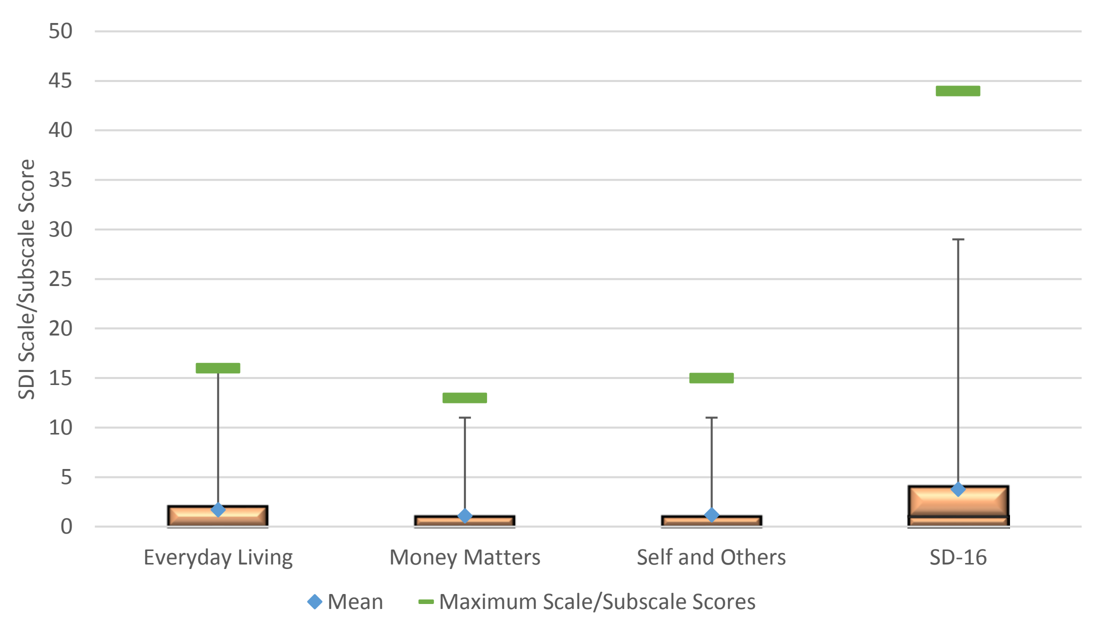
Figure 6.10 Pie charts illustrating colorectal cancer survivors' responses to the Functional Assessment of Cancer Therapy-Colorectal (FACT-C) Ostomy Appliance/Stoma and Bowel Control Questions

6.4.1.3 Social Difficulties Inventory

Social difficulties experienced by this cohort of colorectal cancer survivors in the past month were evaluated using the Social Difficulties Inventory (SDI) questionnaire in three domains: 1) Everyday Living (EDL), 2) Money Matters (MM), and 3) Self and Others (SO). Five additional miscellaneous items measure difficulties with *living arrangements, holiday plans, sexual concerns, fertility,* and *other challenges*. SDI questions are posed such that the response *no difficulty* indicates a positive response, and the responses *a little*, *quite a bit* or *very much* indicate negative responses. As in the previous subsection, the current subsection will present the proportion of respondents who reported difficulty with each SDI item in bar charts.

Figure 6.11 illustrates the distribution of SDI subscale and Social Difficulties-16 (SD-16) scores. The scores are positively skewed due to the large proportion of survivors who reported no difficulties on many SDI items. Of all the SDI subscales, participants reported the greatest degree of difficulty on the EDL subscale ($\bar{x}$=1.7, *SD*=2.9, $\tilde{x}$=0.0, range=0.0-16.0, *N*=281), followed by the MM subscale ($\bar{x}$=1.1, *SD*=2.2, $\tilde{x}$=0.0, range=0.0-11.0, *N*=261) and the SO subscale ($\bar{x}$=1.2, *SD*=2.1, $\tilde{x}$=0.0, range=0.0-11.0, *N*=267). On average, the sample reported low social difficulty scores (SD-16: $\bar{x}$=3.8, *SD*=5.7, $\tilde{x}$=1.0, range=1.0-29.0, *N*=253). Despite these positive results, more than one-tenth achieved an SD-16 score of ≥10, indicating clinically significant levels of social distress (13.4%, *n*=34) (Wright *et al.* 2007).

The EDL mean score (Figure 6.11) reflects the low levels of difficulty with domestic and personal matters in this sample (Figure 6.12). The greatest proportion of participants indicated difficulties with domestic chores (32.5%, *n*=92) and recreational activities (28.6%, *n*=83). More than one-third of those who reported difficulties with domestic chores did so *quite a bit* or *very much* (34.8%, *n*=32). Most of those reporting difficulties with recreational activities indicated *a little* difficulty (59.0%, *n*=49). Despite these challenges, relatively few had difficulty maintaining their



Scale	Everyday Living (EDL) (0-16)	Money Matters (MM) (0-13)	Self and Others (SO) (0-15)	SD-16 (0-44)
N	281	261	267	253
Mean	1.7	1.1	1.2	3.8
SD	2.9	2.2	2.1	5.7
Median	0.0	0.0	0.0	1.0
Min	0.0	0.0	0.0	0.0
Max	16.0	11.0	11.0	29.0

Figure 6.11 Box plot and table depicting the distribution of colorectal cancer survivors' scores on the Social Difficulties Inventory (SDI) subscales

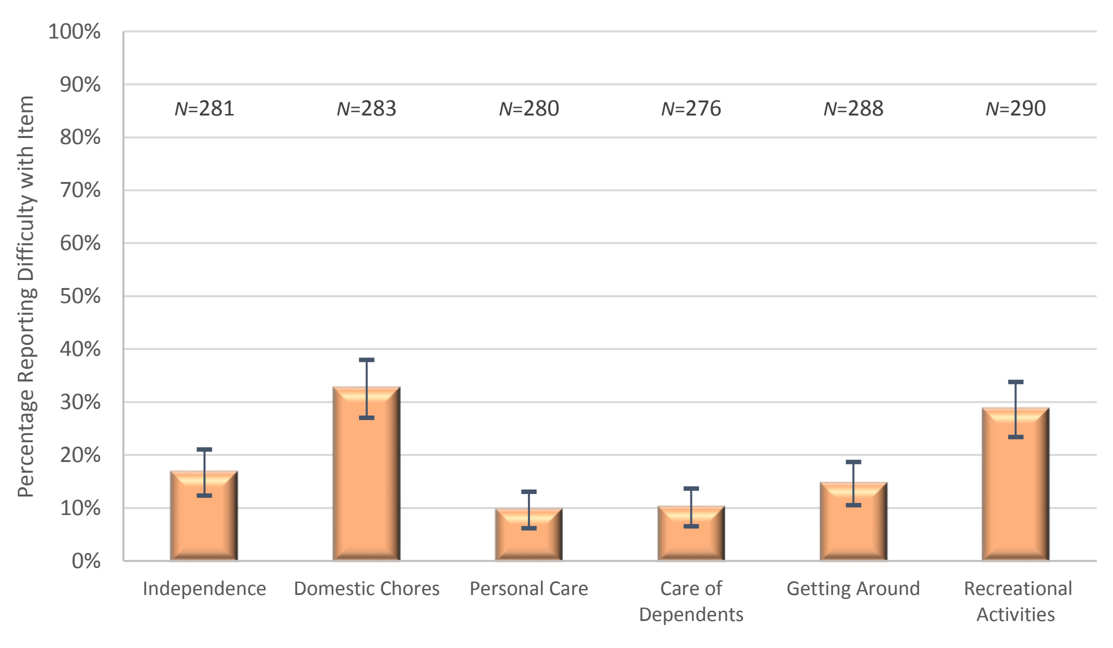


Figure 6.12 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with Everyday Living (EDL) subscale items in the past month

independence (16.7%, *n*=47) or getting around (14.6%, *n*=42); more than half of those reporting these issues did so at the lowest level (*a little*; 55.3%, *n*=26; 57.1%, *n*=24, respectively). Fewer participants had difficulty looking after those that depended on them over the past month (10.1%, *n*=28). The responses to this item contrasted with the FACT-C item *I Have Trouble Meeting the Needs of My Family*, as more than twice as many respondents reported difficulty in the past seven days (22.9%, *n*=60; Figure 6.4).

Of the MM subscale responses (Figure 6.13), the greatest difficulties experienced by colorectal cancer survivors related to financial concerns (25.4%, *n*=71), planning for the family's future (17.8%, *n*=49) and difficulty with financial services (16.9%, *n*=47). Although many participants who reported these issues did so at the lowest level (*a little*), one-third (32.3%, *n*=23) indicated financial difficulties affected them *quite a bit* or *very much*. Of those who had difficulty with benefits (10.2%, *n*=28), over two-fifths experienced difficulty *quite a bit* or *very much* (42.8%, *n*=12). Furthermore, almost half of those having trouble with welfare benefits also reported difficulties with their work (45.8%, *n*=11). Despite these difficulties, the low mean score for the SDI MM subscale (Figure 6.11) is reflective of the large proportion of participants who reported few or no difficulties with this domain.

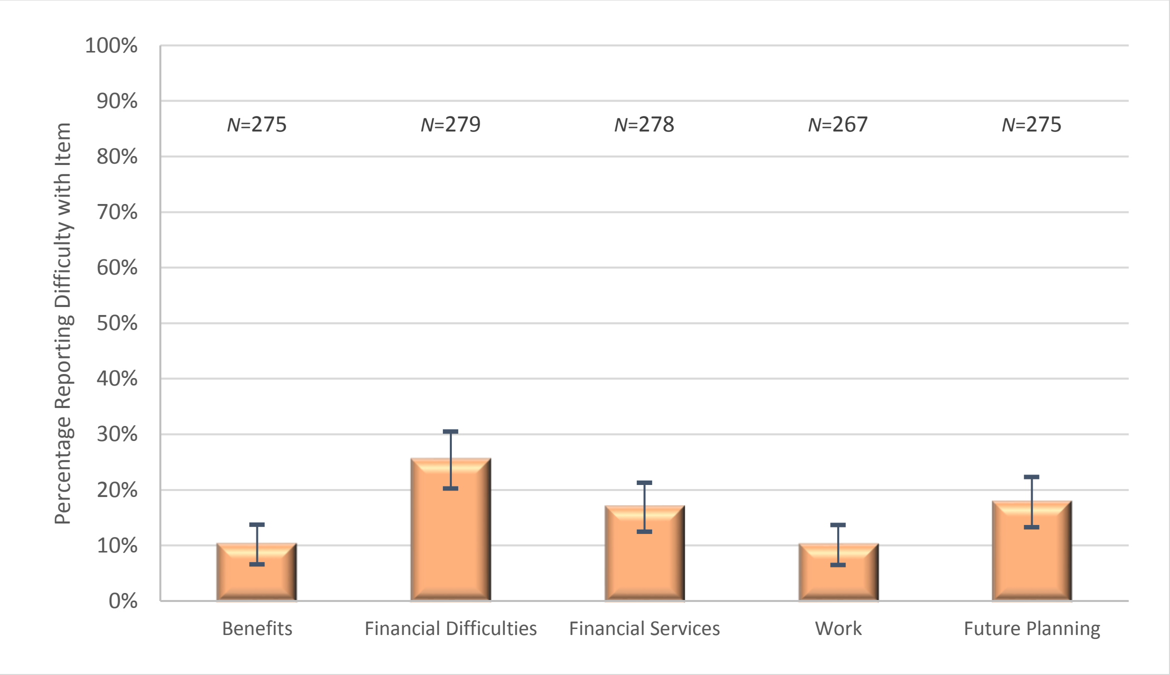


Figure 6.13 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with Money Matters (MM) subscale items in the past month

The SO subscale achieved the lowest ranked mean scores of the three SDI subscales (Figure 6.11). One of the most concerning findings on this scale was the considerable proportion of colorectal cancer survivors who reported difficulty with isolation (25.2%, *n*=72) and communicating with those close to them (17.9%, *n*=52) and others (13.1%, *n*=38; Figure 6.14). Although most indicated problems with these items at the lowest possible level (*a little*), large proportions of those experiencing isolation also had difficulty communicating with those close to them (55.6%, *n*=40), or with others (43.1%, *n*=31). More than one-quarter of the sample indicated concerns about their appearance or body image (28.0%, *n*=80; Figure 6.14). When compared to responses on the FACT-C item which enquired of colorectal cancer survivors' satisfaction with their body image in the seven days preceding the survey, more than twice as many respondents described difficulties on the FACT-C item compared to the SDI item (73.7%, *n*=202; Figure 6.8).

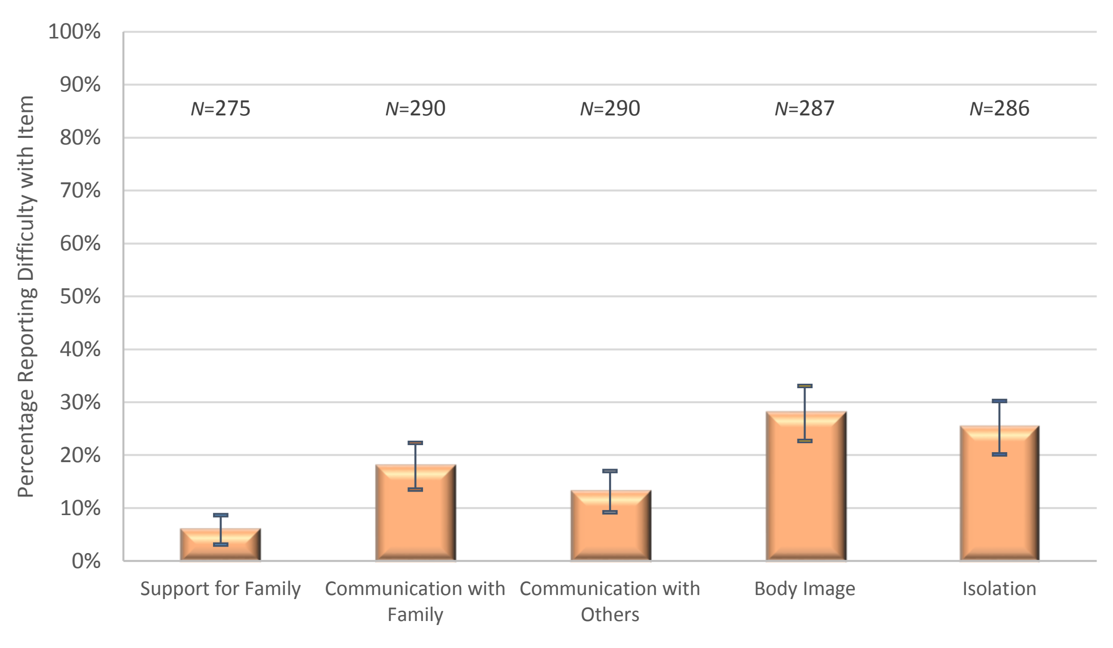


Figure 6.14 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with Self and Others (SO) subscale items in the past month

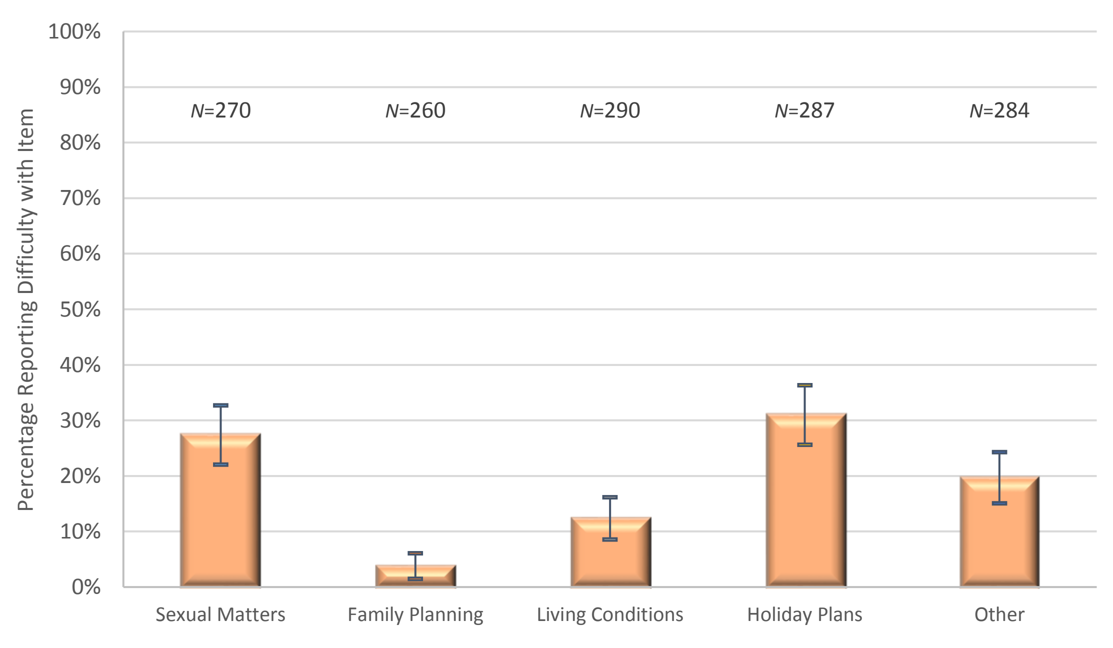


Figure 6.15 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulty with miscellaneous items on the Social Difficulties Inventory (SDI) in the past month

Figure 6.15 demonstrates the miscellaneous social difficulties items which do not contribute to SDI scale or subscale scores. Difficulty with plans to take a holiday was the second most common SDI concern reported by this sample (31%, *n*=89). Unlike the FACT-C sexual satisfaction item (Figure 6.5), 84.9% of the sample answered the SDI sexual concerns item (*n*=270); more than one-quarter indicated some degree of difficulty with sexual concerns (27.4%, *n*=74).

6.4.2 The Physical and Psychosocial Effects of Colorectal Cancer

Additional symptoms experienced in the week preceding the survey were explored using items derived from the National Cancer Institute Common Terminology Criteria for Adverse Events V4.03 (Figure 6.16). Psychosocial concerns were highly ranked by this group. Fear of cancer recurrence (59.6%, *n*=159) and cancer spread (51.3%, *n*=137) were the most common symptoms experienced by this sample. Although most who reported fear of recurrence at low to moderate levels, a considerable proportion indicated it was a concern *quite a bit* or *very much* (22.6%, *n*=36); a smaller proportion rated fear of cancer spread at these levels (17.5%, *n*=24). Memory loss and concentration difficulties were *a little bit* problematic for most (65.1%, *n*=82 and 46.9%, *n*=53, respectively). However, the overall proportion experiencing these symptoms is a cause for concern. Irritability and mood swings were *a little bit* or *somewhat* problematic for most who experienced these symptoms (88.1%, *n*=96; 88.2%, *n*=98, respectively). A large proportion of this sample experienced tingling in the hands or feet (47.0%, *n*=131). An important observation in this data was the large proportion who ranked this symptom problematic *quite a bit* or *very much* (49.6%, *n*=65). Other symptoms which were notable within this sample were the sizeable proportions who experienced constipation (37.2%, *n*=102) and skin-related symptoms (40.4%, *n*=110; Figure 6.16).

6.4.3 Colorectal Cancer Survivors' Experience of Healthcare

6.4.3.1 Continuity of Care

Colorectal cancer survivors' experiences of continuity of care were measured using the Patient Continuity of Care Questionnaire (PCCQ) in five domains: 1) Information Transfer, 2) Management of Follow-up, 3) Management of Communication Among Providers, 4) Relationships with Healthcare Providers, and 5) Management of Forms. Responses to PCCQ items are structured such that *strongly agree* represents the most positive response. In this subsection, the range of responses reported by colorectal cancer survivors are illustrated in bar charts.

Figure 6.17 illustrates the distribution of PCCQ subscale and Continuity of Care-18 (CC-18) scores. The scores are negatively skewed, reflecting the positive responses to most PCCQ items. Of the five PCCQ subscales, Information Transfer ranked the lowest on average, followed by Management of Communication Among Providers. Relationships with Healthcare Providers was the most positively ranked subscale overall. Scores in each domain of the PCCQ reflected highly positive ratings of

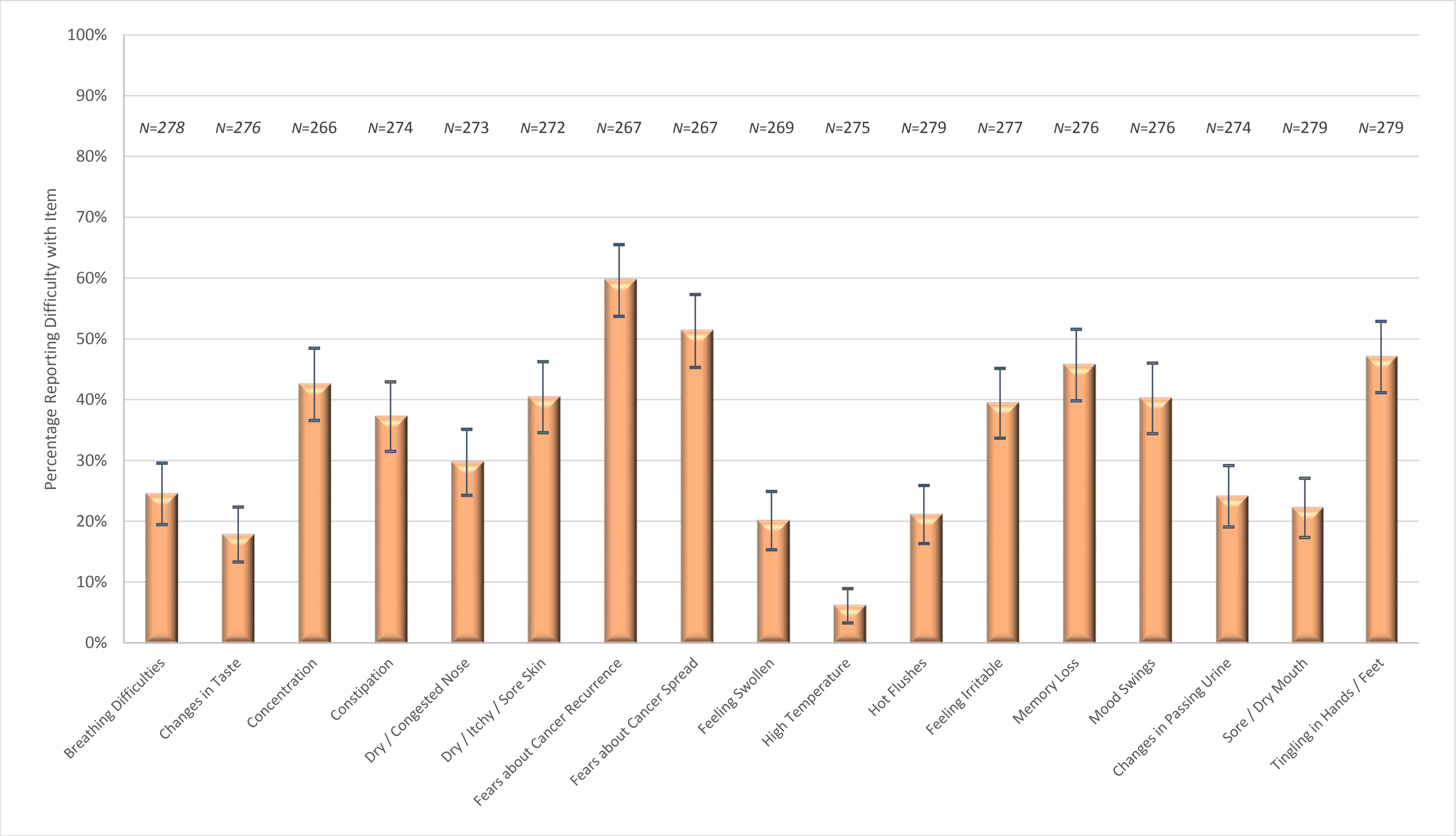
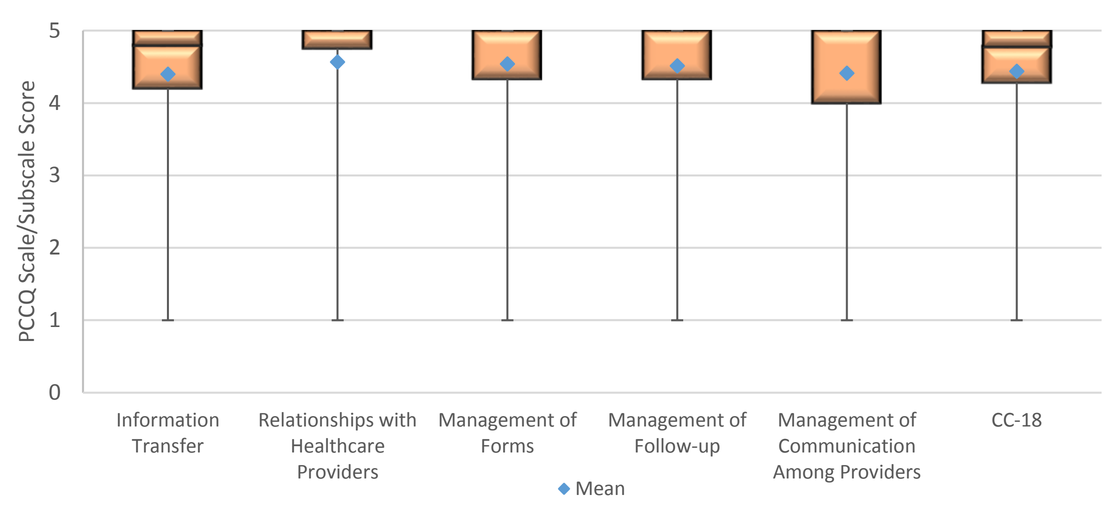


Figure 6.16 Bar chart illustrating the proportions (%) and 95% confidence intervals of colorectal cancer survivors who reported difficulties with additional symptoms in the past seven days



Subscale	Information Transfer	Relationships with Healthcare Providers	Management of Forms	Management of Follow-up	Communication Among Providers	CC-18
N	254	225	237	277	231	234
Mean	4.4	4.5	4.4	4.6	4.5	4.4
SD	1.0	1.0	0.9	1.0	0.9	0.9
Median	4.8	5.0	5.0	5.0	5.0	4.8
Min	1.0	1.0	1.0	1.0	1.0	1.0
Max	5.0	5.0	5.0	5.0	5.0	5.0

Figure 6.17 Box plot and table depicting the distribution of colorectal cancer survivors' scores on the Patient Continuity of Care Questionnaire (PCCQ) subscales

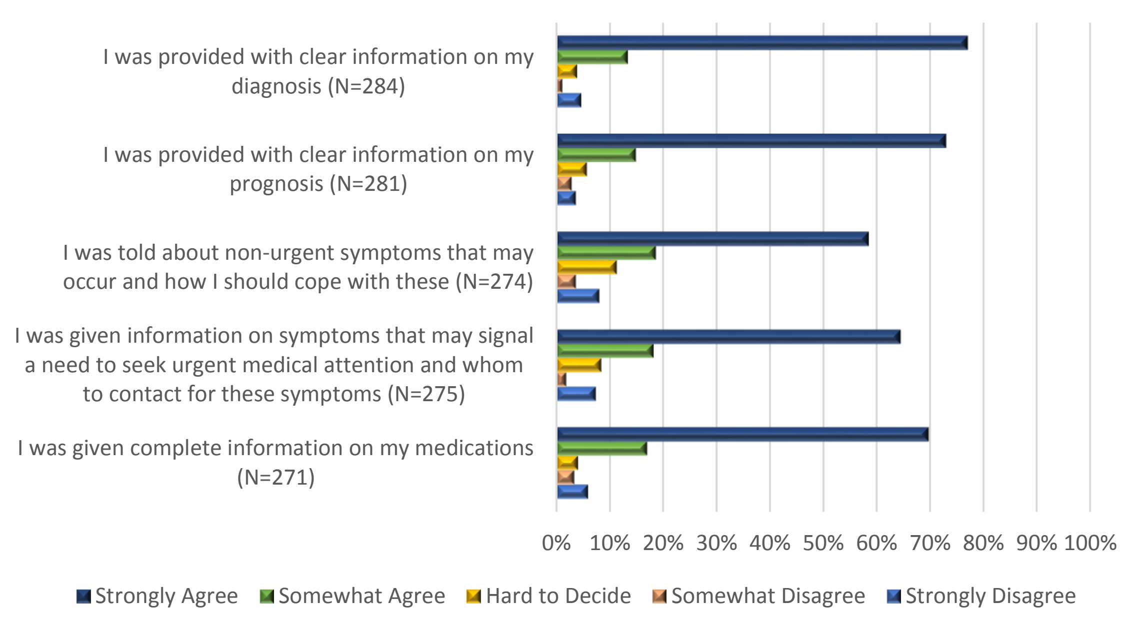


Figure 6.18 Bar chart illustrating colorectal cancer survivors' responses to Information Transfer subscale items

overall continuity of care and contribute to the relatively high overall continuity of care score (CC-18: $\bar{x}$=4.4, *SD*=0.9, $\tilde{x}$=4.8, range=1.0-5.0, *N*=234).

Colorectal cancer survivors rated delivery of information by healthcare providers very highly ($\bar{x}$=4.4, *SD*=1.0, $\tilde{x}$=4.8, range=1.0-5.0, *N*=254; Figure 6.17). Three-quarters *strongly agreed* that they had received clear information about their diagnosis (77.1%, *n*=219) and prognosis (73.0%, *n*=205). However, symptom information items were positively rated by a smaller proportion of participants. Almost one-quarter did not agree that they had received adequate information about non-urgent symptoms (*disagree* or *strongly disagree*; 23%, *n*=63). Meanwhile, only 82.5% (*n*=227) believed they were sufficiently informed about urgent symptoms and who to contact should such symptoms occur (*agree* or *strongly agree;* Figure 6.18).

Overall, the sample reported positive Relationships with Healthcare Providers since discharge ($\bar{x}$=4.5, *SD*=1.0, $\tilde{x}$=5.0, range=1.0-5.0, *N*=225; Figure 6.17). More than three-quarters *strongly agreed* that they had confidence in (79.7%, *n*=189) and felt known by their healthcare providers (76.2%, *n*=176; Figure 6.19). The majority *agreed* or *strongly agreed* that they had ample time to discuss their care with healthcare professionals (90.3%, *n*=216). Compared to Information Transfer scale items, a greater proportion reported satisfaction with the information they received from the healthcare providers responsible for their survivorship care (*agree* or *strongly agree*, 89.4%, *n*=211).

Three items evaluated the management of colorectal cancer survivors' healthcare-related paperwork in the time following discharge from treatment (Figure 6.20). This subscale was the second-highest rated of the PCCQ subscales ($\bar{x}$=4.4, *SD*=0.9, $\tilde{x}$=5.0, range=1.0-5.0, *N*=237; Figure 6.17). The majority

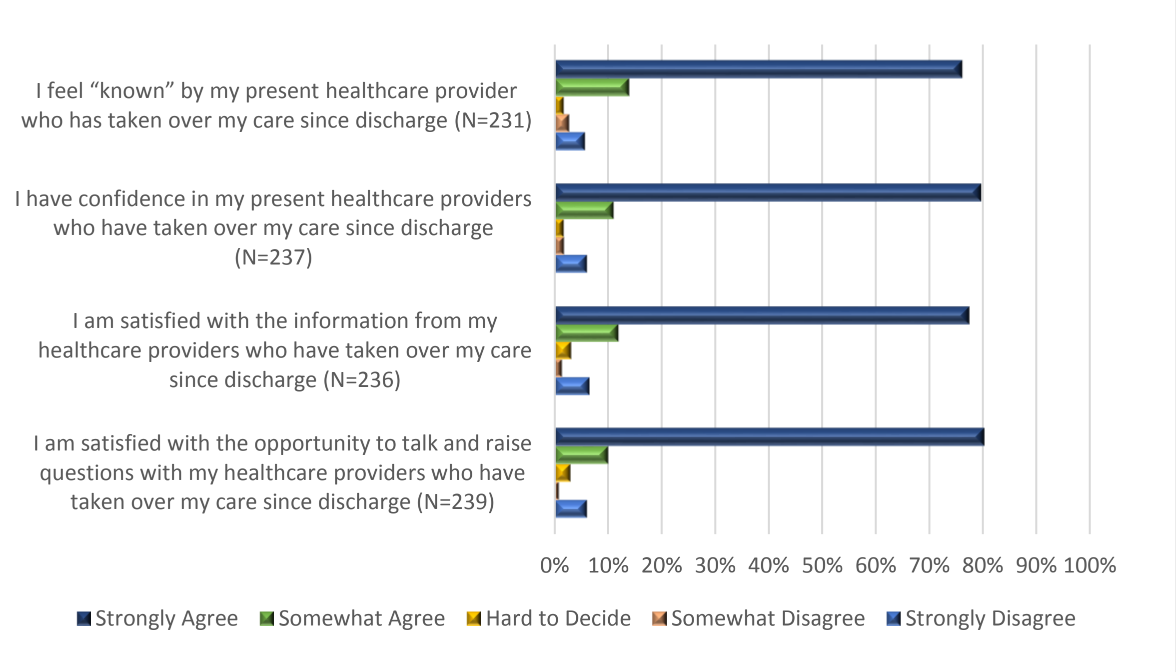


Figure 6.19 Bar chart illustrating colorectal cancer survivors' responses to Relationships with Healthcare Providers subscale items

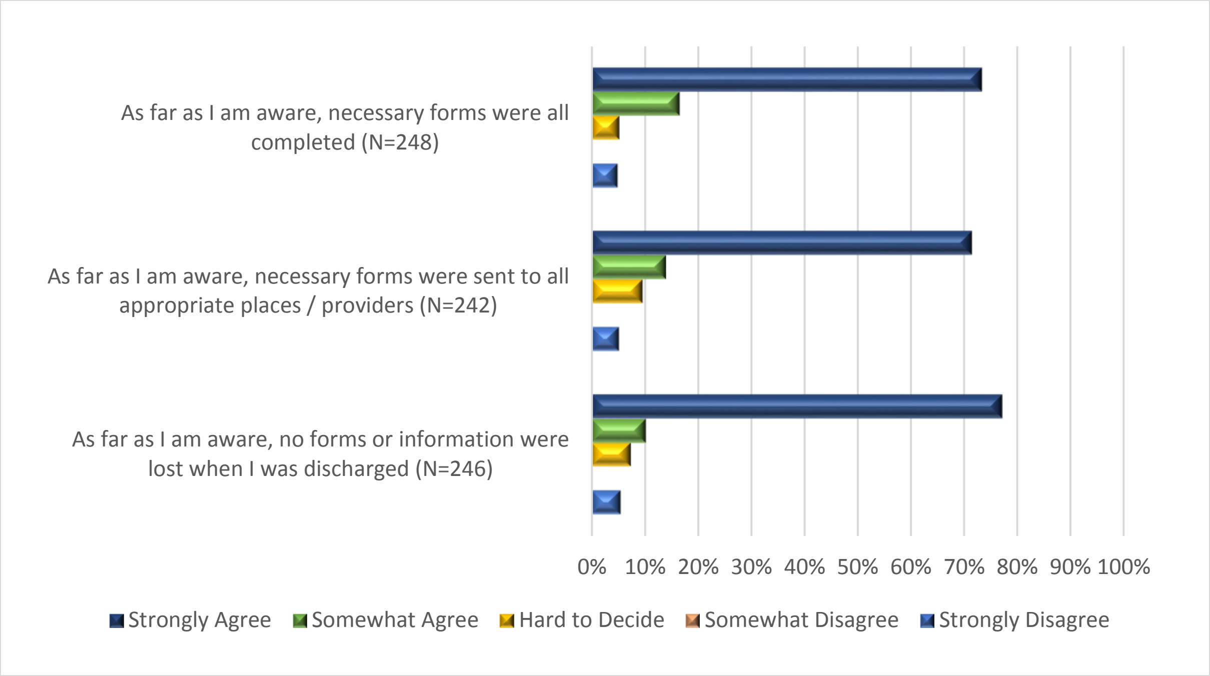


Figure 6.20 Bar chart illustrating colorectal cancer survivors' responses to Form Management subscale items

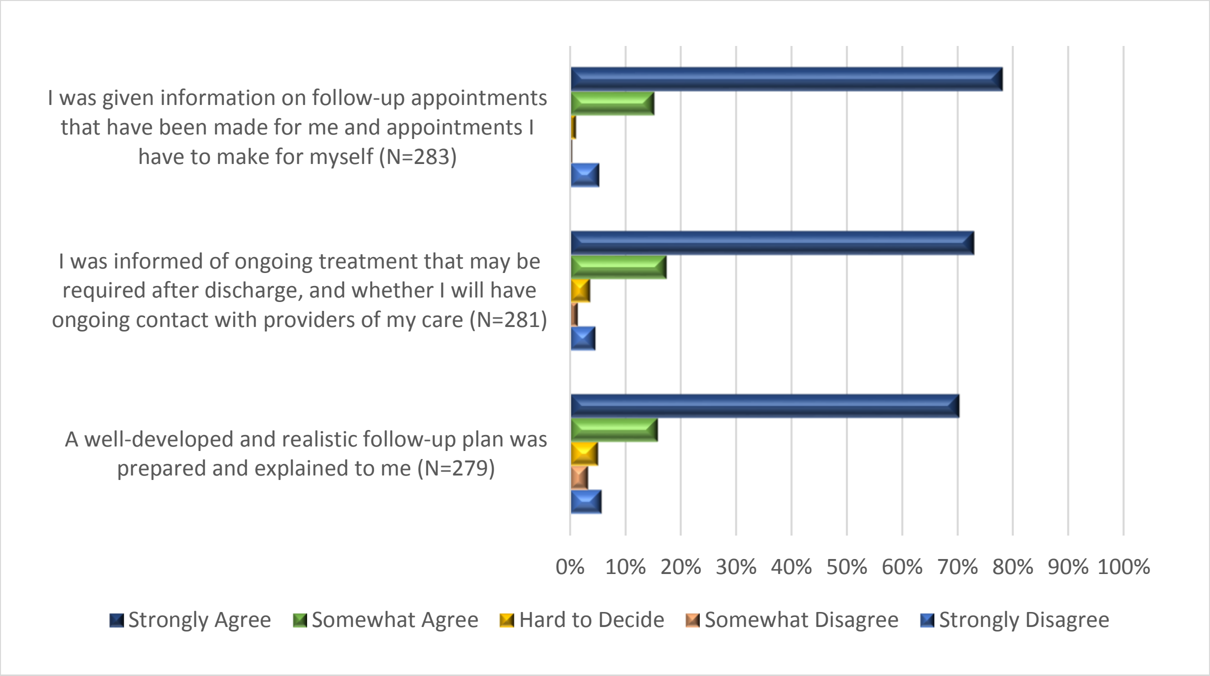


Figure 6.21 Bar chart illustrating colorectal cancer survivors' responses to Management of Follow-up subscale items

agreed or *strongly agreed* that appropriate forms were completed (89.9%, *n*=223), sent to the relevant healthcare professionals (85.5%, *n*=207) and no forms were lost (87.4%, *n*=215). However, more than 10% responded negatively (*strongly disagree*) or neutrally (*hard to decide*) to each of these items.

The sample's high average scores on the Management of Follow-up subscale ($\bar{x}$=4.6, *SD*=1.0, $\tilde{x}$=5.0, range=1.0-5.0, *N*=277; Figure 6.17) is reflective of the high proportion of colorectal cancer survivors who *agreed* and *strongly agreed* with each item on the subscale (Figure 6.21). The majority believed they had received a clear plan for their follow-up care (*agree* or *strongly agree*; 86.1%, *n*=240), and informed of their responsibilities for planning future appointments (*agree* or *strongly agree*; 93.3%, *n*=264). Less than 10% were unsure about ongoing treatment and contact with healthcare professionals (*disagree* or *strongly disagree*; 9.6%, *n*=27).

Overall the sample reported positive mean scores on the Management of Communication among Healthcare Providers scale ($\bar{x}$=4.5, *SD*=0.9, $\tilde{x}$=5.0, range=1.0-5.0, *N*=231; Figure 6.17). Two-thirds *strongly agreed* with items on this scale (Figure 6.22). Few indicated issues with healthcare providers communication in hospital or convalescent care (*neutral*, *disagree* or *strongly disagree*; 13.0%, *n*=36). Furthermore, communication with community (84.3%, *n*=199) and primary care practitioners (85.2%, *n*=218) was positively evaluated by most (*somewhat agree* or *strongly agree*). This is pertinent information given the proportion of survivors who did not require or receive adequate support from community services (35.4%, *n*=99) or their general practice (23.8%, *n*=67; Table 6.7).

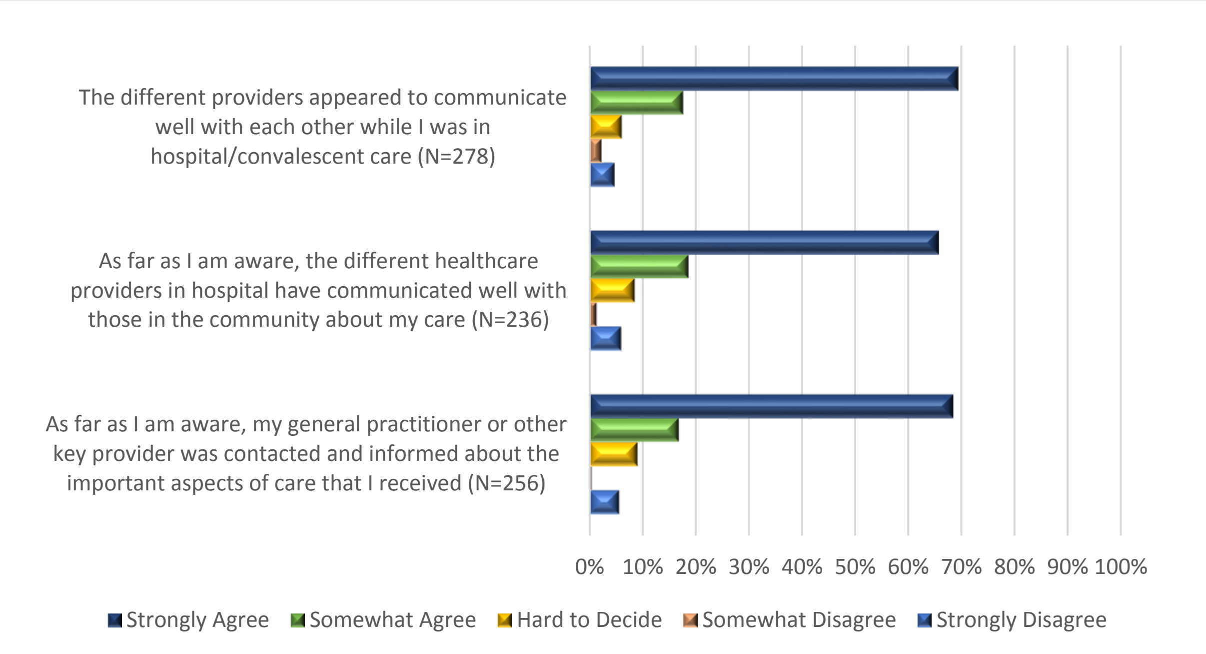


Figure 6.22 Bar chart illustrating colorectal cancer survivors' responses to Management of Communication Among Providers subscale items

6.4.3.2 Support Within the Healthcare Setting

Figure 6.23 displays the proportions of colorectal cancer survivors who have received i) a cancer survivorship care plan documenting the goals of the survivor's cancer care, and ii) a treatment summary containing information about the survivor's treatment history. Overall, less than one-third received a survivorship care plan (26.9%, *n*=76) or a treatment summary (34.6%, *n*=97). Colorectal cancer survivors who received a survivorship care plan (56.6%, *n*=43; *yes, definitely* or *yes, I think so*) were more likely to have received a treatment summary than those who had not (26.2%, *n*=53; χ^2=22.487, *p*≤0.0005, Odds Ratio [*OR*]=3.663). However, receipt of a cancer survivorship care plan or a treatment summary were not related to differences in responses to PCCQ Information Transfer items about diagnosis, prognosis, non-urgent symptoms or urgent symptoms (all *p*>0.05).

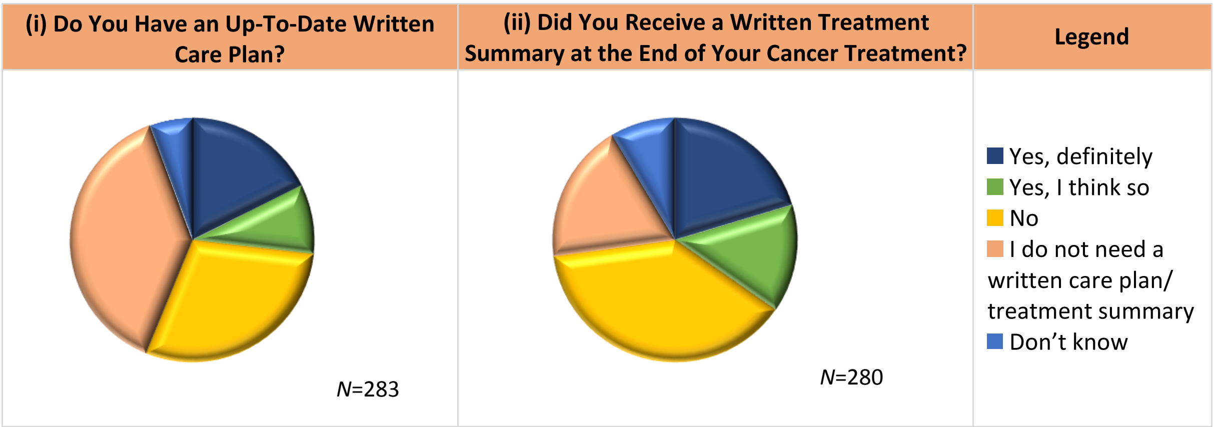


Figure 6.23 Pie charts illustrating colorectal cancer survivors' responses to (i) the cancer survivorship care plan item and (ii) the treatment summary item

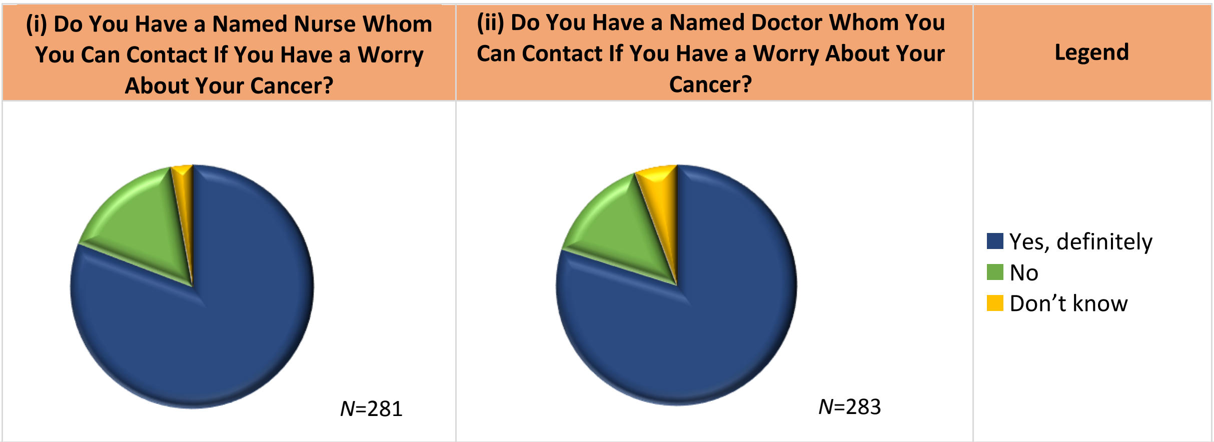


Figure 6.24 Pie charts illustrating the proportions of cancer survivors who have access to (i) a named nurse, and (ii) a named doctor they could contact in the event of any worries about their cancer

Responses (*N*=201)	***n***	**%**
Colorectal Cancer Surgery Clinical Nurse Specialist	94	46.8
Other Nursing Staff	37	18.4
Other Named Doctor	35	17.4
Colorectal Cancer Surgery Consultant	24	11.9
Hospital	24	11.9
General Practitioner	20	10.0
Medical Oncology Consultant	11	5.5
Clinic	9	4.5
Medical Oncology Clinical Nurse Specialist	5	2.5
Public Health Nurse	2	1.0
Other	7	3.5

Table 6.6 Other healthcare professionals identified by colorectal cancer survivors that could be contacted with concerns about any aspect of living with or beyond cancer

Variable (*N*)	**Yes, All of the Time**		**Only Some of the Time**		**Never**		**I Do Not Need Support**		**Not Involved**	
	n	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Hospital Staff (N=283)	247	87.3	22	7.8	2	0.7	12	4.2		
General Practice Staff (N=282)	194	68.8	21	7.4	8	2.8	20	7.1	39	13.8
Health and Social Services Staff (N=280)	126	45.0	45	16.1	21	7.5	88	31.4		

Table 6.7 Proportions of colorectal cancer survivors who believed healthcare staff did everything they could to support them following their cancer treatment

Three items enquired about the healthcare professionals that the colorectal cancer survivor could contact if they had any worries during follow-up (Figure 6.24; Table 6.6). Almost all indicated that they could contact a doctor, nurse or other healthcare professional with concerns about their cancer or survivorship issues (95.1%, *n*=272). Many participants reported they had a named nurse (80.8%, *n*=227) or doctor (79.9%, *n*=226) to contact if they were worried about cancer (Figure 6.24).

Two-thirds (68.2%, *n*=193) reported that they definitely knew whom to contact if concerns arose about their cancer or survivorship issues, and 54 (19.1%) thought they knew who to contact. Of those who definitely knew who to contact, 201 named one or more healthcare professionals they could contact, and 31 (16.2%) failed to specify any (Table 6.6). Colorectal cancer surgery clinical nurse specialists were the most common point of contact (46.8%, *n*=94), followed by other/unspecified nursing staff (18.4%, *n*=37), and other/unspecified medical staff (17.4%, *n*=35).

Most survivors believed that hospital staff did everything they could to support them since their cancer treatment *all* or *some of the time* (95.1%, *n*=269). General practice staff and community services were less positively evaluated. General practitioners were *not involved* in the cancer-related care of 13.8% of participants (*n*=39). Three-quarters (76.2%, *n*=215) believed their general practice provided support *all* or *some of the time*. Of those who required support from social services (68.6%, *n*=192), one-third received less than sufficient support from staff including public health nurses, home help and healthcare assistants (34.3%, *n*=66; Table 6.7).

6.4.3.3 Support Groups and Services

Participants were asked to indicate if they had ever attended a cancer support group meeting or another form of cancer support (Figure 6.25). Of those who attended cancer support group meetings (10.7%, *n*=30), more than half believed support groups were useful *quite a bit* or *very much* (58.6%, *n*=17). A similar proportion had attended other forms of cancer support (10.7%, *n*=29), and more than two-thirds felt these meetings had been useful (*quite a bit* or *very much*; 69.3%, *n*=18). Overall, 14.9% (*n*=42) had attended one or more cancer support groups or services. Participants specified the types of support groups and other services they had attended (Table 6.8). Most had attended a generic cancer support group at some point since their diagnosis (35.7%, *n*=15). Almost one-third had attended psychotherapy or counselling sessions (31%, *n*=13), and eight had used complementary or alternative therapies (19.1%; Table 6.8 and Table 6.9).

In an open-ended question, survivors were asked to describe any other supports or services they had used since their cancer diagnosis (Table 6.9). Overall, 221 (72.6%) responded to the item, of whom, 71.9% (*n*=159) mentioned at least one other source of support. The remainder (28.1%, *n*=62) provided comments explaining they did not access any other support. Family (35.7%, *n*=79) and friends (25.3%, *n*=56) were the most common sources of support. Less than one-fifth used the internet (19.9%, *n*=44),

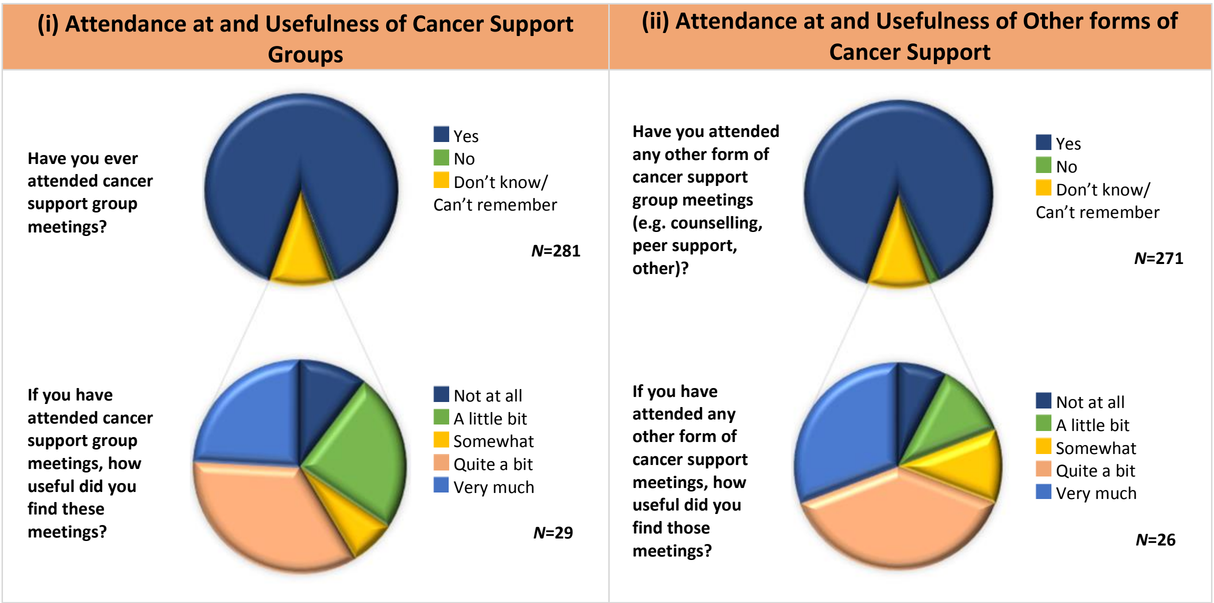


Figure 6.25 Pie charts illustrating the proportions of cancer survivors who have (i) used cancer support groups and (ii) other forms of cancer support, and users' ratings of support usefulness

Support Type	Response (*N*=42)	*n*	%
Cancer Support Groups	*Cancer Survivor Support Group*	5	11.9
	Stoma Support Group	2	4.8
	Men's Cancer Support Group	2	4.8
	Other Cancer Support Group	15	35.7
Other Forms of Cancer Support	*Psychotherapy/Counselling*	13	31.0
	Cancer Support Centre	9	21.4
	Mindfulness	2	4.8
	Complementary Therapy	1	2.4
	Online Cancer Support	1	2.4
	Cancer Helpline	1	2.4
	Yoga	1	2.4
	Other	4	9.5

Table 6.8 Types of cancer support services used by colorectal cancer survivors

and five used online or telephone support (2.3%). Over 10% accessed a healthcare professional for support (12.7%, *n*=28), most commonly a nurse (6.8%, *n*=15).

Colorectal cancer survivors who did not attend formal cancer support services were asked to indicate the reasons they did not use such services (Table 6.10). Almost half did not require these services (47.4%, *n*=91). Others felt they had adequate support from family (17.2%, *n*=33), friends (8.9%, *n*=17), or healthcare professionals (8.3%, *n*=16). However, several described barriers to accessing support, including lack of awareness (13.5%, *n*=26), lack of local availability (2.6%, *n*=5) or lack of support specific to colorectal cancer (1.6%, *n*=3).

6.4.4 Colorectal Cancer Survivors' Information Needs

Participants were asked if it would be helpful to have received more advice or information on 10 cancer treatment and survivorship issues (Figure 6.26; Table 6.11). Survivors had an average of 2.2 unmet

Response (*N*=221)	***n***	**%**
Family	79	35.7
Friends	56	25.3
Information Leaflets	51	23.1
Internet	44	19.9
Nurse	15	6.8
Cancer Support Group or Centre	12	5.4
Cancer Information Website	10	4.5
Doctor	8	3.6
General Practitioner	6	2.7
Other Healthcare Professional	6	2.7
Peer Support	6	2.7
Telephone or Online Support	5	2.3
Print Media	5	2.3
Complementary or Alternative Medicine	5	2.3
Cancer Course or Conference	4	1.8
Other	23	10.4

Table 6.9 Other sources of support used by colorectal cancer survivors

Response (*N*=192)	***n***	**%**
Support from Family	33	17.2
Unaware/Uninformed of Support Services	26	13.5
Support from Friends	17	8.9
Support from Healthcare Professionals	16	8.3
Coping Sufficiently	11	5.7
Positive Treatment Outcome	10	5.2
Independence	9	4.7
Distance/Lack of Local Availability	5	2.6
Felt Adequately Informed	5	2.6
Concerns About Privacy	5	2.6
Lack of Colorectal Cancer-Specific Support Group	3	1.6
No Reason/Not Required	98	51.0
Other	47	24.5

Table 6.10 Reasons cited by colorectal cancer survivors for not attending formal cancer support groups or services

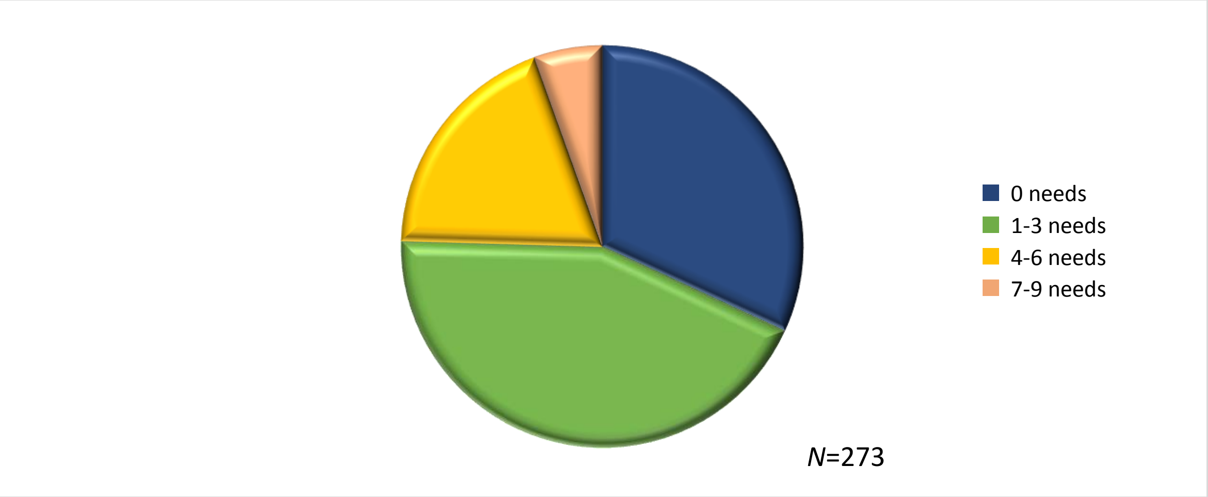


Figure 6.26 Pie chart illustrating the number of information needs expressed by colorectal cancer survivors

Response (*N*=273)	*n*	%
Diet and Lifestyle	99	36.3
Physical Aspects of Living with or After Cancer	82	30.0
Information about Family Members Risk of Cancer	74	27.1
Physical Activity and Exercise	71	26.0
Psychological/Emotional Aspects of Living with or After Cancer	68	24.9
Medical Card Entitlements	58	21.2
Financial Help or Benefits	57	20.9
Information/Advice for Family/Friends/Carer	41	15.0
Returning to or Staying in Work	23	8.5
Other	28	10.3

Table 6.11 Information needs reported by colorectal cancer survivors

information needs (*SD*=2.2). Diet and lifestyle was the most commonly reported information need (36.3%, *n*=99), followed by information about the physical effects of cancer (30%, *n*=82) and information about family members' cancer risk (27.1%, *n*=74; Table 6.11).

6.5 Inferential Analysis of Factors Influencing Colorectal Cancer Survivors' Quality of Life

This section presents the results of the statistical analysis of demographic, cancer-related and healthcare-related differences between colorectal cancer survivors to inform a multivariate logistic regression model. As already discussed, the FACT-C score was transformed using a reflect and square root transformation procedure to achieve a more normal distribution of the data. Consequently, lower scores on the transformed scale represent more positive quality of life ratings, while higher scores on the original scale represent more positive quality of life scores. The transformed FACT-C data met the requirements for parametric testing (Section 6.2). For comparison and transparency, the results of nonparametric tests on the original FACT-C data are presented within the relevant tables of this section. The FACT-C subscale data (PWB, SWB, EWB, FWB, CCS) continued to violate the assumptions underpinning parametric statistical tests following transformation. Therefore, the results of nonparametric tests on the original subscale data are interpreted in the relevant discussions, and the results of corresponding parametric tests on the original FACT-C subscale data are presented in the relevant tables to facilitate comparison. While multiple parametric comparisons may increase the risk of a false positive (Type I error), they are necessary in exploratory research with insufficient empirical evidence to guide statistical model building strategies (Thayer 2002).

6.5.1 Inferential Analysis Techniques and Assumptions

The variance in colorectal cancer survivors' quality of life scores for socio-demographic, cancer-related and healthcare experience items were established using Mann-Whitney *U* Test and Kruskal-Wallis *H* Test (χ^2) for nonparametric analysis, and independent samples *t*-tests and one-way analysis of variance (ANOVA) (*F*) for parametric analysis (Table 6.12; Figure 6.27). For parametric tests where the

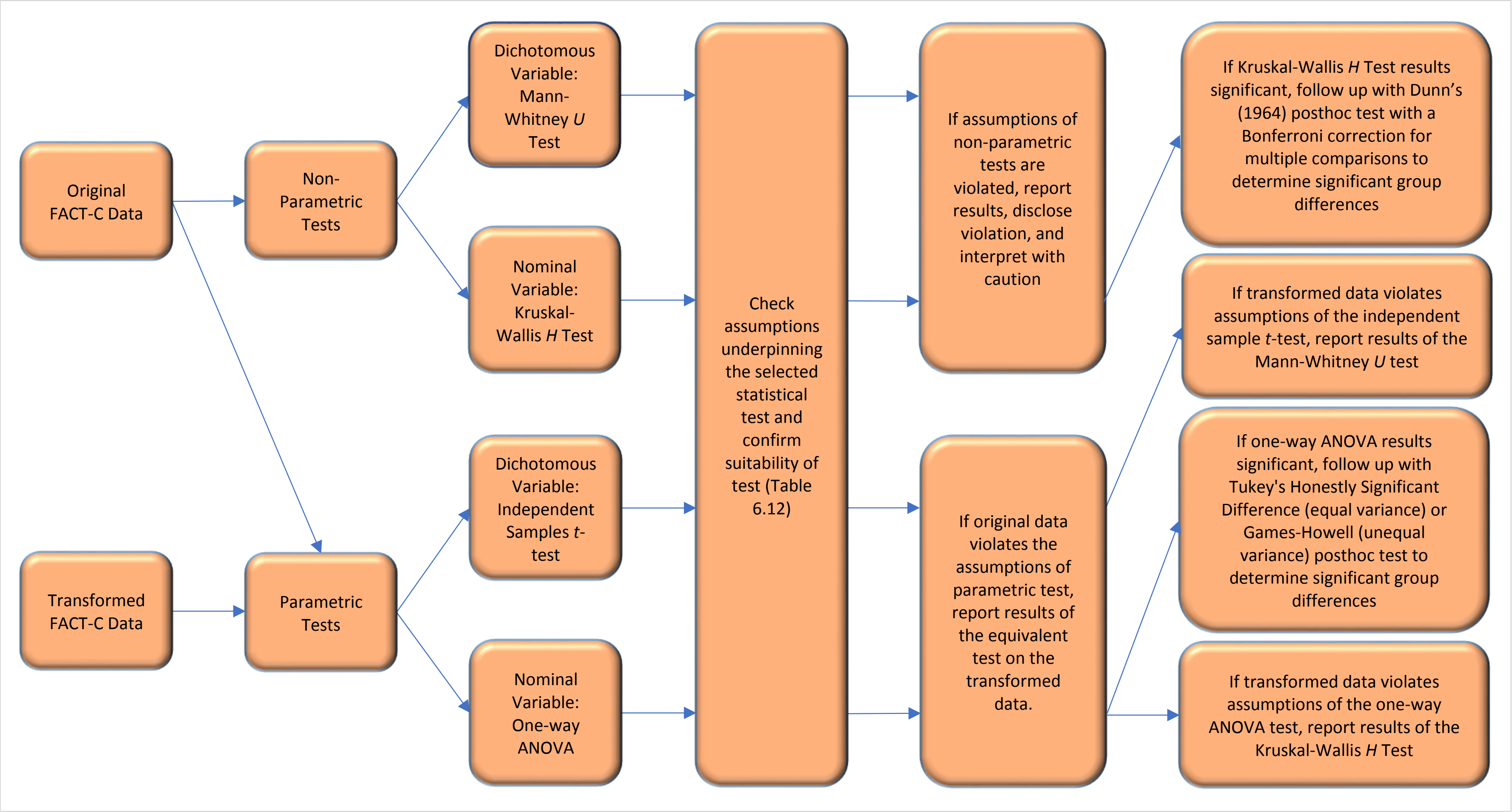


Figure 6.27 Algorithm for statistical test selection and reporting decisions

assumption of homogeneity of variances was violated, the results of the Welch *t*-test and Welch ANOVA are reported with corrected degrees of freedom. The instances where this has occurred are highlighted in the relevant tables.

Parametric Tests		**Nonparametric Tests**	
Independent Samples *t*-test (*t*)	**One-way ANOVA (*F*)**	**Mann-Whitney *U* Test**	**Kruskal Wallis *H* test (χ^2)**
Dichotomous independent variable	Nominal independent variable with two or more groups	Dichotomous independent variable	Nominal independent variable with two or more groups
• A single continuous dependent variable • Independence of observations • No significant outliers in the dependent variable for any level of the independent variable • Dependent variable approximately normally distributed within each group of the independent variable • Variance of dependent variable equal between each group of the independent variable		• A single continuous or ordinal dependent variable • Independence of observations • Similar distribution of dependent variable scores within each group of the independent variable	

Table 6.12 Assumptions underpinning parametric and nonparametric statistical tests (Pallant 2013, Tabachnick & Fidell 2013)

Posthoc testing was undertaken to determine specific group differences where a statistically significant difference between groups was identified by one-way ANOVA or Kruskal-Wallis *H* tests. The *p*-value arising from posthoc tests is presented in all cases where significant differences were identified; the magnitude of differences between groups may be discerned from the related tables referenced throughout the section. Posthoc tests for significant one-way ANOVA results were conducted using Tukey's Honestly Significant Difference where between-group variance was equal for the dependent variable. Where the assumption of equal variance was violated, Games-Howell posthoc test results are presented. Posthoc testing for significant results of Kruskal Wallis H tests was undertaken using Dunn's (1964) procedure, with a Bonferroni correction for multiple comparisons to control for type I error. Within all multiple comparison posthoc tests, the *p*-value was adjusted to control for type I error. The adjusted *p*-value is presented at a significance level of $p \leq 0.05$.

Pearson's product-moment correlations and Spearman's rank-order correlations were calculated to identify the relationships between overall quality of life (FACT-C, PWB, SWB, EWB, FWB and CCS) and 1) social difficulties (SD-16, EDL, MM, SO), 2) continuity of care (CC-18, Information Transfer, Relationships with Healthcare Providers, Management of Forms, Management of Follow-up, Management of Communication Among Providers), and 3) level of unmet information need. Parametric correlation testing assumes a linear relationship between independent and dependent variables, no outliers in each variable and bivariate normality. In cases where these assumptions were not met, the results of Spearman's rank-order correlations are reported. The relationship between FACT-C subscale scores and the subscales of SDI and PCCQ questionnaires were only assessed in cases where strong correlations (r_s≥0.70) were identified between SD-16/CC-18 scores and FACT-C subscale scores.

6.5.2 Socio-Demographic Variables and Quality of Life

6.5.2.1 FACT-C Scale

The transformed FACT-C data did not violate the assumptions underpinning parametric tests. Therefore, these results are presented throughout the discussion in this subsection. The results of nonparametric tests on the original FACT-C data are presented alongside parametric tests performed on the transformed results in all tables for comparison. The primary socio-demographic variables demonstrating differences in quality of life scores were age (*p*≤0.0005), current employment status (*p*≤0.0005), pre-cancer employment status (*p*=0.015), change in employment status between diagnosis and survey participation (*p*=0.037), and the type of hospital attended (*p*≤0.0005; Table 6.13). Those who had private health insurance had more positive quality of life scores than those who did not (*p*=0.042). Survivors who reported one or more co-morbid conditions reported poorer quality of life scores than those who did not have co-morbid conditions (*p*=0.006). No differences were identified between groups based on gender (*male*/*female*; *p*=0.051), living arrangements (*with family or friends*/*alone*; *p*=0.581) or area of residence (*urban*/*rural*; *p*=0.370; Table 6.14).

Tukey's Honestly Significant Difference posthoc tests revealed older colorectal cancer survivors (≥75 years) reported more positive quality of life scores than those under the age of 55 years (*p*=0.001), and those aged 55-64 years (*p*=0.001). Survivors who were unable to engage with the workforce at the time of the study reported poorer FACT-C scores than those who were employed at the time of the study (*p*=0.001) and those who disengaged from the workforce due to retirement, study or work in the home (*p*≤0.0005). Survivors who had disengaged from the workforce before diagnosis due to retirement, work in the home or study reported more positive FACT-C scores than their counterparts who were unable to engage with the workforce before diagnosis (*p*=0.035). Those who became disengaged with the labour force between the time of their diagnosis and the time of the study reported poorer quality of life scores than those who were not engaged in employment at the time of diagnosis by choice and those who remained employed at the time of the survey (*p*=0.033). Those who attended follow-up care in regional hospitals indicated poorer average quality of life scores than those attending a private hospital (*p*=0.013) or cancer centre of excellence (*p*=0.001).

6.5.2.2 FACT-C Subscales

The FACT-C subscales evaluate colorectal cancer survivors' well-being in physical (PWB), social (SWB), emotional (EWB), functional (FWB) and colorectal cancer (CCS) domains. Higher scores on each subscale indicate more positive well-being and fewer concerns within the domain. When comparing the results of parametric and nonparametric tests for each independent variable, deviation in the significance of results arose for some independent variable groups on PWB (*Living Arrangements*), EWB (*Gender, Hospital Type, Current Employment, Pre-Cancer Employment* and *Change in Employment*), FWB (*Co-Morbid Conditions*), and CCS (*Co-Morbid Conditions*) subscales. In all cases, the results of nonparametric tests are interpreted throughout this section due to the violation of assumptions underpinning the parametric tests.

Significant differences were identified between age groups on physical (p=0.003), social (p=0.009), emotional (p≤0.0005) and colorectal cancer (p=0.013) subscales (Table 6.15). The oldest group (≥75 years) reported significantly better physical (p=0.011), social (p=0.008) and emotional (p≤0.0005) well-being compared to those under 54 years. Furthermore, survivors aged over 75 years reported higher median scores than those in the 55-64 years group for physical (p=0.026) and emotional (p=0.010) well-being. The 55-64 years group had significantly better emotional well-being than those under 54 years (p=0.009). However, the 55-64 years group reported poorer colorectal cancer subscale scores than the 65-74 years group (p=0.034; Table 6.15). Female gender was associated with poorer median scores on the emotional (p=0.001) and colorectal cancer subscales (p=0.001; Table 6.16). Colorectal cancer survivors living with a co-morbid condition reported consistently lower emotional (p=0.016), functional (p=0.021) and colorectal cancer subscale scores (p=0.013; Table 6.17).

Employment status at the time of the study was associated with discrepancies in physical (p=0.008), social (p≤0.0005), emotional (p=0.010) and functional (p=0.001) well-being (Table 6.18). Survivors who were unable to work at the time of the study reported significantly poorer physical (p=0.044), social (p≤0.0005), emotional (p=0.034) and functional (p=0.001) well-being than those who were engaged in the workforce. Furthermore, those who were unable to work at the time of the survey also reported significantly poorer physical (p=0.005), social (p≤0.0005), emotional (p=0.007) and functional quality of life (p≤0.0005).

Likewise, employment status at diagnosis influenced colorectal cancer survivors' quality of life. Pre-diagnosis employment status was associated with significant differences in social (p=0.016) and emotional well-being (p=0.019; Table 6.19). However, adjusted pairwise comparisons revealed no difference between groups based on pre-diagnosis employment status on either scale. A change in colorectal cancer survivors' employment status between diagnosis and the survey was associated with differences in emotional well-being (p=0.016; Table 6.20). Those who became disengaged from the labour force between diagnosis and the survey reported poorer emotional quality of life compared to their counterparts who were disengaged at the time of diagnosis and remained so (p=0.012).

Colorectal cancer survivors with private health insurance achieved more positive social (p=0.024) and functional well-being (p=0.012) compared to those with no insurance or a medical card (Table 6.21). Similarly, the type of hospital attended for follow-up care was associated with differences on physical (p≤0.0005), emotional (p=0.025), functional (p=0.005) and colorectal cancer (p=0.004) subscales (Table 6.22). Compared to survivors attending a regional hospital, those attending a cancer centre of

Variable	**Groups**	***n***	**Original FACT-C Data**						**Transformed FACT-C Data**				
			Mean[a]	***SD***	**Median**[a]	**Kruskal-Wallis *H* Test**			**Mean**[b]	**SD**	**One-Way ANOVA**		
						df	χ^2	***p***			***df***	***F***	***p***
Age Groups (Years)	*0-54*	33	106.07	18.55	109.00	3	17.70	0.001*	5.30	1.72	3, 234	6.81	0.000*
	55-64	51	107.31	20.84	115.60				5.10	1.93			
	65-74	107	114.13	17.19	117.17				4.45	1.77			
	> 75	47	120.26	12.61	124.00				3.77	1.61			
	Total	238	112.76	18.05	116.60				4.57	1.83			
Current Employment Status	*Engaged with Labour Force*	61	114.63	12.99	116.67	2	21.77	0.000*	4.52	1.40	2, 53.8	11.18[1]	0.000*
	Not Engaged with Labour Force by Choice	157	114.18	18.62	119.00				4.39	1.89			
	Unable to Engage with Labour Force	21	94.43	17.87	92.60				6.30	1.73			
	Total	239	112.56	18.12	116.60				4.59	1.84			
Pre-Diagnosis Employment Status	*Engaged with Labour Force*	95	111.19	16.38	113.00	2	10.00	0.007*	4.82	1.63	2, 238	4.30	0.015*
	Not Engaged with Labour Force by Choice	134	114.57	18.76	119.50				4.34	1.91			
	Unable to Engage with Labour Force	12	100.93	18.61	95.50				5.70	1.99			
	Total	241	112.56	18.05	116.33				4.59	1.83			
Change in Employment Status	*Remained/Became Engaged with Labour Force*	61	114.63	12.99	116.67	2	6.88	0.032*	4.52	1.40	2, 98.1	3.41[1]	0.037*
	Remained Disengaged with Labour Force	139	113.52	19.41	118.80				4.43	1.98			
	Became Disengaged with Labour Force	39	105.89	19.14	108.00				5.29	1.81			
	Total	239	112.56	18.12	116.60				4.59	1.84			
Hospital Type	*Centre of Excellence*	136	115.36	16.44	119.50	2	16.51	0.000*	4.31	1.75	2, 238	8.03	0.000*
	Private	22	117.82	19.12	124.30				4.00	1.83			
	Regional	83	106.49	18.94	109.00				5.22	1.82			
	Total	241	112.53	18.07	116.33				4.60	1.83			

[a] Higher scores indicate better quality of life on the original FACT-C scale; [b] Lower scores indicate better quality of life on the transformed FACT-C scale;
[1] Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.13 Results of Kruskal-Wallis H Tests and one-way ANOVA tests on the original and transformed Functional Assessment of Cancer Therapy-Colorectal (FACT-C) data to identify socio-demographic factors associated with differences in colorectal cancer survivors' FACT-C scores

Variable	Groups	*n*	Original FACT-C Data						Transformed FACT-C Data					
			Mean[a]	*SD*	Median[a]	Mann Whitney *U* Test			Mean[b]	SD	*t*-test			
						U	*Z*	*p*			95% CI	*df*	*t*	*p*
Gender	*Male*	131	114.79	16.21	118.00	6236.50	-1.575	0.115	4.36	1.81	-0.93, 0.00	237	-1.959	0.051
	Female	108	110.44	19.85	115.40				4.82	1.83				
	Total	239	112.82	18.04	116.60				4.57	1.83				
Living Arrangements	*With Spouse/Family/Friends*	196	113.03	18.22	117.00	3581.00	-0.622	0.534	4.54	1.84	-0.81, 0.45	233	-0.553	0.581
	I Live Alone	39	111.77	16.80	113.80				4.71	1.75				
	Total	235	112.82	17.97	116.60				4.57	1.83				
Residence Area	*Urban*	180	113.14	18.46	116.92	4741.50	-0.861	0.389	4.51	1.89	-0.80, 0.30	235	-0.897	0.370
	Rural	57	111.81	16.68	113.80				4.76	1.62				
	Total	237	112.82	18.02	116.60				4.57	1.83				
Insurance Status	*Private Insurance*	124	115.51	16.21	118.00	8383.50	2.217	0.027*	4.34	1.65	-0.95, -0.02	224.2	-2.048[1]	0.042*
	Medical Card/Public	116	109.89	19.39	112.25				4.82	1.98				
	Total	240	112.79	18.00	116.60				4.57	1.83				
Co-Morbid Conditions	*Yes*	181	110.50	18.65	113.80	6061.50	2.919	0.004*	4.80	1.85	0.23, 1.36	232	2.781	0.006*
	No	53	117.94	16.40	121.83				4.01	1.75				
	Total	234	112.19	18.40	116.17				4.62	1.86				

[a] Higher scores indicate better quality of life on the original FACT-C scale; [b] Lower scores indicate better quality of life on the transformed FACT-C scale;
[1] Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.14 Results of Mann-Whitney U tests and t-tests on the original and transformed Functional Assessment of Cancer Therapy-Colorectal (FACT-C) data to identify socio-demographic factors associated with differences in colorectal cancer survivors' FACT-C scores

FACT-C Subscale	Age Group	*n*	One-Way ANOVA					Kruskal-Wallis *H* test			
			Mean^a	*SD*	*df*	*F*	*p*	Median^a	*df*	χ^2	*p*
Physical Well-being (PWB)	*0-54*	33	23.15	5.12	3, 95.9	4.261^1	0.007*	25.00	3	13.900	0.003*
	55-64	54	23.73	4.85				25.83			
	65-74	111	25.11	3.74				26.00			
	> 75	52	25.85	2.74				27.00			
	Total	250	24.71	4.12				26.00			
Social Well-being (SWB)	*0-54*	35	22.60	4.43	3, 106.7	5.103^1	0.002*	23.80	3	11.641	0.009*
	55-64	57	22.46	6.48				25.00			
	65-74	114	23.80	4.69				25.00			
	> 75	56	25.33	3.39				26.30			
	Total	262	23.68	4.96				25.00			
Emotional Well-being (EWB)	*0-54*	35	18.44	3.77	3, 257	5.251	0.002*	19.00	3	22.759	0.000*
	55-64	56	19.68	3.97				20.00			
	65-74	114	20.42	3.80				21.00			
	> 75	56	21.49	3.40				23.00			
	Total	261	20.22	3.84				21.00			
Functional Well-being (FWB)	*0-54*	35	21.02	5.64	3, 263	1.136	0.335	21.00	3	3.670	0.299
	55-64	57	20.22	7.32				22.00			
	65-74	114	21.98	5.94				23.50			
	> 75	61	21.96	6.80				24.00			
	Total	267	21.47	6.42				23.00			
Colorectal Cancer Subscale (CCS)	*0-54*	35	21.16	5.02	3, 264	3.097	0.027*	22.00	3	10.773	0.013*
	55-64	57	21.00	5.00				21.00			
	65-74	114	23.03	4.49				24.00			
	> 75	62	22.73	4.97				24.50			
	Total	268	22.28	4.84				23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.15 Results of one-way ANOVA and Kruskal-Wallis H tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify age-related differences in colorectal cancer survivors' scores on each FACT-C subscale

FACT-C Subscale	Gender	*n*	*t*-test						Mann-Whitney *U* Test			
			Mean[a]	*SD*	95% CI	*df*	*t*	*p*	Median[a]	*U*	*Z*	*p*
Physical Well-being (PWB)	*Male*	139	25.04	3.77	-0.32, 1.73	249	1.354	0.177	26.00	7072.50	-1.261	0.207
	Female	112	24.33	4.49					26.00			
	Total	251	24.72	4.11					26.00			
Social Well-being (SWB)	*Male*	145	23.15	5.54	-2.20, 0.30	262	-1.498	0.135	24.50	9484.50	1.406	0.160
	Female	119	24.10	4.60					25.67			
	Total	264	23.58	5.15					25.00			
Emotional Well-being (EWB)	*Male*	148	21.00	3.04	0.85, 2.68	188.6	3.602[1]	0.490	21.50	6468.50	-3.270	0.001*
	Female	114	19.24	4.50					20.00			
	Total	262	20.23	3.84					21.00			
Functional Well-being (FWB)	*Male*	150	21.79	6.54	-0.73, 2.42	267	1.057	0.291	23.00	8002.50	-1.462	0.144
	Female	119	20.95	6.51					23.00			
	Total	269	21.42	6.53					23.00			
Colorectal Cancer Subscale (CCS)	*Male*	151	23.07	4.64	0.68, 3.01	268	3.116	0.002*	24.00	6881.00	-3.312	0.001*
	Female	119	21.22	5.07					22.00			
	Total	270	22.25	4.91					23.00			

[a] Higher scores indicate better quality of life on the original FACT-C subscale; [1] Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.16 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify gender-related differences in colorectal cancer survivors' scores on each FACT-C subscale

FACT-C Subscale	Co-Morbid Condition	*n*	*t*-test						Mann-Whitney *U*			
			Mean[a]	*SD*	95% CI	*df*	*t*	*p*	Median[a]	*U*	*Z*	*p*
Physical Well-being (PWB)	*Yes*	188	24.44	4.28	-2.15, 0.38	242	-1.372	0.171	26.00	6129.50	1.892	0.059
	No	56	25.32	4.01					26.50			
	Total	244	24.64	4.23					26.00			
Social Well-being (SWB)	*Yes*	202	23.22	5.36	-2.31, 0.89	256	-0.872	0.384	24.50	6389.00	1.501	0.133
	No	56	23.93	5.47					26.00			
	Total	258	23.38	5.38					25.00			
Emotional Well-being (EWB)	*Yes*	199	19.93	3.97	-2.32, -0.04	254	-2.036	0.043*	20.00	6846.00	2.408	0.016*
	No	57	21.11	3.43					22.00			
	Total	256	20.19	3.88					21.00			
Functional Well-being (FWB)	*Yes*	204	20.75	6.59	-3.75, 0.11	260	-1.855	0.065	22.00	7090.00	2.315	0.021*
	No	58	22.57	6.58					25.00			
	Total	262	21.15	6.62					23.00			
Colorectal Cancer Subscale (CCS)	*Yes*	206	21.90	4.84	-2.65, 0.23	261	-1.652	0.100	23.00	6011.50	2.492	0.013*
	No	57	23.11	5.10					25.00			
	Total	263	22.16	4.91					23.00			

[a]Higher scores indicate better quality of life on the original FACT-C scale; [1]Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.17 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' co-morbid conditions

FACT-C Subscale	Current Employment Status	*n*	One-Way ANOVA					Kruskal-Wallis *H* test			
			Mean^a	SD	*df*	*F*	*p*	Median^a	*df*	χ^2	*p*
Physical Well-being (PWB)	*Engaged with Labour Force*	64	24.96	3.79	2, 51.1	3.752^1	0.030*	26.00	2	9.758	0.008*
	Not Engaged with Labour Force by Choice	164	25.01	3.89				26.30			
	Unable to Engage with Labour Force	22	21.73	5.44				22.00			
	Total	250	24.71	4.11				26.00			
Social Well-being (SWB)	*Engaged with Labour Force*	69	23.96	3.76	2, 53.6	9.979^1	0.000*	25.00	2	26.098	0.000*
	Not Engaged with Labour Force by Choice	173	24.17	4.74				25.67			
	Unable to Engage with Labour Force	23	16.37	8.15				18.20			
	Total	265	23.44	5.35				25.00			
Emotional Well-being (EWB)	*Engaged with Labour Force*	69	20.54	3.08	2, 259	2.462	0.087	20.00	2	9.185	0.010*
	Not Engaged with Labour Force by Choice	171	20.32	4.14				21.00			
	Unable to Engage with Labour Force	22	18.53	3.26				18.50			
	Total	262	20.23	3.84				21.00			
Functional Well-being (FWB)	*Engaged with Labour Force*	69	22.43	6.16	2, 266	6.070	0.003*	24.50	2	15.086	0.001*
	Not Engaged with Labour Force by Choice	177	21.40	6.60				23.00			
	Unable to Engage with Labour Force	23	17.09	5.39				17.00			
	Total	269	21.30	6.52				23.00			
Colorectal Cancer Subscale (CCS)	*Engaged with Labour Force*	68	22.06	4.19	2, 61.0	1.074^1	0.348	23.00	2	5.008	0.082
	Not Engaged with Labour Force by Choice	179	22.43	5.18				24.00			
	Unable to Engage with Labour Force	23	21.05	4.15				21.00			
	Total	270	22.22	4.87				23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.18 Results of one-way ANOVA and Kruskal-Wallis H tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' current employment status

FACT-C Subscale	Pre-Diagnosis Employment Status	*n*	One-Way ANOVA					Kruskal-Wallis *H* test			
			Mean[a]	SD	*df*	*F*	*p*	Median[a]	*df*	χ^2	*p*
Physical Well-being (PWB)	*Engaged with Labour Force*	101	24.40	4.14	2, 249	1.043	0.354	25.00	2	2.558	0.278
	Not Engaged with Labour Force by Choice	139	25.03	3.92				26.00			
	Unable to Engage with Labour Force	12	23.75	5.64				26.00			
	Total	252	24.72	4.10				26.00			
Social Well-being (SWB)	*Engaged with Labour Force*	107	23.09	5.09	2, 28.4	3.586[1]	0.041*	24.00	2	8.315	0.016*
	Not Engaged with Labour Force by Choice	148	24.21	4.58				25.67			
	Unable to Engage with Labour Force	12	17.60	10.57				21.50			
	Total	267	23.46	5.34				25.00			
Emotional Well-being (EWB)	*Engaged with Labour Force*	106	20.07	3.21	2, 32.9	1.527[1]	0.232	20.00	2	7.898	0.019*
	Not Engaged with Labour Force by Choice	145	20.47	4.19				22.00			
	Unable to Engage with Labour Force	13	18.45	4.11				19.00			
	Total	264	20.21	3.84				21.00			
Functional Well-being (FWB)	*Engaged with Labour Force*	106	21.81	6.11	2, 268	1.934	0.147	23.00	2	4.212	0.122
	Not Engaged with Labour Force by Choice	152	21.25	6.75				23.00			
	Unable to Engage with Labour Force	13	18.08	6.30				17.00			
	Total	271	21.32	6.51				23.00			
Colorectal Cancer Subscale (CCS)	*Engaged with Labour Force*	106	21.63	4.55	2, 269	1.284	0.279	22.00	2	5.648	0.059
	Not Engaged with Labour Force by Choice	153	22.61	5.13				24.00			
	Unable to Engage with Labour Force	13	21.92	4.50				22.00			
	Total	272	22.20	4.89				23.00			

[a]Higher scores indicate better quality of life on the original FACT-C subscale; [1]Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.19 Results of one-way ANOVA and Kruskal-Wallis H tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' employment status before diagnosis

FACT-C Subscale	Change in Employment Status	*n*	One-Way ANOVA					Kruskal-Wallis *H* test			
			Mean^a	SD	*df*	*F*	*p*	Median^a	*df*	χ^2	*p*
Physical Well-being (PWB)	*Remained/Became Engaged with Labour Force*	64	24.96	3.79	2, 247	1.714	0.182	26.00	2	5.598	0.061
	Remained Disengaged with Labour Force	144	24.94	4.15				26.72			
	Became Disengaged from the Labour Force	42	23.54	4.34				24.00			
	Total	250	24.71	4.11				26.00			
Social Well-being (SWB)	*Remained/Became Engaged with Labour Force*	69	23.96	3.76	2, 103.1	1.921^1	0.152	25.00	2	3.475	0.176
	Remained Disengaged with Labour Force	153	23.65	5.57				25.20			
	Became Disengaged from the Labour Force	43	21.84	6.42				23.33			
	Total	265	23.44	5.35				25.00			
Emotional Well-being (EWB)	*Remained/Became Engaged with Labour Force*	69	20.54	3.08	2, 259	2.443	0.089	20.00	2	8.317	0.016*
	Remained Disengaged with Labour Force	150	20.42	4.15				22.00			
	Became Disengaged from the Labour Force	43	19.06	3.68				20.00			
	Total	262	20.23	3.84				21.00			
Functional Well-being (FWB)	*Remained/Became Engaged with Labour Force*	69	22.43	6.16	2, 266	1.523	0.220	24.50	2	3.624	0.163
	Remained Disengaged with Labour Force	157	21.02	6.78				23.00			
	Became Disengaged from the Labour Force	43	20.49	6.02				22.00			
	Total	269	21.30	6.52				23.00			
Colorectal Cancer Subscale (CCS)	*Remained/Became Engaged with Labour Force*	68	22.06	4.19	2, 267	1.869	0.156	23.00	2	5.260	0.072
	Remained Disengaged with Labour Force	158	22.62	5.02				24.00			
	Became Disengaged from the Labour Force	44	21.04	5.17				21.00			
	Total	270	22.22	4.87				23.00			

[a]Higher scores indicate better quality of life on the original FACT-C subscale; [1]Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.20 Results of one-way ANOVA and Kruskal-Wallis H tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to a change in survivors' employment status between diagnosis and the time of the study

FACT-C Subscale	Type of Health Insurance	*n*	t-test						Mann-Whitney *U*			
			Mean^a	*SD*	95% CI	*df*	*t*	*p*	Median^a	*U*	*Z*	*p*
Physical Well-being (PWB)	*Private Insurance*	126	24.93	4.09	-0.62, 1.42	250	0.765	0.445	26.00	7513.50	-0.744	0.457
	Medical Card/Public	126	24.53	4.14					26.00			
	Total	252	24.73	4.11					26.00			
Social/Family Well-being (SWB)	*Private Insurance*	133	24.57	3.74	0.76, 3.22	217.2	3.200^1	0.002*	25.67	7392.00	-2.250	0.024*
	Medical Card/Public	132	22.57	6.10					24.00			
	Total	265	23.57	5.14					25.00			
Emotional Well-being (EWB)	*Private Insurance*	130	20.55	3.57	-0.32, 1.54	261	1.302	0.194	21.00	7925.50	-1.179	0.238
	Medical Card/Public	133	19.94	4.07					20.00			
	Total	263	20.24	3.83					21.00			
Functional Well-being (FWB)	*Private Insurance*	134	22.68	5.35	1.02, 4.09	247.6	3.286^1	0.001*	24.00	7505.00	-2.516	0.012*
	Medical Card/Public	136	20.13	7.30					21.00			
	Total	270	21.40	6.52					23.00			
Colorectal Cancer Subscale (CCS)	*Private Insurance*	134	22.65	4.79	-0.36, 1.98	269	1.357	0.176	23.50	8279.50	-1.398	0.162
	Medical Card/Public	137	21.84	5.01					23.00			
	Total	271	22.24	4.91					23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.21 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify health insurance-related differences in colorectal cancer survivors' scores on each FACT-C subscale

FACT-C Subscale	Hospital Type	*n*	One-Way ANOVA					Kruskal-Wallis *H* test			
			Mean^a	SD	*df*	*F*	*p*	Median^a	*df*	χ^2	*p*
Physical Well-being (PWB)	*Centre of Excellence*	146	25.59	2.94	2, 50.7	8.302^1	0.001*	26.42	2	16.470	0.000*
	Private	22	24.98	5.18				27.00			
	Regional	85	23.15	5.00				25.00			
	Total	253	24.72	4.10				26.00			
Social/Family Well-being (SWB)	*Centre of Excellence*	151	23.59	5.51	2, 264	1.473	0.231	25.20	2	3.335	0.189
	Private	22	24.90	3.22				25.67			
	Regional	94	22.84	5.43				24.00			
	Total	267	23.43	5.34				25.00			
Emotional Well-being (EWB)	*Centre of Excellence*	147	20.47	3.54	2, 262	2.209	0.112	21.00	2	7.395	0.025*
	Private	22	21.02	4.68				22.00			
	Regional	96	19.57	3.98				20.00			
	Total	265	20.19	3.82				21.00			
Functional Well-being (FWB)	*Centre of Excellence*	154	22.03	6.26	2, 269	4.828	0.009*	24.00	2	10.801	0.005*
	Private	22	23.23	5.95				25.33			
	Regional	96	19.74	6.78				21.00			
	Total	272	21.32	6.52				23.00			
Colorectal Cancer Subscale (CCS)	*Centre of Excellence*	154	22.72	4.72	2, 270	4.288	0.015*	24.00	2	10.832	0.004*
	Private	22	23.68	5.18				26.00			
	Regional	97	21.14	4.88				21.00			
	Total	273	22.24	4.88				23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.22 Results of one-way ANOVA and Kruskal-Wallis H tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to the type of hospital attended by the survivor for follow-up

Variable	**Groups**	***n***	**Original FACT-C Data**						**Transformed FACT-C Data**				
			Mean^{a}	**SD**	**Median^{a}**	**Kruskal-Wallis *H* Test**			**Mean^{b}**	**SD**	**One-Way ANOVA**		
						df	**χ^2**	***p***			***df***	***F***	***p***
Diagnosis	*Colon*	160	113.22	17.49	116.63	2	1.46	0.481	4.53	1.82	2, 245	1.00	0.370
	Rectum	59	111.39	19.65	116.60				4.70	1.88			
	Other	29	107.17	23.18	108.67				5.04	2.13			
	Total	248	112.08	18.77	116.47				4.63	1.87			
Time Since Diagnosis	*< 1 year*	38	108.68	22.04	115.72	4	1.42	0.841	4.91	2.09	4, 226	0.53	0.714
	1-2 years	56	114.15	17.85	117.10				4.36	1.99			
	2-3 years	48	112.22	17.06	115.83				4.71	1.63			
	3-4 years	37	113.85	13.50	118.00				4.60	1.43			
	4-5 years	52	111.16	21.47	118.90				4.66	2.06			
	Total	231	112.13	18.66	116.60				4.63	1.87			
Number of Past Treatment	*1*	92	114.62	16.60	118.40	2	3.97	0.137	4.37	1.82	2, 237	2.67	0.072
	2	97	111.12	18.68	115.60				4.76	1.81			
	≥3	51	107.07	22.06	111.00				5.10	2.00			
	Total	240	111.60	18.84	115.92				4.68	1.87			
Disease Status	*In Remission*	194	114.40	16.82	118.00	2	18.68	0.000*	4.41	1.77	2, 229	11.31	0.000*
	Active Disease	20	94.28	20.74	97.92				6.33	1.66			
	Uncertain	18	104.39	26.21	112.00				5.25	2.31			
	Total	232	111.89	18.94	116.47				4.64	1.89			
Stoma	*Still Present*	42	112.16	14.30	113.67	2	4.03	0.133	4.76	1.51	2, 114.4	1.29^{1}	0.279
	Reversed	64	110.22	16.53	113.17				4.93	1.60			
	Not Applicable	133	112.43	21.24	119.33				4.50	2.09			
	Total	239	111.79	18.94	116.00				4.66	1.88			

^{a}Higher scores indicate better quality of life on the original FACT-C scale; ^{b}Lower scores indicate better quality of life on the transformed FACT-C scale;
^{1}Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.23 Results of Kruskal-Wallis H tests and one-way ANOVA tests on the original and transformed Functional Assessment of Cancer Therapy-Colorectal (FACT-C) data to identify cancer-related factors associated with differences in colorectal cancer survivors' FACT-C scores

Variable	Groups	*n*	Original FACT-C Data						Transformed FACT-C Data					
			Mean^{a}	*SD*	Median^{a}	Mann Whitney *U* Test			Mean^{b}	SD	*t*-test			
						U	*Z*	*p*			95% CI	*df*	*t*	*p*
Radiotherapy	*No Radiotherapy*	191	113.53	17.16	116.83	4563.00	-1.853	0.064	4.50	1.80	-1.17, -0.68	246	-2.210	0.028*
	Radiotherapy	57	106.79	22.72	111.33				5.12	2.02				
	Total	248	111.98	18.75	116.17				4.64	1.87				
Chemotherapy	*No Chemotherapy*	97	115.78	16.44	120.00	5957.50	-2.478	0.013*	4.24	1.80	-1.12, -0.18	246	-2.710	0.007*
	Chemotherapy	151	109.54	19.76	113.00				4.90	1.87				
	Total	248	111.98	18.75	116.17				4.64	1.87				
Surgery	*No Surgery*	22	109.93	20.73	116.47	2592.50	0.332	0.740	4.81	2.04	-0.64, 1.00	246	0.433	0.666
	Surgery	226	112.18	18.58	116.00				4.62	1.86				
	Total	248	111.98	18.75	116.17				4.64	1.87				
Current Treatment	*Any Current Treatment*	27	96.06	19.73	98.00	4532.50	4.695	0.000*	6.19	1.67	1.02, 2.44	241	4.780	0.000*
	No Current Treatment	243	111.98	18.58	116.00				4.65	1.85				
	Total	216	113.97	17.48	118.00				4.46	1.79				

[a]Higher scores indicate better quality of life on the original FACT-C scale; [b]Lower scores indicate better quality of life on the transformed FACT-C scale;
[1]Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.24 Results of Mann-Whitney U tests and t-tests on the original and transformed Functional Assessment of Cancer Therapy-Colorectal (FACT-C) data to identify treatment-related factors associated with differences in colorectal cancer survivors' FACT-C scores

FACT-C Subscale	Disease Status	*n*	One-Way ANOVA					Kruskal-Wallis *H* test			
			Mean[a]	SD	*df*	*F*	*p*	Median[a]	*df*	χ^2	*p*
Physical Well-being (PWB)	*In Remission*	204	25.22	3.60	2, 25.4	8.566[1]	0.001*	26.00	2	23.653	0.000*
	Active Disease	20	19.60	6.31				21.50			
	Uncertain	18	22.95	5.92				25.50			
	Total	242	24.59	4.37				26.00			
Social/Family Well-being (SWB)	*In Remission*	214	23.61	5.36	2, 251	1.168	0.313	25.43	2	4.930	0.085
	Active Disease	21	21.77	4.99				22.40			
	Uncertain	19	23.45	4.25				24.00			
	Total	254	23.45	5.26				25.00			
Emotional Well-being (EWB)	*In Remission*	213	20.55	3.39	2, 27.7	4.973[1]	0.014*	21.00	2	9.405	0.009*
	Active Disease	21	17.33	5.49				18.00			
	Uncertain	20	18.00	5.99				20.00			
	Total	254	20.09	3.98				21.00			
Functional Well-being (FWB)	*In Remission*	217	21.79	6.34	2, 256	4.538	0.012*	23.00	2	10.146	0.006*
	Active Disease	21	17.98	5.86				17.00			
	Uncertain	21	19.18	7.92				21.00			
	Total	259	21.27	6.53				23.00			
Colorectal Cancer Subscale (CCS)	*In Remission*	218	22.59	4.55	2, 29.3	5.139[1]	0.012*	23.00	2	9.380	0.009*
	Active Disease	21	18.38	6.31				20.00			
	Uncertain	21	20.63	6.22				20.00			
	Total	260	22.09	4.99				23.00			

[a] Higher scores indicate better quality of life on the original FACT-C subscale; [1] Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.25 Results of one-way ANOVA and Kruskal-Wallis H tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' current disease status

FACT-C Subscale	Radiotherapy	*n*	*t*-test						Mann-Whitney *U*			
			Mean^{a}	*SD*	95% CI	*df*	*t*	*p*	Median^{a}	*U*	*Z*	*p*
Physical Well-being (PWB)	*No Radiotherapy*	199	24.94	3.86	0.20, 3.18	80.6	2.252^{1}	0.027*	26.00	5153.50	-1.981	0.048*
	Radiotherapy	62	23.26	5.49					25.00			
	Total	261	24.54	4.35					26.00			
Social Well-being (SWB)	*No Radiotherapy*	209	23.68	5.32	-0.29, 2.66	273	1.585	0.114	25.67	5720.50	-2.114	0.034*
	Radiotherapy	66	22.49	5.21					24.00			
	Total	275	23.39	5.31					25.00			
Emotional Well-being (EWB)	*No Radiotherapy*	206	20.13	3.75	-0.93, 1.26	270	0.297	0.767	20.00	6990.50	0.350	0.727
	Radiotherapy	66	19.96	4.48					21.00			
	Total	272	20.09	3.93					20.70			
Functional Well-being (FWB)	*No Radiotherapy*	212	21.66	6.27	0.32, 3.93	277	2.322	0.021*	23.00	5883.00	-2.126	0.033*
	Radiotherapy	67	19.54	7.34					21.00			
	Total	279	21.15	6.59					23.00			
Colorectal Cancer Subscale (CCS)	*No Radiotherapy*	212	22.45	4.78	0.30, 3.02	277	2.404	0.017*	24.00	5752.00	-2.351	0.019*
	Radiotherapy	67	20.79	5.39					21.00			
	Total	279	22.05	4.97					23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch *t*-test reported where homogeneity of variance was violated; **p*≤0.05

Table 6.26 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' history of treatment with radiotherapy

FACT-C Subscale	Chemotherapy	*n*	*t*-test						Mann-Whitney *U*			
			Mean[a]	*SD*	95% CI	*df*	*t*	*p*	Median[a]	*U*	*Z*	*p*
Physical Well-being (PWB)	*No Chemotherapy*	103	25.90	2.73	1.31, 3.19	252.9	4.716[1]	0.000*	27.00	5634.50	-4.251	0.000*
	Chemotherapy	158	23.66	4.95					25.00			
	Total	261	24.54	4.35					26.00			
Social Well-being (SWB)	*No Chemotherapy*	111	23.50	5.92	-1.12, 1.46	273	0.262	0.794	25.67	8367.00	-1.150	0.250
	Chemotherapy	164	23.32	4.87					24.50			
	Total	275	23.39	5.31					25.00			
Emotional Well-being (EWB)	*No Chemotherapy*	112	20.54	3.46	-0.18, 1.72	270	1.586	0.114	21.00	8130.00	-1.313	0.189
	Chemotherapy	160	19.77	4.21					20.00			
	Total	272	20.09	3.93					20.70			
Functional Well-being (FWB)	*No Chemotherapy*	115	21.97	6.03	-0.19, 2.96	277	1.730	0.085	23.33	8379.00	-1.591	0.112
	Chemotherapy	164	20.58	6.92					22.00			
	Total	279	21.15	6.59					23.00			
Colorectal Cancer Subscale (CCS)	*No Chemotherapy*	115	22.59	4.99	-0.27, 2.11	277	1.527	0.128	24.00	8188.50	-1.876	0.061
	Chemotherapy	164	21.67	4.94					22.00			
	Total	279	22.05	4.97					23.00			

[a]Higher scores indicate better quality of life on the original FACT-C subscale; [1]Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.27 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' history of treatment with chemotherapy

FACT-C Subscale	Number of Previous Treatments	*n*	One-Way ANOVA					Kruskal-Wallis *H* test			
			Mean^a	*SD*	*df*	*F*	*p*	Median	*df*	χ^2	*p*
Physical Well-being (PWB)	*1*	98	25.77	2.77	2, 120.8	9.298^1	0.000*	27.00	2	13.422	0.001*
	2	98	23.93	4.63				25.00			
	≥3	56	23.16	5.64				25.00			
	Total	252	24.47	4.40				26.00			
Social/Family Well-being (SWB)	*1*	105	23.43	5.55	2, 263	1.157	0.316	25.67	2	3.759	0.153
	2	103	23.75	5.23				25.20			
	≥3	58	22.43	5.17				23.33			
	Total	266	23.34	5.35				25.00			
Emotional Well-being (EWB)	*1*	104	20.28	3.54	2, 260	0.326	0.722	20.50	2	0.100	0.951
	2	102	19.90	4.09				20.70			
	≥3	57	19.83	4.49				21.00			
	Total	263	20.04	3.97				21.00			
Functional Well-being (FWB)	*1*	107	21.61	6.31	2, 267	2.698	0.069	23.00	2	4.795	0.091
	2	105	21.53	6.39				23.00			
	≥3	58	19.31	7.32				20.50			
	Total	270	21.08	6.61				22.58			
Colorectal Cancer Subscale (CCS)	*1*	108	22.37	5.19	2, 268	1.918	0.149	24.00	2	4.653	0.098
	2	105	22.19	4.51				22.40			
	≥3	58	20.86	5.31				21.00			
	Total	271	21.98	4.98				23.00			

[a] Higher scores indicate better quality of life on the original FACT-C subscale; [1] Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.28 Results of one-way ANOVA and Kruskal-Wallis H tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to the number of treatment modalities survivors had received

FACT-C Subscale	Current Treatment	*n*	*t*-test						Mann-Whitney *U*			
			Mean^{a}	*SD*	95% CI	*df*	*t*	*p*	Median^{a}	*U*	*Z*	*p*
Physical Well-being (PWB)	*Any Current Treatment*	28	19.96	5.98	-7.58, -2.89	29.6	-4.515^{1}	0.000*	21.50	5111.00	5.379	0.000*
	No Current Treatment	226	25.18	3.69					26.00			
	Total	254	24.61	4.31					26.00			
Social Well-being (SWB)	*Any Current Treatment*	29	21.77	4.88	-3.86, 0.32	266	-1.668	0.096	22.40	4376.50	2.338	0.019*
	No Current Treatment	239	23.54	5.46					25.00			
	Total	268	23.35	5.42					25.00			
Emotional Well-being (EWB)	*Any Current Treatment*	31	19.01	5.23	-3.21, 0.73	34.1	-1.280^{1}	0.209	20.00	4031.00	0.932	0.351
	No Current Treatment	236	20.25	3.71					21.00			
	Total	267	20.10	3.93					21.00			
Functional Well-being (FWB)	*Any Current Treatment*	31	17.10	7.06	-7.02, -2.29	270	-3.877	0.000*	18.00	5251.50	3.692	0.000*
	No Current Treatment	241	21.75	6.19					23.00			
	Total	272	21.22	6.45					23.00			
Colorectal Cancer Subscale (CCS)	*Any Current Treatment*	31	19.30	5.50	-5.00, -1.37	270	-3.460	0.001*	21.00	5035.50	3.162	0.002*
	No Current Treatment	241	22.48	4.74					23.00			
	Total	272	22.12	4.92					23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.29 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' current treatment with chemotherapy, radiotherapy or surgery

FACT-C Subscale	Stoma	*n*	One-Way ANOVA					Kruskal-Wallis *H* test			
			Mean^a	SD	*df*	*F*	*p*	Median^a	*df*	χ^2	*p*
Physical Well-being (PWB)	*Still Present*	44	24.18	4.49	2, 247	0.194	0.824	25.83	2	3.303	0.192
	Reversed	69	24.64	3.58				26.00			
	None	137	24.63	4.72				27.00			
	Total	250	24.56	4.38				26.00			
Social/Family Well-being (SWB)	*Still Present*	48	23.48	5.12	2, 260	0.325	0.723	25.10	2	3.976	0.137
	Reversed	71	22.96	4.48				23.80			
	None	144	23.57	5.65				26.00			
	Total	263	23.39	5.25				25.00			
Emotional Well-being (EWB)	*Still Present*	47	20.54	3.27	2, 258	0.455	0.635	21.00	2	0.452	0.798
	Reversed	72	20.00	3.93				21.00			
	None	142	19.92	4.14				20.00			
	Total	261	20.05	3.93				21.00			
Functional Well-being (FWB)	*Still Present*	49	20.96	6.25	2, 264	1.470	0.232	22.00	2	4.320	0.115
	Reversed	72	20.10	7.01				21.50			
	None	146	21.73	6.61				24.00			
	Total	267	21.15	6.67				23.00			
Colorectal Cancer Subscale (CCS)	*Still Present*	49	21.73	4.86	2, 264	1.893	0.153	23.00	2	6.838	0.033*
	Reversed	72	21.24	4.77				22.00			
	None	146	22.59	5.19				24.00			
	Total	267	22.07	5.04				23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch ANOVA reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.30 Results of one-way ANOVA and Kruskal-Wallis H tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify stoma-related differences in colorectal cancer survivors' scores on each FACT-C subscale

excellence reported higher median subscale scores on physical (*p*≤0.0005), functional (*p*=0.013) and colorectal cancer subscales (*p*=0.019). Survivors attending regional hospitals also fared worse than those attending private hospitals on emotional (*p*=0.035), functional (*p*=0.038) and colorectal cancer subscales (*p*=0.024).

No statistically significant differences were identified between colorectal cancer survivors on any FACT-C subscales for the variables area of residence (*urban*/*rural*) or living arrangements (*with family or friends*/*alone*) (*p*≥0.05; data not shown).

6.5.3 Cancer-Related Variables and Quality of Life

6.5.3.1 FACT-C Scale

The transformed FACT-C data met the requirements for parametric analysis for each independent variable. The results of nonparametric tests conducted on the original data are presented in the tables throughout this section for comparison. No significant differences in FACT-C scores were identified for tumour site (*colon*/*rectum*; *p*=0.370), time since diagnosis (*<1/1-2/2-3/3-4/4-5 years*; *p*=0.714), number of treatments (*1/2/>3 treatments*; *p*=0.072) or presence of a stoma (*still present*/*absent*/*reversed*; *p*=0.279; Table 6.23). Independent samples *t*-tests identified significant differences between survivors treated with radiotherapy and those who had not (*p*=0.028) and those treated with chemotherapy or not (*p*=0.007). However, there was no difference between survivors treated surgically or non-surgically (*p*=0.666; Table 6.24). At the time of the study, 33 participants were receiving radiotherapy, chemotherapy, or had recently undergone surgery. Compared to those who had completed treatment, this group reported poorer quality of life (*p*≤0.0005; Table 6.24). Similarly, those living with recurrent or metastatic disease reported poorer FACT-C scores compared to those in remission (*p*≤0.0005; Table 6.23).

6.5.3.2 FACT-C Subscales

Due to a violation of the assumptions underpinning parametric tests, Mann-Whitney and Kruskal-Wallis tests were conducted to identify differences in FACT-C subscale scores for cancer-related variables. Parametric and nonparametric tests yielded disparate findings for several cancer-related variables, including SWB (*previous radiotherapy*, *current treatment*), EWB (*previous radiotherapy*) and CCS (*presence of a stoma*). In each case, the results of nonparametric tests conducted with the original data are interpreted.

Significant differences were identified between colorectal cancer survivors based on disease status for physical (*p*≤0.0005), emotional (*p*=0.009), functional (*p*=0.006) and colorectal cancer-related well-being (*p*=0.009; Table 6.25). Survivors in remission reported better physical (*p*≤0.0005), emotional (*p*=0.020), functional (*p*=0.009) and colorectal cancer concerns (*p*=0.010) scores compared to those living with advanced or recurrent disease. Furthermore, survivors in remission reported higher physical well-being scores than those who were uncertain about their disease status (*p*=0.013).

Previous radiotherapy treatment was associated with poorer physical ($p=0.048$), social ($p=0.034$), functional ($p=0.033$) and colorectal cancer subscale scores ($p=0.019$; Table 6.26). Chemotherapy was associated with poorer physical well-being only ($p \leq 0.0005$; Table 6.27). Significant differences were identified between survivors grouped by the number of previous treatments received on the physical well-being subscale ($p=0.001$; Table 6.28). Those who had received a single treatment modality reported more positive median physical well-being than those who had received two ($p=0.004$) or three or more treatments ($p=0.010$).

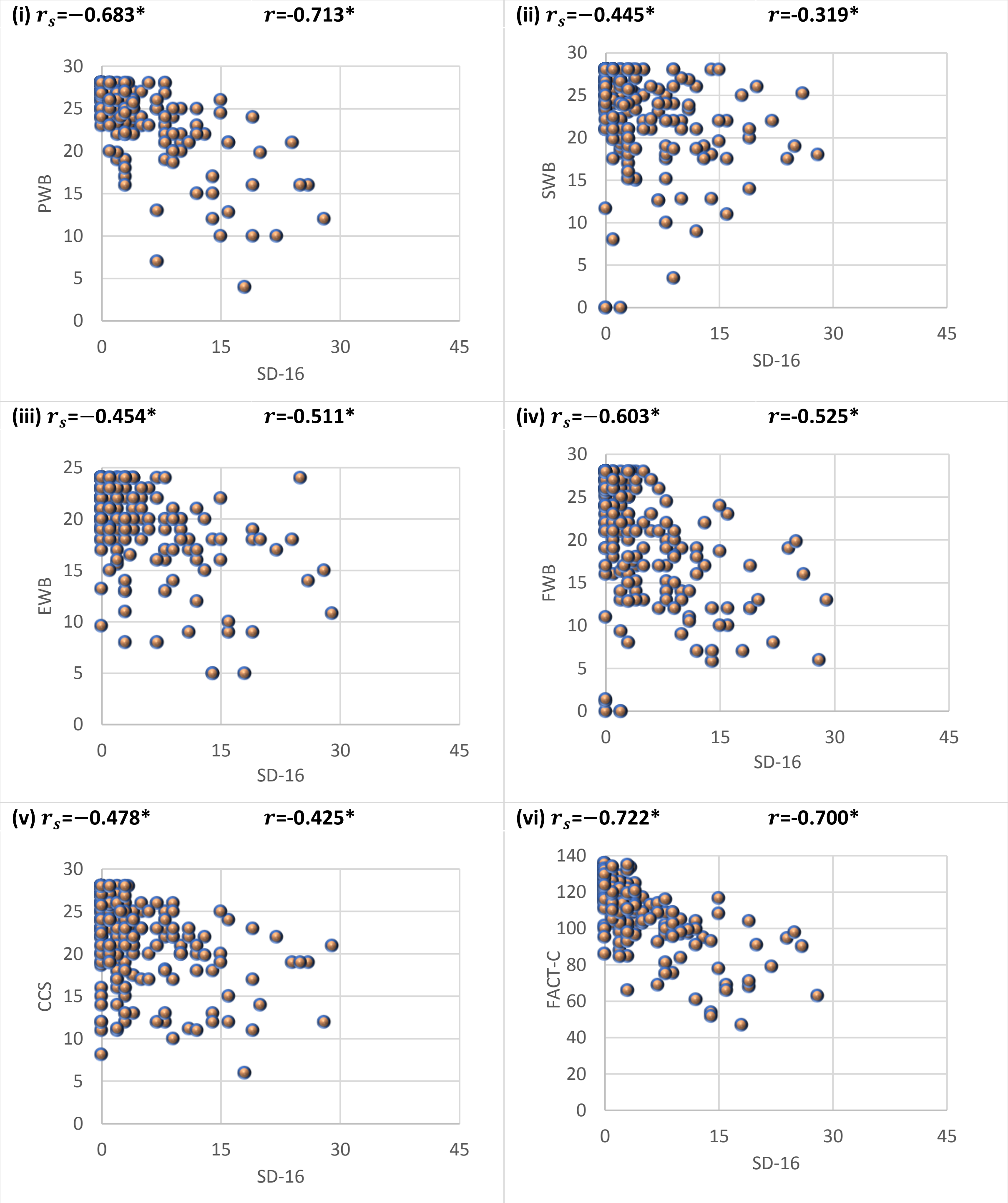
Survivors receiving cancer treatment at the time of the study reported poorer scores on physical ($p \leq 0.0005$), social ($p=0.019$), functional ($p \leq 0.0005$) and colorectal cancer ($p=0.002$) subscales than those who were not receiving treatment (Table 6.29). Finally, Kruskal-Wallis H tests identified a difference between survivors' colorectal cancer subscale scores based on their history of a stoma ($p=0.033$; Table 6.30). Those who had previously had a stoma reported a greater number of concerns than those who had never had a stoma ($p=0.038$).

There were no significant differences between colorectal cancer survivors' quality of life in any of the FACT-C subscales for the variables of diagnosis (*colon/rectum*), time since diagnosis (*<1/1-2/2-3/3-4/4-5 years*), or previous surgical treatment (*surgery/no surgery*; all $p>0.05$; data not shown).

6.5.4 Social Difficulties and Quality of Life

The relationship between social difficulties (SD-16) and quality of life was evaluated using correlation analysis (Figure 6.28). The assumption of bivariate normality was violated on each of the FACT-C subscales, therefore the results of Spearman's rank-order (r_S) correlations are discussed. Pearson's correlations (r) are presented alongside Spearman's rank-order correlations in the figures for the purpose of comparison. SD-16 was significantly correlated with all FACT-C subscales. Strong negative correlations were identified between SD-16 and physical ($p \leq 0.0005$), functional well-being ($p \leq 0.0005$) and overall quality of life ($p \leq 0.0005$). Moderate correlations were identified on all remaining subscales. These results indicate that greater levels of social difficulty were associated with poorer quality of life in all domains of the FACT-C.

The results of nonparametric correlations to determine the relationship between SDI subscales and overall quality of life are presented in Figure 6.29. Strong negative correlations were identified between FACT-C and the Everyday Living subscale ($p \leq 0.0005$) and Self and Others subscale ($p \leq 0.0005$). The Money Matters subscale was moderately negatively associated with quality of life ($p \leq 0.0005$). These results indicate that greater social difficulties in the areas of Everyday Living, Money Matters or Self and Others were associated with poorer overall quality of life. As the correlation between FACT-C subscale scores and the social difficulties subscale scores was moderate, no further analysis was undertaken to examine the relationships between SDI subscale score and FACT-C subscale scores.



(i) r_s=−0.683* r=-0.713*

(ii) r_s=−0.445* r=-0.319*

(iii) r_s=−0.454* r=-0.511*

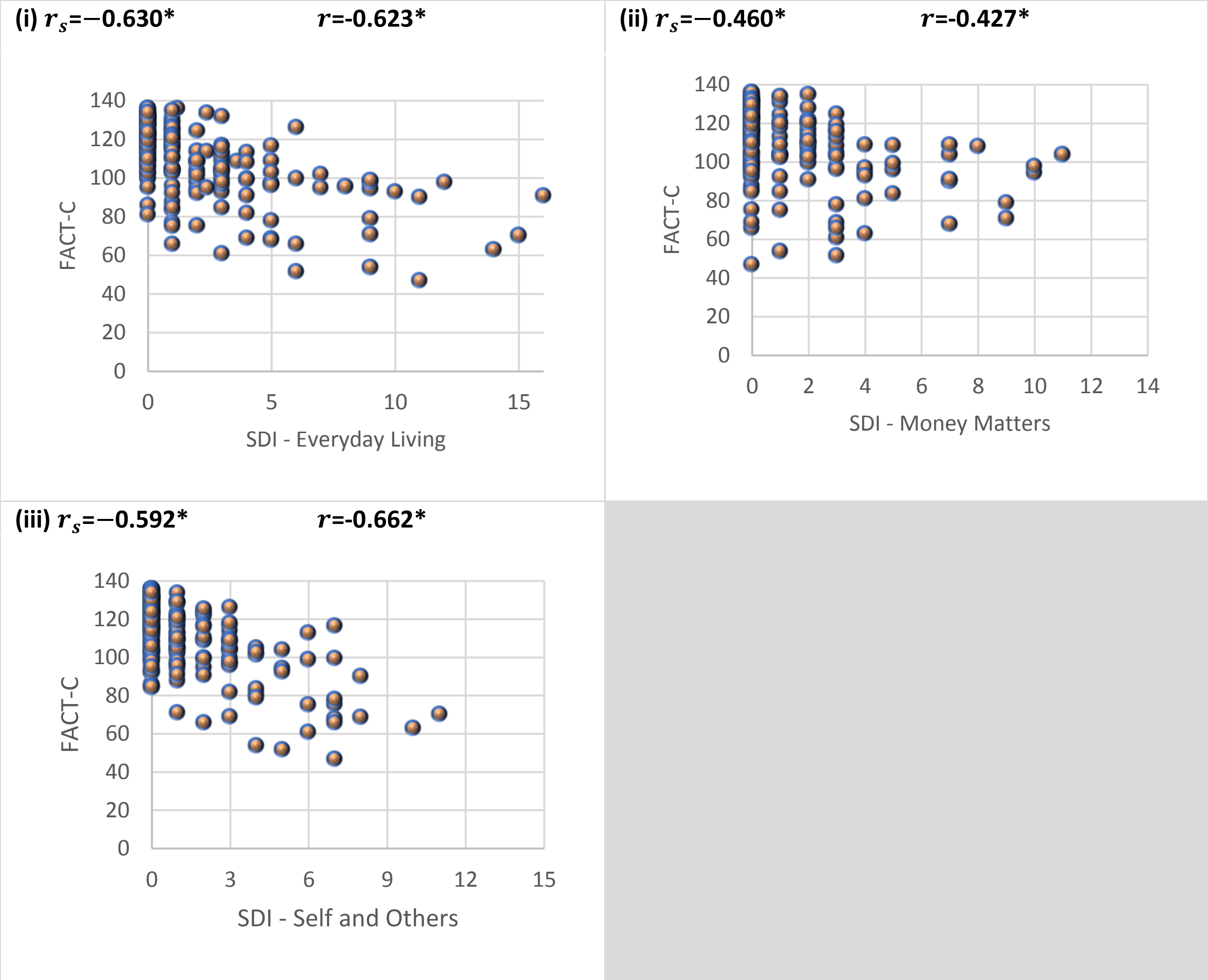
(iv) r_s=−0.603* r=-0.525*

(v) r_s=−0.478* r=-0.425*

(vi) r_s=−0.722* r=-0.700*

*p≤0.05

Figure 6.28 Results of Spearman's rank-order correlations (r_s), Pearson's correlations (r) and scatterplots of colorectal cancer survivors' scores on (i) Physical Well-being (PWB), (ii) Social/Family Well-being (SWB), Emotional Well-being (EWB), (iv) Functional Well-being (FWB), (v) Colorectal Cancer Subscale (CCS), and (vi) Functional Assessment of Cancer Therapy-Colorectal (FACT-C) scales plotted against survivors' Social Difficulties scores (SD-16)


(i) r_s=−0.630* r=-0.623*

(ii) r_s=−0.460* r=-0.427*

(iii) r_s=−0.592* r=-0.662*

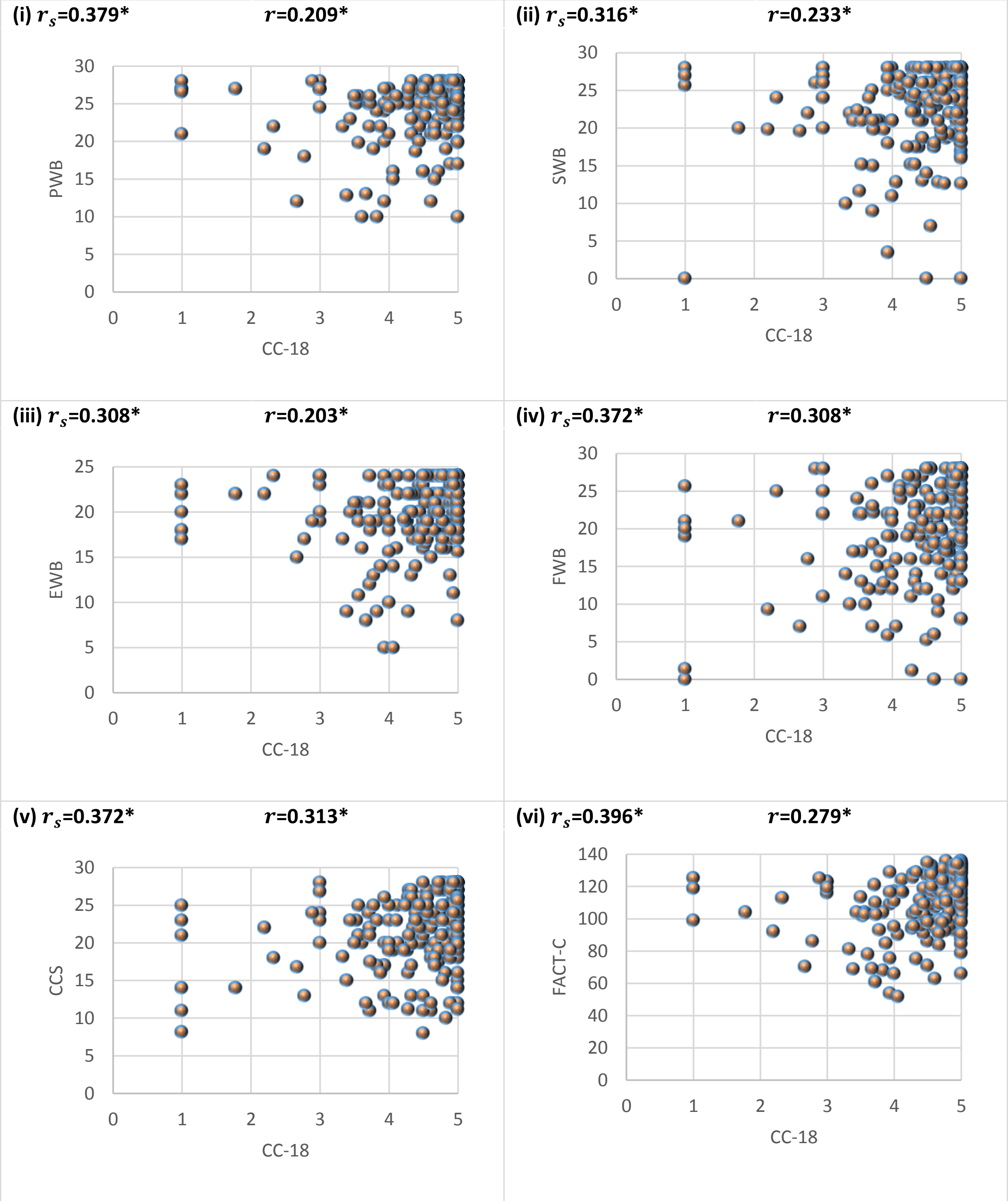
*$p\leq0.05$

Figure 6.29 Results of Spearman's rank-order correlations (r_s), Pearson's correlations (r) and scatterplots of colorectal cancer survivors' Functional Assessment of Cancer Therapy-Colorectal (FACT-C) scores plotted against survivors' Social Difficulties Inventory (SDI) subscales scores

6.5.5 Continuity of Care and Quality of Life

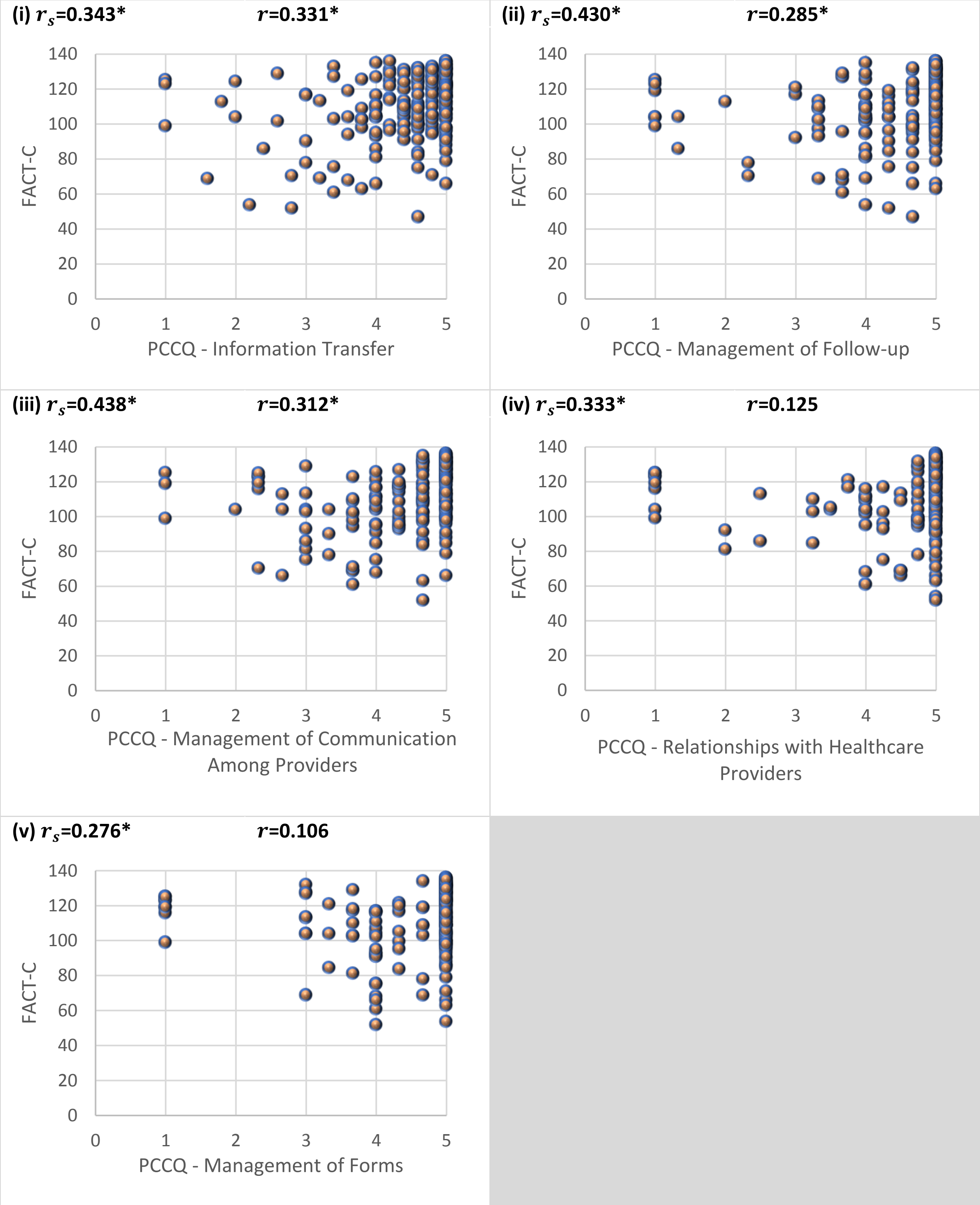
The relationship between continuity of care (CC-18) and quality of life on all subscales was examined (Figure 6.30). As in the correlative analysis of the SDI subscales, the assumptions of bivariate normality were violated on each of the FACT-C subscales, therefore the results of Spearman's rank-order correlations (r_s) are interpreted, and the results of equivalent Pearson's correlations (r) are presented in related figures for ease of comparison. Colorectal cancer survivors' perceptions of continuity of care were moderately positively correlated with quality of life on all FACT-C subscales. The strongest correlations were reported between continuity of care and quality of life overall ($p\leq0.0005$), and in physical ($p\leq0.0005$), functional ($p\leq0.0005$) and colorectal cancer domains ($p\leq0.0005$). These results suggest colorectal cancer survivors' quality of life was related to their perceptions of continuity of care, such that more positive evaluations of care were linked to more positive quality of life scores.

Correlations between PCCQ subscales and survivors' FACT-C scores were all significant for Spearman's rank-order correlations but were of moderate strength (Figure 6.31). Deviation between parametric



*$p \leq 0.05$

Figure 6.30 Results of Spearman's rank-order correlations (r_s), Pearson's correlations (r) and scatterplots of colorectal cancer survivors' scores on (i) Physical Well-being (PWB), (ii) Social/Family Well-being (SWB), Emotional Well-being (EWB), (iv) Functional Well-being (FWB), (v) Colorectal Cancer Subscale (CCS), and (vi) Functional Assessment of Cancer Therapy-Colorectal (FACT-C) scales plotted against survivors' Continuity of Care (CC-18) Scores



(i) r_s=0.343* r=0.331*

(ii) r_s=0.430* r=0.285*

(iii) r_s=0.438* r=0.312*

(iv) r_s=0.333* r=0.125

(v) r_s=0.276* r=0.106

*$p \leq 0.05$

Figure 6.31 Results of Spearman's rank-order correlations (r_s), Pearson's correlations (r) and scatterplots of colorectal cancer survivors' Functional Assessment of Cancer Therapy-Colorectal (FACT-C) scores plotted against survivors' Patient Continuity of Care (PCCQ) subscale scores

and nonparametric tests occurred on two subscales; no parametric associations were identified between FACT-C scores and 1) Relationships with Healthcare Providers and 2) Management of Forms. The strongest nonparametric associations with FACT-C scores were survivors' perceptions of Follow-up Care Management ($p \leq 0.0005$) and Communication between Healthcare Providers ($p \leq 0.0005$). These results suggest that quality of life was moderately related to colorectal cancer survivors' evaluations of continuity of care on each domain of the PCCQ. As the correlation between the overall PCCQ score and FACT-C subscales was moderate, no further analysis was undertaken to examine the relationships between PCCQ subscale score and FACT-C subscale scores.

6.5.6 Experience of Care and Quality of Life

This section reports the results of analyses undertaken to establish variance in colorectal cancer survivors' quality of life relating to their experiences of healthcare, including 1) receipt of a cancer survivorship care plan and treatment summary, 2) access to a named healthcare professional to discuss concerns regarding cancer or survivorship, 3) support from primary care and hospital-based healthcare professionals, and 4) use of cancer support services in the community. As the assumptions underpinning parametric tests of transformed data were violated, the results of nonparametric tests performed on the untransformed FACT-C data are presented throughout this section.

Only four healthcare experience variables were associated with differences in survivors' quality of life scores. Survivors who had 1) access to a named doctor (p=0.001), 2) who did not receive support from social services (p=0.014), 3) who had not attended a cancer support group (p=0.005) and 4) who had not attended another form of cancer support ($p \leq 0.0005$) reported significantly more positive quality of life on the FACT-C scale (Table 6.31).

No difference in FACT-C subscale scores were identified between colorectal cancer survivors who did or did not have a cancer survivorship care plan or named nurse (all p>0.05; data not shown). Possessing a treatment summary was associated with better physical well-being (n=246; U=4456.50, Z=-0.612, p=0.541; data not shown). Those who had a named doctor to contact about cancer-related concerns reported more positive social ($p \leq 0.0005$), functional (p=0.003) and colorectal cancer subscales scores (p=0.018; Table 6.32). Furthermore, those who knew whom to contact if they had any concern about living with or after cancer had more positive emotional well-being (p=0.002; Table 6.33). There was no difference in quality of life scores between colorectal cancer survivors who had or had not received support from hospital staff and general practice staff ($p \geq 0.05$; data not shown). However, those who believed that the health and social services had given them enough care achieved more positive social (p=0.017) and functional well-being (p=0.027) scores compared to survivors who did not believe this was true (Table 6.34). There were significant differences between survivors who had attended cancer support group meetings and those who had not on physical (p=0.002), emotional (p=0.005) and colorectal cancer (p=0.044) subscales. In all cases, colorectal cancer survivors who had not availed of

Variable	Groups	*n*	Original FACT-C Data						Transformed FACT-C Data					
						Mann Whitney *U* Test					*t*-test			
			Mean^a	*SD*	Median^a	*U*	*Z*	*p*	Mean^b	SD	95% CI	*df*	*t*	*p*
Care Plan	*Yes*	60	114.75	16.44	119.50	4968.50	-0.806	0.420	4.39	1.74	-0.78, 0.30	236	-0.881	0.379
	No	178	112.05	18.67	116.00				4.63	1.87				
	Total	238	112.73	18.14	116.63				4.57	1.84				
Treatment Summary	*Yes*	78	114.12	17.60	119.50	5746.00	-0.843	0.399	4.42	1.85	-0.72, 0.28	234	-0.854	0.394
	No	158	112.11	18.53	116.17				4.64	1.85				
	Total	236	112.78	18.21	116.75				4.56	1.85				
Named Nurse	*Yes*	190	113.11	18.43	117.00	3996.00	-0.900	0.368	4.52	1.86	-0.83, 0.36	234	-0.784	0.434
	No	46	111.46	16.78	112.17				4.76	1.73				
	Total	236	112.79	18.10	116.63				4.57	1.84				
Named Doctor	*Yes*	187	114.86	17.28	119.00	3179.00	-3.474	0.001*	4.35	1.79	-1.52, -0.40	235	-3.370	0.001*
	No	50	105.78	18.06	105.00				5.31	1.75				
	Total	237	112.94	17.80	116.67				4.56	1.82				
Other Named Contact	*Yes*	208	113.36	17.79	117.00	2582.50	-1.787	0.074	4.51	1.81	-1.31, 0.07	237	-1.771	0.078
	No	31	107.21	19.40	108.00				5.13	1.88				
	Total	239	112.56	18.09	116.60				4.59	1.83				
Hospital Staff Supportive	*Yes*	226	112.75	17.89	116.63	1010.50	-1.487	0.137	4.58	1.82	-1.88, 0.23	236	-1.541	0.125
	No	12	104.97	20.04	109.68				5.41	1.75				
	Total	238	112.36	18.04	116.17				4.62	1.82				
GP Staff Supportive	*Yes*	177	111.92	19.24	117.00	5275.00	-0.076	0.939	4.62	1.94	-0.44, 0.50	135.6	0.116[1]	0.907
	No	60	113.85	14.27	115.92				4.59	1.45				
	Total	237	112.41	18.10	116.33				4.61	1.83				
Health and Social Services Staff Supportive	*Yes*	139	110.24	18.89	113.33	9319.00	1.662	0.097	4.82	1.88	0.12, 1.06	232	2.464	0.014*
	No	95	116.36	15.45	119.33				4.23	1.66				
	Total	234	112.73	17.80	116.63				4.58	1.81				
Cancer Support	*Yes*	26	103.42	18.97	104.38	3619.50	2.761	0.006*	5.57	1.62	0.33, 1.79	233	2.860	0.005*
	No	209	113.42	17.66	117.00				4.51	1.80				
	Total	235	112.31	18.04	116.33				4.63	1.81				
Other Form of Cancer Support	*Yes*	26	101.72	18.06	104.00	4641.50	3.499	0.000*	5.74	1.55	0.60, 2.03	229	3.620	0.000*
	No	205	114.30	16.98	118.80				4.43	1.76				
	Total	231	112.88	17.52	116.60				4.58	1.79				

[a] Higher scores indicate better quality of life on the original FACT-C scale; [b] Lower scores indicate better quality of life on the transformed FACT-C scale;
[1] Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.31 Results of Mann-Whitney U tests and t-tests on the original and transformed Functional Assessment of Cancer Therapy-Colorectal (FACT-C) data to identify healthcare-related factors associated with differences in colorectal cancer survivors' FACT-C scores

FACT-C Subscale	Access to a Named Doctor	*n*	*t*-test						Mann-Whitney *U* Test			
			Mean^a	*SD*	95% CI	*df*	*t*	*p*	Median^a	*U*	*Z*	*p*
Physical Well-being (PWB)	*Yes*	197	24.87	4.14	-0.81, 1.68	247	0.691	0.490	26.00	4457.50	-1.458	0.145
	No	52	24.44	3.68					25.00			
	Total	249	24.78	4.05					26.00			
Social Well-being (SWB)	*Yes*	209	24.10	4.97	1.58, 4.74	260	2.932	0.000*	25.67	3567.50	-4.051	0.000*
	No	53	20.95	6.12					21.00			
	Total	262	23.47	5.36					25.00			
Emotional Well-being (EWB)	*Yes*	204	20.46	3.67	-0.30, 1.90	258	1.426	0.155	21.00	4924.50	-1.596	0.110
	No	56	19.66	3.87					20.00			
	Total	260	20.29	3.72					21.00			
Functional Well-being (FWB)	*Yes*	211	22.02	6.28	0.81, 4.59	237	3.654	0.000*	24.00	4401.00	-2.947	0.003*
	No	56	19.32	6.78					19.92			
	Total	267	21.45	6.47					23.00			
Colorectal Cancer Subscale (CCS)	*Yes*	212	22.49	5.09	-0.38, 2.51	197.7	1.680^1	0.096	24.00	4716.00	-2.372	0.018*
	No	56	21.42	3.98					21.50			
	Total	268	22.26	4.89					23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.32 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' access to a named doctor to discuss cancer-related worries

FACT-C Subscale	Access to a Healthcare Professional	*n*	*t*-test						Mann-Whitney *U* Test			
			Mean[a]	*SD*	95% CI	*df*	*t*	*p*	Median[a]	*U*	*Z*	*p*
Physical Well-being (PWB)	*Yes*	217	24.85	4.12	-0.77, 2.26	248	0.971	0.333	26.00	3180.50	-1.048	0.295
	No	33	24.10	4.11					26.00			
	Total	250	24.75	4.12					26.00			
Social Well-being (SWB)	*Yes*	229	23.61	5.12	-0.56, 3.31	261	1.399	0.163	25.00	3464.50	-1.048	0.295
	No	34	22.23	6.70					24.00			
	Total	263	23.43	5.35					25.00			
Emotional Well-being (EWB)	*Yes*	227	20.46	3.69	0.65, 3.38	259	2.906	0.004*	21.00	2595.50	-3.109	0.002*
	No	34	18.45	4.30					18.50			
	Total	261	20.20	3.83					21.00			
Functional Well-being (FWB)	*Yes*	234	21.64	6.34	-0.11, 4.52	267	1.875	0.062	23.00	3349.00	-1.746	0.081
	No	35	19.43	7.45					22.00			
	Total	269	21.35	6.52					23.00			
Colorectal Cancer Subscale (CCS)	*Yes*	234	22.40	4.84	-0.13, 3.36	267	1.772	0.078	23.00	3292.50	-1.875	0.061
	No	35	20.79	5.19					21.00			
	Total	269	22.19	4.91					23.00			

[a] Higher scores indicate better quality of life on the original FACT-C subscale; [1] Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.33 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' access to a healthcare professional to discuss cancer survivorship issues

FACT-C Subscale	Adequate Support from Health and Social Services	*n*	*t*-test						Mann-Whitney *U* Test			
			Mean^a	*SD*	95% CI	*df*	*t*	*p*	Median^a	*U*	*Z*	*p*
Physical Well-being (PWB)	*Yes*	145	24.31	4.42	-2.11, -0.16	242.3	-2.285^1	0.023*	26.00	8279.50	1.767	0.077
	No	101	25.45	3.34					26.83			
	Total	246	24.78	4.04					26.00			
Social Well-being (SWB)	*Yes*	160	22.79	5.91	-3.00, -0.55	253.7	-2.849^1	0.005*	24.00	9304.00	2.390	0.017*
	No	99	24.56	4.09					26.00			
	Total	259	23.46	5.35					25.00			
Emotional Well-being (EWB)	*Yes*	156	20.21	3.90	-1.08, 0.80	255	-0.290	0.772	21.00	7820.00	-0.101	0.920
	No	101	20.35	3.47					20.00			
	Total	257	20.27	3.73					21.00			
Functional Well-being (FWB)	*Yes*	163	20.63	6.87	-3.47, -0.39	240.4	-2.469^1	0.014*	22.00	9557.50	2.209	0.027*
	No	101	22.56	5.71					24.00			
	Total	264	21.37	6.51					23.00			
Colorectal Cancer Subscale (CCS)	*Yes*	163	21.77	5.01	-2.27, 0.16	263	-1.706	0.089	23.00	9319.00	1.662	0.097
	No	102	22.82	4.70					24.00			
	Total	265	22.17	4.91					23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.34 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' perceptions of support from health and social services staff

FACT-C Subscale	Use of Cancer Support Groups	*n*	*t*-test						Mann-Whitney *U* Test			
			Mean^a	*SD*	95% CI	*df*	*t*	*p*	Median^a	*U*	*Z*	*p*
Physical Well-being (PWB)	*Yes*	26	22.98	4.42	-3.59, -0.25	245	-2.260	0.025*	24.50	3920.00	3.078	0.002*
	No	221	24.90	4.06					26.00			
	Total	247	24.70	4.13					26.00			
Social Well-being (SWB)	*Yes*	28	21.57	6.49	-4.16, 0.04	258	-1.931	0.055	24.25	3925.50	1.823	0.068
	No	232	23.63	5.19					25.00			
	Total	260	23.41	5.37					25.00			
Emotional Well-being (EWB)	*Yes*	29	18.57	4.00	-3.32, -0.38	256	-2.471	0.014*	19.00	4383.50	2.836	0.005*
	No	229	20.42	3.77					21.00			
	Total	258	20.21	3.83					21.00			
Functional Well-being (FWB)	*Yes*	29	20.50	5.43	-3.38, 1.69	263	-0.657	0.512	21.00	3946.00	1.351	0.177
	No	236	21.35	6.67					23.00			
	Total	265	21.25	6.54					23.00			
Colorectal Cancer Subscale (CCS)	*Yes*	29	20.82	4.35	-3.33, 0.46	264	-1.491	0.137	21.00	4223.00	2.017	0.044*
	No	237	22.26	4.96					23.00			
	Total	266	22.10	4.91					23.00			

^{a}Higher scores indicate better quality of life on the original FACT-C subscale; ^{1}Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.35 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' use of cancer support groups

FACT-C Subscale	Use of Other Forms of Cancer Support	*n*	*t*-test						Mann-Whitney *U* Test			
			Mean[a]	*SD*	95% CI	*df*	*t*	*p*	Median[a]	*U*	*Z*	*p*
Physical Well-being (PWB)	*Yes*	26	23.54	4.43	-3.03, 0.23	239	-1.689	0.092	25.00	3504.00	2.140	0.032*
	No	215	24.95	3.94					26.00			
	Total	241	24.79	4.01					26.00			
Social Well-being (SWB)	*Yes*	29	21.30	6.00	-4.52, -0.62	253	-2.591	0.010*	23.80	4286.50	2733	0.006*
	No	226	23.87	4.89					25.10			
	Total	255	23.57	5.08					25.00			
Emotional Well-being (EWB)	*Yes*	28	17.73	4.37	-4.30, -1.46	248	-4.005	0.000*	19.00	4399.50	3.619	0.000*
	No	222	20.61	3.48					21.00			
	Total	250	20.29	3.69					21.00			
Functional Well-being (FWB)	*Yes*	29	19.15	5.33	-5.03, -0.10	255	-2.052	0.041*	19.00	4358.00	2.803	0.005*
	No	228	21.72	6.45					23.50			
	Total	257	21.43	6.38					23.00			
Colorectal Cancer Subscale (CCS)	*Yes*	29	19.47	4.91	-4.99, -1.30	256	-3.352	0.001*	19.83	4641.50	3.499	0.000*
	No	229	22.62	4.74					24.00			
	Total	258	22.27	4.85					23.00			

[a]Higher scores indicate better quality of life on the original FACT-C subscale; [1]Welch *t*-test reported where homogeneity of variance was violated; *$p \leq 0.05$

Table 6.36 Results of t-tests and Mann-Whitney U tests on the original Functional Assessment of Cancer Therapy-Colorectal (FACT-C) subscale data to identify differences in colorectal cancer survivors' scores on each FACT-C subscale relating to survivors' use of other forms of cancer support

these services achieved more positive median scores (Table 6.35). Similarly, survivors who attended other cancer support services achieved less positive median scores on all FACT-C subscales than those who had not (all $p \leq 0.05$; Table 6.36). However, chi-squared analysis revealed survivors who attended a cancer support group or other cancer support services were no less likely to have access to a named nurse (χ^2=1.038, p=0.308, *OR*=1.505), a named doctor (χ^2=0.930, p=0.335, *OR*=0.638) or other healthcare professional (χ^2=0.024, p=0.876, *OR*=0.923), and were just as likely to receive support from hospital staff (χ^2=0.721, p=0.396, *OR*=0.420), general practice staff (χ^2=0.105, p=0.746, *OR*=0.877) and health and social services staff (χ^2=0.040, p=0.841, *OR*=0.933).

6.5.7 Information Needs and Quality of Life

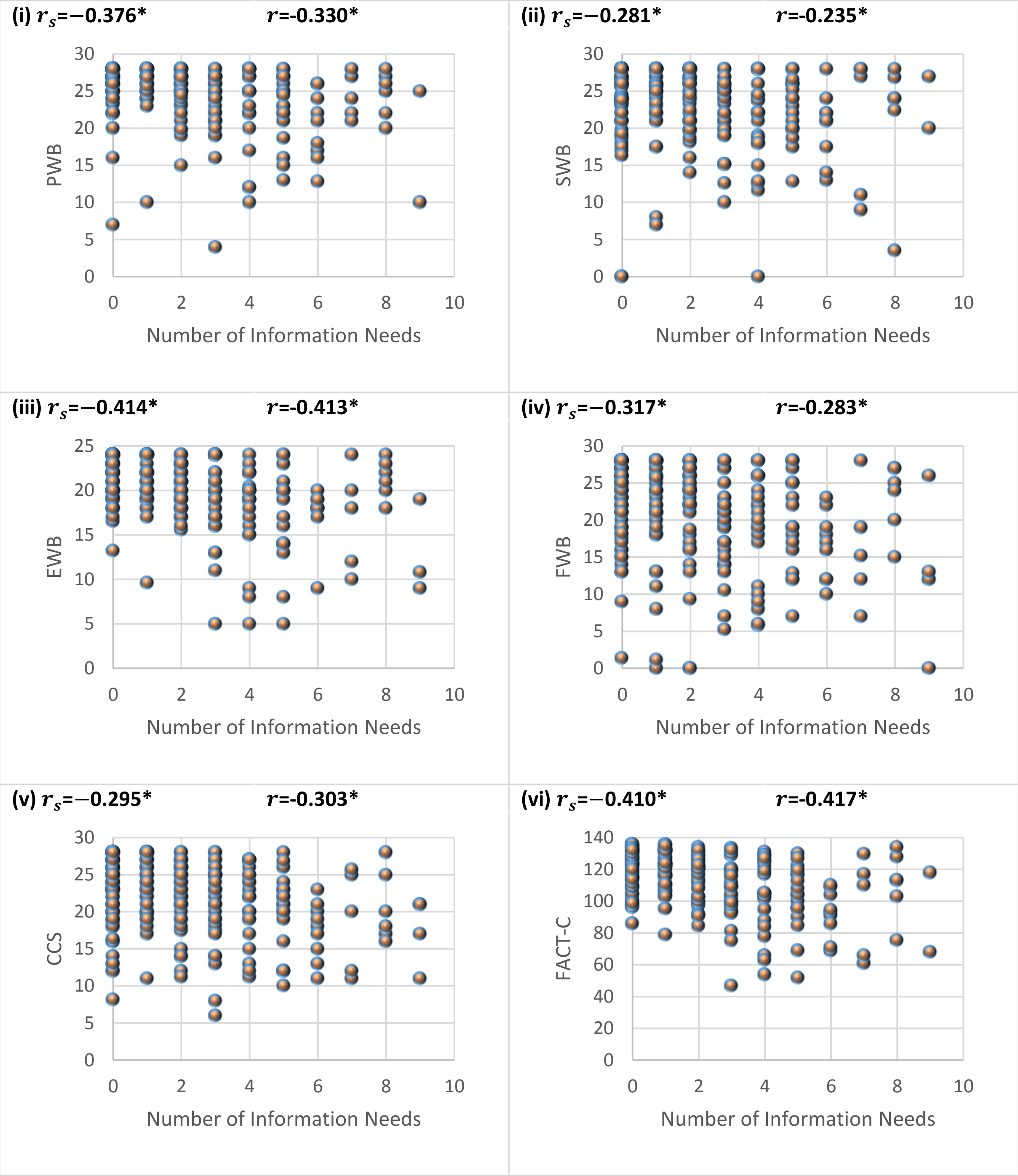
Spearman's rank-order correlations (r_s) were conducted to ascertain the relationship between the number of information needs experienced by survivors and their quality of life. The results of Pearson's correlations (r) are also presented in Figure 6.32. The scatterplots suggest greater levels of unmet information needs are associated with poorer quality of life on FACT-C subscales. The strongest correlations were noted on the EWB subscale ($p \leq 0.0005$) and overall quality of life ($p \leq 0.0005$).

6.6 Multivariate Analysis of Factors Influencing Colorectal Cancer Survivors' Quality of Life

6.6.1 Assumptions of Multivariate Regression Analysis

This section describes the results of multivariate analysis undertaken to determine the influence of several explanatory variables on colorectal cancer survivors' quality of life. Regression analysis permits the functional relationship between the dependent variable and the independent, explanatory or predictor variables to be expressed as a model or equation (Chatterjee 2012). The linear regression equation may be used to describe the direction and strength of a relationship between the dependent variable and one or more independent variables. The equation may also be used to predict the value of a dependent variable given a combination of explanatory variables and can control for the effect of selected independent variables (Montgomery 2013). Several assumptions underpin multivariate linear regression analysis. Multiple linear regression requires a continuous dependent variable and one or more independent variables measured at the continuous or nominal levels. The model assumes 1) a linear relationship between the dependent variable and each of the independent variables both individually and collectively, 2) equal variance and approximately normal distribution of dependent variable residuals for all levels of the independent variables, 3) no correlation of residual terms, 4) no multicollinearity between independent variables and 5) no outlying observations for the dependent variable (Field 2013, Tabachnick & Fidell 2013). However, the highly skewed nature of the FACT-C, SDI and PCCQ scores in the current study violated assumptions underpinning linear regression modelling.

Logistic regression analysis was a suitable alternative to linear regression, as it is robust to 1) non-



(i) $r_s = -0.376$* r=-0.330*

(ii) $r_s = -0.281$* r=-0.235*

(iii) $r_s = -0.414$* r=-0.413*

(iv) $r_s = -0.317$* r=-0.283*

(v) $r_s = -0.295$* r=-0.303*

(vi) $r_s = -0.410$* r=-0.417*

*$p \leq 0.05$

Figure 6.32 *Results of Spearman's rank-order correlations (r_s), Pearson's correlations (r) and scatterplots of colorectal cancer survivors' scores on (i) Physical Well-being (PWB), (ii) Social/Family Well-being (SWB), Emotional Well-being (EWB), (iv) Functional Well-being (FWB), (v) Colorectal Cancer Subscale (CCS), and (vi) Functional Assessment of Cancer Therapy-Colorectal (FACT-C) scales plotted against the number of unmet information needs*

normally distributed independent variables, 2) non-linear relationships between the independent and dependent variables, and 3) unequal variance within each group (Pallant 2013, Tabachnick & Fidell 2013). While linear regression modelling supports prediction of the dependent variable outcome for a set of independent variables, the intention behind logistic regression is prediction of the probability of a dependent variable value for a known set of independent variable values (Field 2013). However, like multivariate linear regression modelling, logistic regression is governed by several assumptions. The dependent variable must be ordinal or dichotomous and the independent variables included in the regression model may be continuous or nominal. The categories of the dichotomous dependent variable and nominal independent variables should be mutually exclusive and exhaustive. Similar to linear regression, there must be independence of observations and no multicollinearity between the independent variables in the model. It is expected that there is linearity between continuous independent variables and logistic transformations of the dependent variable. Finally, there must be adequate cases in each category of the independent variable, no outlying cases and independence of errors (Spitznagel 2007, Tabachnick & Fidell 2013).

In the logistic regression equation, the linear regression equation is expressed in logarithmic terms. By doing so, the relationship between the dependent variable and independent variables are treated as linear, even where the relationship itself is nonlinear (Field 2013). The value resulting from the logistic regression equation indicates the likelihood of Y occurring and ranges from 0 to 1, with a higher value indicating a greater likelihood of Y occurring (Field 2013). Quality of life measured by the original FACT-C data was the dependent variable in the analysis presented in this section. Section 6.5 identified 31 of 40 potential independent variables drawn from six analytical categories which were associated with quality of life. Two further variables, diagnosis and time since diagnosis did not significantly influence quality of life in any domain, but were included in the modelling procedure as previous studies have highlighted differences among colorectal cancer survivors based on these variables (Table 6.37) (Steginga *et al.* 2009, Serpentini *et al.* 2011, Chambers *et al.* 2012b). All healthcare experience items were retained for pre-modelling checks regardless of significance, as an exploratory approach to regression modelling was adopted to identify the healthcare factors which influence colorectal cancer survivors' quality of life.

6.6.2 Preparation of the Data for Multivariate Logistic Regression Analysis

The objective of the proposed regression model was to identify the explanatory variables which influenced colorectal cancer survivors' quality of life (*continuity of care, experience of healthcare, social difficulty* and *unmet information needs*). The model was designed to control for socio-demographic and cancer-related variables which have demonstrated significant relationships with quality of life. The regression model will provide an estimate of intercepts and regression coefficients which may assist in predicting colorectal cancer survivors' quality of life, based on the explanatory variables within the model. Finally, the model will provide results which describe the direction of the relationship between quality of life and the explanatory variables (Field 2013, Tabachnick & Fidell 2013).

Several variable transformations were conducted to prepare the data for logistic regression modelling (Table 6.38). Each independent variable was screened alone and in relation to the dependent variable to ensure adequate cell counts. An ordinal logistic regression analysis was planned, however, as no participant reported a 'low' score on the FACT-C scale (≤45.3), the score was transformed into a

Variable	PWB	SWB	EWB	FWB	CCS	FACT-C	Included
Socio-Demographic							
Age Groups	X	X	X		X	X	✓
Gender			X		X		✓
Current Employment Status	X	X	X	X		X	✓
Pre-Cancer Employment Status		X	X			X	✓
Change in Employment Status			X			X	✓
Hospital Types	X		X	X	X	X	✓
Health Insurance Status				X		X	✓
Co-Morbid Conditions			X	X	X	X	✓
Living Arrangement							
Area of Residence							
Cancer-Related							
Diagnosis							✓
Time Since Diagnosis							✓
Disease Status	X		X	X	X	X	✓
Stoma					X		
Number of Past Treatments	X						
Previous Radiotherapy	X	X		X	X	X	✓
Previous Chemotherapy	X					X	✓
Previous Surgery							✓
Current Treatment	X	X		X	X	X	✓
Continuity of Care							
Information Transfer	**Not Assessed**					X	✓
Management of Follow-up						X	✓
Management of Communication Among Providers						X	✓
Relationships with Healthcare Providers						X	✓
Management of Forms						X	✓
CC-18	X	X	X	X	X	X	✓
Experience of Care							
Treatment Summary	X						✓
Survivorship Care Plan							✓
Named Nurse							✓
Named Doctor		X		X	X	X	✓
Other Contact			X				✓
Hospital Staff							✓
General Practitioner Staff							✓
Health and Social Services Staff		X		X		X	✓
Cancer Support Groups	X		X		X	X	✓
Other Cancer Support Groups	X	X	X	X	X	X	✓
Social Difficulties							
Everyday Living	**Not Assessed**					X	✓
Money Matters						X	✓
Self and Others						X	✓
SD-16	X	X	X	X	X	X	✓
Information Needs							
Number of Information Needs	X	X	X	X	X	X	✓

Table 6.37 Variables significantly associated with colorectal cancer survivors' FACT-C and FACT-C subscale scores in inferential statistical analysis

Concept	Variable	Response Level	Comment/Interpretation
Quality of Life	*FACT-C*	Lower	FACT-C Score < 116.00
		Higher	FACT-C Score ≥ 116.00
Patient Continuity of Care (PCCQ)	*Information Transfer*	Less Satisfied	Information Transfer ≤ 4
		More Satisfied	Information Transfer > 4
	Follow-up Management	Less Satisfied	Follow-up Management ≤ 4
		More Satisfied	Follow-up Management > 4
	Management of Communication Among Providers	Less Satisfied	Communication Management ≤ 4
		More Satisfied	Communication Management > 4
	Relationships with Healthcare Providers	Less Satisfied	Healthcare Professional Relationships ≤ 4
		More Satisfied	Healthcare Professional Relationships > 4
	Management of Forms	Less Satisfied	Form Management ≤ 4
		More Satisfied	Form Management > 4
	Continuity of Care	Less Satisfied	Score ≤4 on one or more PCCQ subscales
		More Satisfied	Score > 4 on one or more PCCQ subscales
Social Difficulties Inventory (SDI)	*SD-16*	Lower	SD-16 < 10
		Higher	SD-16 ≥ 10

Table 6.38 Dependent and independent variable transformations for multivariate logistic regression analysis

dichotomous variable. Participants' quality of life was categorised by FACT-C scores above (higher quality of life) or below (lower quality of life) the median FACT-C score (116.00), similar to the approach adopted by Sisler *et al.* (2012). This procedure ensured each category had adequate numbers to conduct the analysis (Tabachnick & Fidell 2013). Furthermore, several dependent variables, including *Insurance Status, Time Since Diagnosis, Disease Status, Receipt of a Treatment Summary, Receipt of a Care Plan, Support from Hospital Staff, Support from General Practice Staff, Support from Health and Social Services* Staff and *Any Cancer Support* were collapsed into binary responses (See Table 6.39 for response structure).

Given the clustering of scores at the upper end of the PCCQ scale and subscales, and at the lower end of the SDI scale and subscales, a decision was taken to dichotomise each into positive or negative responses. Due to the highly skewed nature of the CC-18 scores for this sample, continuity of care was dichotomised using the method described by Sisler *et al.* (2012b). Participants who included a mean score of four or less on one or more of the PCCQ subscales (*Information Transfer, Follow-up Management, Management of Communication Among Providers, Relationships with Healthcare Providers* and *Management of Forms*) were dichotomised into a *less satisfied with continuity of care* group, while those with a mean score of more than four on all subscales formed the *more satisfied with continuity of care* group.

The SD-16 score was dichotomised to reflect a clinically significant level of social difficulty (≥10), as recommended by Wright *et al.* (2011). A score of less than 10 is considered a clinically acceptable level of social difficulty. To address the low number of participants who reported current treatment, the previous and current treatment variables were merged to reflect receipt of each treatment modality at present or in the past (*Any Radiotherapy, Any Chemotherapy* and *Any Surgery*). Similarly, the variables *Cancer Support Groups* and *Other Support Groups* were merged to form the variable *Any Cancer Support Group Use*. When all pre-modelling preparations were complete, 23 variables were retained for pre-modelling checks (Table 6.39).

6.6.3 Pre-Modelling Checks

The patterns of missing responses on the dependent variables for the questionnaire were evaluated, any participant who failed to provide a clear response to more than seven of the proposed dependent and independent variables were excluded from the analysis. This resulted in a final sample of 286 participants included in the logistic regression analysis. Case processing summaries were generated for each variable in SPSS to assess the adequacy of cell counts during univariate logistic regression analysis. The statistical diagnosis revealed two dependent variables had more than 5% missing data, *Time Since Diagnosis* (8.4%) and *Disease Status* (8.7%). Following consultation with a statistician, these variables were retained for pre-modelling univariate analysis, as there were sufficient cases in each category of the variables for inclusion in the analysis.

Two variables showed unacceptable levels of multicollinearity, *Pre-Cancer Employment: Engaged with Labour Force* (Tolerance=0.086, VIF=11.642), *Pre-Cancer Employment: Not Engaged with the Labour Force by Choice* (Tolerance=0.077, VIF=12.971) and *Change in Employment Status: Remained Unengaged with the Labour Force* (Tolerance=0.066, VIF=15.170). A decision was taken to remove *Pre-Cancer Employment Status* and *Current Employment Status* and retain *Change in Employment Status*. Violation of the assumption of linearity between continuous dependent variables (CC-18 and SD-16) and the logistic transformation of the independent variable was avoided, as all continuous variables were converted into dichotomous variables due to the skewed nature of the data (Table 6.38). The indicator category for each analysis is the first dummy variable (coding) listed for each independent variable in Table 6.39.

6.6.4 Model Building Strategy

In keeping with the recommendations of Thayer (2002), univariate logistic regression was undertaken to test the association of quality of life with each dependent variable retained after pre-modelling checks (Table 6.39). Univariate analyses revealed *Age* (*p*=0.265), *Gender* (*p*=0.384), *Change in Employment Status* (*p*=0.079), *Diagnosis* (*p*=0.816), *Time Since Diagnosis* (*p*=0.591), *Any Radiotherapy* (*p*=0.869), *Any Chemotherapy* (*p*=0.136), *Any Surgery* (*p*=0.556), *Receipt of a Care Plan* (*p*=0.414), *Receipt of a Treatment Summary* (*p*=0.768), *Access to a Named Nurse Contact* (*p*=0.301), *Supportiveness of Hospital Staff* (*p*=0.700), *Supportiveness of General Practice Staff* (*p*=0.958) and *Supportiveness of Social Services Staff* (*p*=0.272) were not statistically associated with the FACT-C score. Variables with a *p*-value of greater than 0.25 were not included in the multivariate logistic regression model. A higher *p*-value was used to guide variable selection as traditional levels ($p \leq 0.05$)

Independent Variable	Independent Variable Levels	*n*	OR	95% CI OR: Lower	95% CI OR: Upper	*p*
Age	*0-54*	35				.265
	55-64	58	.559	.235	1.331	.189
	65-74	119	.496	.226	1.088	.080
	Over 75	68	.437	.188	1.018	.055
Gender	*Female*	123				
	Male	159	.811	.506	1.300	.384
Change in Employment Status	*Remained/Became Engaged with Labour Force*	71				.079
	Remained Unengaged with Labour Force	165	1.110	.636	1.939	.713
	Became disengaged with Labour Force	45	2.303	1.060	5.002	.035
Hospital Type	*Centre of Excellence*	162				.006
	Private	24	.714	.295	1.724	.453
	Regional	98	2.141	1.278	3.586	.004
Insurance Status	*Any Private Health Insurance*	138				
	Medical Card/Public Health	145	1.790	1.118	2.868	.015
Co-Morbid Condition	*No Co-Morbid Condition*	62				
	Any Co-Morbid Condition	215	2.142	1.198	3.831	.010
Diagnosis	*Colon*	181				.816
	Rectal	63	.958	.540	1.700	.884
	Other	36	1.236	.602	2.537	.563
Time Since Diagnosis	*<2 years*	101				
	>2 years	161	.873	.530	1.436	.591
Disease Status	*In Remission*	218				
	Recurrence/Metastatic Disease/Uncertain	43	3.497	1.677	7.293	.001
Radiotherapy	*No Radiotherapy*	219				
	Any Radiotherapy	65	1.048	.602	1.824	.869
Chemotherapy	*No Chemotherapy*	123				
	Any Chemotherapy	161	1.431	.893	2.293	.136
Surgery	*No Surgery*	24				
	Any Surgery	259	1.287	.556	2.978	.556
CC-18 (PCCQ)	*Satisfied with Continuity of Care*	178				
	Dissatisfied with Continuity of Care	108	2.931	1.776	4.839	.000
Care Plan	*Care Plan*	75				
	No Care Plan	207	1.247	.734	2.117	.414
Treatment Summary	*Treatment Summary*	96				
	No Treatment Summary	183	1.077	.657	1.766	.768
Named Nurse Contact	*Named Nurse Contact*	226				
	No Named Nurse Contact	54	1.372	.754	2.498	.301
Named Doctor Contact	*Named Doctor Contact*	225				
	No Named Doctor Contact	57	2.286	1.242	4.206	.008
Hospital Staff Supportive	*Hospital Staff Supportive*	268				
	Hospital Staff Never Supportive/Unneeded	14	1.237	.418	3.663	.700
General Practice Staff Supportive	*General Practice Staff Supportive*	214				
	General Practice Staff Never Supportive/Unneeded	67	1.015	.586	1.758	.958
Health and Social Services Staff Supportive	*Health and Social Services Staff Supportive*	170				
	Health and Social Services Staff Never Supportive/Unneeded	109	.763	.471	1.236	.272
Any Cancer Support	*Did not use Cancer Support Groups*	238				
	Used Cancer Support Groups	42	2.674	1.307	5.472	.007
SD-16 (SDI)	*< 10 Social Difficulties*	252				
	≥ 10 Social Difficulties	34	39.947	5.380	296.607	.000
Number of Unmet Needs	*None*	87				.005
	1 to 3	118	1.613	.919	2.828	.096
	4 to 6	52	3.507	1.691	7.275	.001
	7 to 9	15	3.118	.981	9.912	.054

Table 6.39 Predictors of quality of life on the Functional Assessment of Cancer Therapy–Colorectal (FACT-C) scale identified in univariate logistic regression analysis

are too stringent and may result in relevant variables being excluded from the analysis when they are in fact associated with the outcome in multivariate analysis (Hosmer & Lemeshow 1989).

6.6.5 Backwards Stepwise Regression Modelling

The objective of the multivariate regression analysis was to identify the variables which most likely predicted colorectal cancer survivors' likelihood of scoring lower (FACT-C <116.0=0) or higher (FACT-C ≥116.0=1) quality of life. Once the pre-modelling checks were complete, 12 independent variables met the assumptions and level of significance set for inclusion in the binary regression analysis model (*Age, Change in Employment Status, Hospital Type, Insurance Status, Co-morbid Condition, Disease Status, Any Chemotherapy, Satisfaction with Continuity of Care, Access to a Named Doctor, Any Cancer Support, Social Difficulties* and *Number of Unmet Needs*). All independent variables were categorical. One was ordinal (*Age*), two were nominal measures (*Change in Employment Status* and *Hospital Type*), and eight were dichotomous (*Co-Morbid Condition, Disease Status, Any Chemotherapy, Satisfaction with Continuity of Care, Access to a Named Doctor, Any Cancer Support, Social Difficulties and Number of Unmet Needs*). Backwards stepwise regression was used to aid selection of the most appropriate combinations of variables to explain the maximum amount of variation in FACT-C scores. Although highly criticised, stepwise regression is an acceptable approach to exploratory research, as it assists the researcher in generating regression models by continuously evaluating the independent variables which may be removed from the model without substantially influencing the goodness of fit (Lomax & Hahs-Vaughn 2012, Field 2013). Therefore, all independent variables were entered into the model simultaneously.

Fifty-one cases had missing values on independent variables (17.8%). Using listwise deletion, SPSS removed these cases from the analysis automatically, leaving a total of 235 cases for analysis (82.2%). There was one outlying studentised residual with a value of -3.276 standard deviations which was kept in the analysis. Analysis of the outlier revealed this was a genuine outlier, the participant's FACT-C score of 116.6 placed them in the *Higher Quality of Life* category, however the participant had a clinically significant level of social difficulty (SD-16=15.0), thus the model predicted the participant's grouping should have been the *Lower Quality of Life* category. The backward regression model was run with, and without the outlying case, in both cases, a test of the full model with all 12 independent variables included was statistically significant compared to the constant-only model[2]. Further analysis of the outlying case[3] led to the decision to retain the case in subsequent analysis. The Hosmer and Lemeshow goodness of fit test was not statistically

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[2] Outlier retained model: χ^2(18, *n*=235)=72.20, *p*≤0.0005; Outlier excluded model: χ2(18, *n*=234)=78.27, *p*≤0.0005).

[3] The outlying case accounted for <5% of the of cases with a standardised residual of >2. Cook's distance of the outlying case was 0.997, DFBeta values were <2 and the leverage value of the case (0.085) was within the limit of 3(K+1)/n recommended by Stevens (2002).

significant, confirming improvement of the model fit compared to the constant-only model χ^2(8, *n*=235)=4.99, *p*=0.759. The model had a sensitivity of 61.9% and a specificity of 72.6%, with an overall successful classification rate of 67.2%. The positive predictive rate of the model was 69.5% and the negative predictive rate was 65.4%. Finally, the Cox & Snell and Nagelkerke pseudo-R^2 statistics indicated the model explained between 26.5% and 35.3% of variance within the model.

Despite these positive diagnostics, many independent variables were not found to contribute to the model in a statistically meaningful way. Only *Disease Status* (*p*=0.043), *Use of Any Cancer Support* (*p*=0.027) and *Social Difficulties* (*p*=0.002) were statistically significant in the first step of the model. The backward stepwise command in SPSS produced seven further iterations of the model, six variables that did not contribute significantly to the model were removed in the order *Age Group* (Wald χ^2(3)=1.129, *p*=0.770), *Number of Unmet Needs* (Wald χ^2(3)=1.619, *p*=0.655), *Access to a Named Doctor* (Waldχ^2(1)=0.298, *p*=0.585), *Change in Employment Status* (Wald χ^2(2)=1.292, *p*=0.524), *Any Chemotherapy* (Wald χ^2(1)=0.502, *p*=0.479), *Hospital Type* (Wald χ^2(2)=1.867, *p*=0.393), and *Any Co-Morbid Conditions* (Wald χ^2(1)=1.933, *p*=0.164). Each version of the model demonstrated a statistically significant ability to differentiate between those who would indicate a higher and lower quality of life (*p*≤0.0005), the model demonstrated acceptable goodness of fit (*p*>0.05) and explained between 24.3% and 34.8% of the variance within each model.

The eighth step of the model (Model Eight) included *Insurance Status, Disease Status, Satisfaction with Continuity of Care, Use of Cancer Support* and *Social Difficulties* (Table 6.40). Compared to the constant-only model, this version of the model was statistically significant (*p*≤0.0005). The Hosmer and Lemeshow test of goodness of fit indicated the model fit had improved on the constant-only model fit (χ^2(5, *n*=235)=1.48, *p*=0.915). Pseudo-R^2 results indicated the model explained between 23.7% and 31.6% of variance. The model had a sensitivity of 60.2% and a specificity of 76.9%, with an overall successful classification rate of 68.5%, an improvement on the constant-only rate (50.2%). The positive predictive value of the model was 72.5% and the negative predictive value was 65.7%. *Insurance status* (*p*=0.038), *Disease Status* (*p*=0.012)*, Satisfaction with Continuity of*

Step	**Variable**	**B**	**S.E.**	**Wald**	**df**	**Sig.**	**Exp(B)**	**95% CI for EXP(B)**	
								Lower	**Upper**
8	*Uninsured (Medical Card/Public Health)*	.626	.302	4.312	1	.038	1.871	1.036	3.379
	Recurrent/Metastatic Disease	1.092	.436	6.290	1	.012	2.981	1.270	6.999
	Less Satisfied with Continuity of Care	.746	.309	5.818	1	.016	2.108	1.150	3.863
	Use of Any Cancer Support Group	1.126	.432	6.793	1	.009	3.084	1.322	7.194
	Clinically Significant Social Difficulties	3.542	1.041	11.573	1	.001	34.549	4.489	265.930
	Constant	-1.169	.258	20.547	1	.000	.311		

Table 6.40 Results of the final logistic regression model (Model 8) generated through the backwards stepwise procedure in SPSS

Care (p=0.016)*, Use of Cancer Support* (p=0.009) and *Social Difficulties* (p=0.001) each significantly contributed to the model.

However, when comparing the iterations of the stepwise models, Model Seven (Table 6.41) appeared to perform marginally better than step eight (Table 6.40). Similar to Model Eight, Model Seven was statistically significant compared to the constant-only model ($p \leq 0.0005$). The Hosmer and Lemeshow statistic was also acceptable $\chi^2(7, n=235)=4.09$, p=0.770. The pseudo-R^2 results indicated the model performed marginally better explaining between 24.3% and 32.4% of variance. Furthermore, the sensitivity (63.6%), specificity (74.4%), overall successful classification rate (68.9%), and positive (71.4%) and negative (66.9%) predictive values were comparable or better than Model Seven. Within this model, *Insurance Status* (p=0.044), *Disease Status* (p=0.017)*, Satisfaction with Continuity of Care* (p=0.023)*, Use of Cancer Support* (p=0.010) and *Social Difficulties* (p=0.001) each significantly contributed to the model, however, *Co-Morbid Conditions* did not (p=0.164; Table 6.41).

Step	**Variable**	**B**	**S.E.**	**Wald**	**df**	**Sig.**	**Exp (B)**	**95% CI for EXP(B)**	
								Lower	**Upper**
7	*Uninsured (Medical Card/Public Health)*	.609	.303	4.048	1	.044	1.839	1.016	3.330
	Any Co-morbid Condition	.519	.373	1.933	1	.164	1.680	.808	3.491
	Recurrent/Metastatic Disease	1.047	.437	5.743	1	.017	2.850	1.210	6.711
	Less Satisfied with Continuity of Care	.706	.311	5.142	1	.023	2.025	1.100	3.726
	Use of Any Cancer Support Group	1.107	.432	6.551	1	.010	3.024	1.296	7.056
	Clinically Significant Social Difficulties	3.589	1.045	11.785	1	.001	36.187	4.664	280.783
	Constant	-1.546	.383	16.281	1	.000	.213		

Table 6.41 Results of Model 7 of the logistic regression model generated through the backwards stepwise procedure in SPSS

6.6.6 Forced Entry Regression Model

As a final step, a decision was taken to compare Model Seven and Model Eight by re-running each using a standard forced entry approach. The variables of Model Eight were entered in block one in the order: *Insurance Status, Disease Status, Satisfaction with Continuity of Care, Use of Cancer Support* and *Social Difficulties.* The variables of Model Seven were entered in block two in the order: *Insurance status, Co-Morbid Conditions, Disease Status, Satisfaction with Continuity of Care, Use of Cancer Support* and *Social Difficulties.* By doing so, all participants that responded to the independent and dependent variables were included in the model. Forty cases (14%) had missing values and were excluded from the analysis, leaving a total of 246 cases available for analysis (86%). A single outlier was identified on the casewise list, with a studentised residual value of -3.674 standard deviations. Using the same procedures outlined in Section 6.6.5, the forced entry model was run including and excluding the outlying case, in both cases the models were statistically significant compared to the constant-only model for Model Seven[4] and Model Eight[5]. Similar to the backward stepwise regression modelling strategy (Section 5.6.5), the results of further analysis of the outlying case were all within recommended parameters[6]. Therefore, the case was retained in further analysis.

6.6.6.1 Model Seven (Block Two)

The model's ability to differentiate between those who would indicate higher and lower quality of life was statistically significant (χ^2(6, *n*=246)=69.88, *p*≤0.0005), and the Hosmer and Lemeshow test indicated acceptable goodness of fit (χ^2(7, *n*=240)=2.77, *p*=0.906). The Cox & Snell and Nagelkerke pseudo-R^2 indicated the model explained between 24.7% and 33.0% of variance within the model. The model sensitivity value indicated 62.9% of true positives were correctly classified, and the specificity value indicated 75.4% of true negatives were correctly classified, with an overall successful classification rate of 69.1%. The positive predictive rate was 72.2% and the negative predictive rate was 66.7%. All classification values were similar to the final step in the backwards stepwise regression model. However, in this model all but one predictor variable was significant. As in iteration 7 of the backward regression model, a diagnosis of *Any Co-Morbid Condition* did not contribute to the model in a statistically significant manner (*p*=0.078; Table 6.42).

Variable	B	S.E.	Wald	df	Sig.	Exp(B)	95% CI for EXP(B)	
							Lower	Upper
Uninsured (Medical Card/Public Health)	.629	.297	4.490	1	.034	1.875	1.048	3.354
Recurrent/Metastatic Disease	1.048	.432	5.870	1	.015	2.851	1.222	6.655
Less Satisfied with Continuity of Care	.726	.305	5.654	1	.017	2.067	1.136	3.761
Use of Any Cancer Support Group	1.116	.428	6.809	1	.009	3.054	1.320	7.064
Clinically Significant Social Difficulties	3.607	1.047	11.871	1	.001	36.859	4.736	286.881
Any Co-Morbid Condition	.647	.367	3.101	1	.078	1.909	.930	3.921
Constant	-1.651	.382	18.714	1	.000	.192		

Table 6.42 Results of the logistic regression model generated in Block 2 (Model 7) of the forced entry procedure in SPSS

6.6.6.2 Model Eight (Block One)

In the forced entry procedure, the model generated in block one was statistically significant compared to the constant-only model χ^2(5, *n*=246)=66.67, *p*≤0.0005. The goodness of fit of the model achieved an acceptable significance level χ^2(6, *n*=246)=1.53, *p*=0.957. Between 23.7% and 31.7% of variance in the model was explained by the independent variables according to the Cox & Snell and Nagelkerke pseudo-R^2 statistics. The model sensitivity value indicated 59.7% of true

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[4] Model Seven Outlier Retained: χ^2(5, *n*=246)=69.88, *p*≤0.0005; Outlier Excluded: χ^2(5, *n*=245)=75.80, *p*≤0.0005.

[5] Model Eight Outlier Retained: χ^2(5, *n*=246)=66.67, *p*≤0.0005; Outlier Excluded: χ^2(5, *n*=245)=72.08, *p*≤0.0005.

[6] The outlying case accounted for <5% of the of cases with a standardised residual of >2. Although the residual had a Cook's distance of 1.04, DFBeta values were <2 and the leverage value of the case (0.072) was within the limit of 3(K+1)/n recommended by Stevens (2002).

positives were correctly classified, and the specificity value indicated 77.9% of true negatives were correctly classified, with an overall successful classification rate of 68.7%. The positive predictive rate was 73.3% and the negative predictive rate was 65.5%. Finally, in this model, all predictor variables were significant (*p*=0.001; Table 6.43). Compared to Model Seven, Model Eight achieved better goodness of fit. Although Model Eight explained a marginally smaller amount of variance, the sensitivity, specificity and significance of variables included in the Model indicate that it is a more appropriate model to explain the factors which may predict quality of life among colorectal cancer survivors.

Variable	B	S.E.	Wald	df	Sig.	Exp(B)	95% CI for EXP(B)	
							Lower	Upper
Uninsured (Medical Card/Public Health)	.638	.295	4.690	1	.030	1.893	1.062	3.374
Recurrent/Metastatic Disease	1.105	.430	6.599	1	.010	3.019	1.299	7.015
Less Satisfied with Continuity of Care	.785	.303	6.722	1	.010	2.191	1.211	3.965
Use of Any Cancer Support Group	1.140	.427	7.129	1	.008	3.126	1.354	7.216
Clinically Significant Social Difficulties	3.544	1.041	11.591	1	.001	34.590	4.498	266.008
Constant	-1.180	.256	21.244	1	.000	.307		

Table 6.43 Results of the logistic regression model generated in Block 1 (Model 8) of the forced entry procedure in SPSS

6.6.7 Interpretation of the Final Multivariate Regression Model Results

To illustrate the relationship between each independent variable and colorectal cancer survivors' quality of life, the odd's ratios derived from Model Eight are interpreted (Column Exp(B), Table 6.43). The results of odd's ratios indicate the probability that a colorectal cancer survivor will report a lower level of quality of life (FACT-C <116.00). The strongest predictor of a lower quality of life report was a clinically significant level of social difficulty (SD-16 score ≥10). Holding all covariates constant, those with more social difficulty were over 34 times more likely to record a lower quality of life score than those without social difficulty (Wald χ^2(1)=11.59 *p*=0.001, *OR*=34.590, 95% CI [4.498, 266.008]). Those who attended any form of cancer support were three times more likely to report lower levels of quality of life than those who had not availed of such support (Wald χ^2(1)=7.129, *p*=0.008, *OR*=3.126, 95% CI [1.354, 7.216]). Disease status was the third ranked variable contributing to the model, those who were living with metastatic or recurrent disease, or who were uncertain about their disease at the time of the study were three times more likely to report lower quality of life scores as those who were in remission (Wald χ^2(1)=6.599, *p*=0.010, *OR*=3.019, 95% CI [1.299, 7.015]). Any dissatisfaction with continuity of care was associated with a greater likelihood of reporting poorer quality of life scores compared to those who indicated satisfaction on all PCCQ subscales (Wald χ^2 (1)=6.722, *p*=0.010, OR=2.191, 95% CI [1.211, 3.965]). Finally, not having private health insurance was significantly associated with reports of poorer quality of life among colorectal cancer survivors compared to those who reported having health insurance (Wald χ^2(1)=4.690, *p*=0.030, *OR*=1.893, 95% CI [1.062, 3.374]).

Although access to and support from healthcare professionals was not associated with quality of life in the logistic regression model, they may have an indirect relationship mediated by survivors' continuity of care. Chi-square analysis revealed colorectal cancer survivors who had access to a named nurse ($\chi^2(1)=10.592$, $p=0.001$, $OR=2.678$, 95% CI [1.461-4.908]), a named doctor ($\chi^2(1)=14.479$, $p\leq 0.0005$, $OR=4.098$, 95% CI [1.704-5.635]), or another healthcare professional ($\chi^2(1)=7.389$, $p=0.007$, $OR=2.621$, 95% CI [1.285-5.344]) and who felt supported by hospital staff ($\chi^2(1)=7.080$, $p=0.008$, $OR=4.433$, 95% CI [1.354-14.513]) or general practice staff ($\chi^2(1)=5.097$, $p=0.024$, $OR=1.888$, 95% CI 1.083-3.292]) were more likely to report greater satisfaction with overall continuity of care.

6.7 Chapter Summary

This chapter presented the results of the statistical analysis of survey data within this mixed methods study to explore the impact of healthcare experiences upon the quality of life of colorectal cancer survivors between six months and five years following diagnosis who are receiving follow-up care in tertiary oncology healthcare settings in Ireland. The results of the statistical analysis suggest that the majority of colorectal cancer survivors rate their quality of life positively, despite experiencing ongoing symptoms in the aftermath of treatment. A relatively small proportion of the sample reported social difficulty, unmet information needs, inadequate continuity of care or difficulties accessing information or support from healthcare professionals in the aftermath of treatment. Few survivors accessed advocacy-led cancer support services, most believed they did not require these services or had adequate support from family, friends or healthcare professionals. Comparison between colorectal cancer survivors' quality of life scores in the context of demographic, cancer-related, and healthcare outcomes variables revealed several variables were independently associated with differences in survivors' quality of life scores and guided the development of a logistic regression model.

Univariate regression analysis identified 12 variables which potentially contributed to predicting colorectal cancer survivors' likelihood of experiencing higher or lower quality of life up to five years following diagnosis. Backward stepwise regression modelling indicated five of these variables contributed meaningfully to the statistical model: 1) insurance status, 2) disease status, 3) satisfaction with continuity of care, 4) use of cancer support and 5) social difficulties. Chapter Six will now report the analysis of qualitative interviews designed to explore colorectal cancer survivors' individual and complex experiences of quality of life outcomes and healthcare experiences and gain further insight into survivors' interpretation of the potential impact of healthcare experiences upon their quality of life outcomes.

Chapter Seven – Phase 2 Interview Findings

7.1 Introduction

This chapter presents the qualitative Phase 2 findings of this mixed method study. The qualitative phase extends and enhances the results of the quantitative Phase (Chapter Six), offering an in-depth exploration of the individual experiences and complexities of colorectal cancer survivors' quality of life outcomes, providing a more in-depth understanding of the potential impact of healthcare experiences upon survivors' quality of life. The specific objectives of the qualitative phase of this study were:

1. To explore the impact of physical, psychological and social effects upon colorectal cancer survivors' quality of life,
2. To provide a contextual understanding of the healthcare experiences and unmet needs reported by colorectal cancer survivors in the quantitative study, and
3. To map the formal and informal sources of support enlisted by colorectal cancer survivors to address unmet information and supportive care needs.

The findings were derived from 1) interviews with 22 colorectal cancer survivors about their quality of life and experiences of healthcare in relation to their colorectal cancer, 2) survey margin comments and 3) responses to open-ended survey items provided by 276 colorectal cancer survivors. The themes emerging from each dataset were consistent. However, the interview data provided the richest representations of the themes. Therefore, the illustrative quotations used to represent each theme are largely derived from interview data.

The chapter opens with an overview of the characteristics of the interview participants (Section 7.2). The findings are presented in four sections. Section 7.3 discusses survivors' recollections of quality of life during the period of diagnosis and treatment, which continued to impact upon them in later stages of survivorship. Section 7.4 describes the impact of physical, psychological and social issues experienced by colorectal cancer survivors at the time of the study. Section 7.5 examines survivors' dialogues about their experiences of the healthcare system from the time of diagnosis to their current stage of follow-up. This section describes the healthcare factors which survivors believe have influenced their well-being and shaped their experience of survivorship during diagnosis and treatment (Section 7.5.1) and follow-up for colorectal cancer (Section 7.5.3). Section 7.6 identifies the resources and strategies colorectal cancer survivors use to overcome unmet needs in their follow-up care. The findings of this section will demonstrate that survivors' quality of life experiences appear to be influenced and driven by a multitude of met and unmet needs, suggesting that quality of life is influenced by survivors' experiences of the healthcare system. Access to a network of support structures beyond the realms of the traditional healthcare system are essential

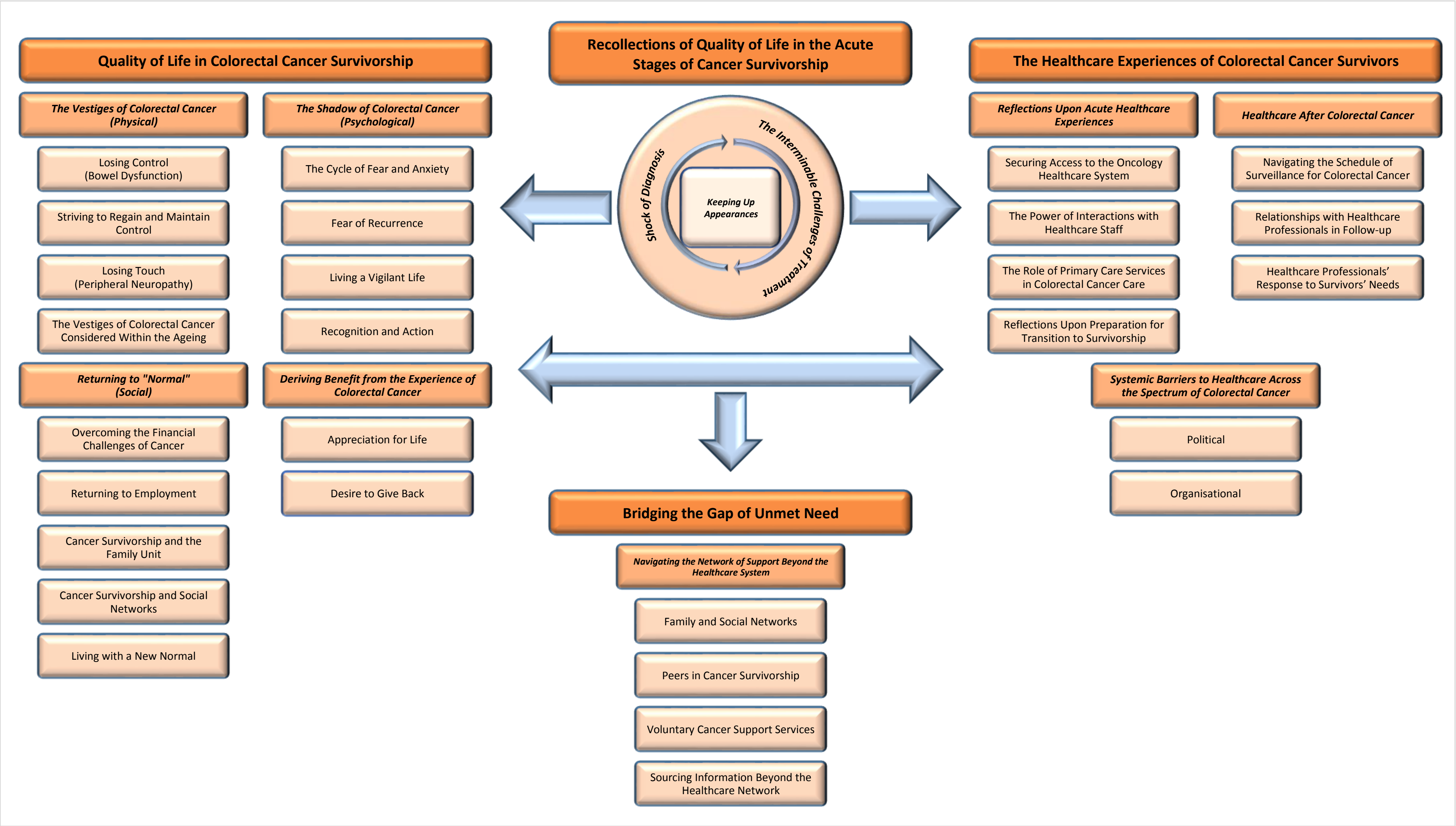

Figure 7.1 Conceptual map of the results of qualitative data analysis

to support survivors to overcome the needs which the healthcare system fails to satisfy. A thematic map illustrating the main findings of the qualitative phase of this study is presented in Figure 7.1.

7.2 Characteristics of Interview Participants

Table 7.1 and Table 7.2 present the characteristics of the Phase 2 sample, derived from Phase 1 surveys. The Phase 2 sample had an average age of 64. Most were male (54.5%, *n*=12) and lived with family members (81.8%, *n*=18). Thirteen survivors had colon cancer, and nine had rectal cancer. Many survivors were more than three years since diagnosis (68.2%, *n*=15) and in remission (90.9%, *n*=20). Two survivors disclosed active disease at the time of the interview (9.1%, *n*=2); one experienced disease recurrence since participating in the survey. Five participants had an ostomy; seven had undergone reversal of a temporary ostomy. Most had private health insurance (59.1%, *n*=13) and more than half were satisfied with their continuity of care (54.5%, *n*=12). Few used cancer support services (18.2%, *n*=4), or expressed social difficulties (31.8%, *n*=7). Nine survivors had FACT-C scores above the median cut-off of 116 (40.9%).

Variable	Response	n	%
Age Group (N=22)	*<50*	4	18.2
	50-65 years	8	36.4
	>65 years	10	45.5
Gender (N=22)	*Male*	12	54.5
	Female	10	45.5
Living Arrangement (N=22)	*Alone*	4	18.2
	With Partner/Spouse/Family/Friends	18	81.8
Diagnosis (N=22)	*Colon*	13	59.1
	Rectum	9	40.9
Time Since Diagnosis (N=22)	*<2 years*	7	31.8
	>2 years	15	68.2
Presence of an Ostomy (N=22)	*Ostomy*	5	22.7
	None	10	45.5
	Reversed	7	31.8
Insurance Status (N=22)	*Private*	13	59.1
	Medical Card/Public	9	40.9
Disease Status (N=22)	*In Remission*	20	90.9
	Active Disease	2	9.1
Continuity of Care (N=22)	*More Satisfied*	12	54.5
	Less Satisfied	10	45.5
Use of Cancer Support (N=22)	*No*	18	81.8
	Yes	4	18.2
Social Difficulties (N=22)	*No*	15	68.2
	Yes	7	31.8
FACT-C (N=22)	*Higher*	9	40.9
	Lower	13	59.1
Regression Model (n=22)	*Fit*	5	22.7
	Non-Fit	17	77.3

Table 7.1 Summary of the characteristics of colorectal cancer survivors participating in the Phase 2 interviews

Variable	RCM001	RSM018	RCM013	RSM028	RSM048	ESM036	ESM158	ESM073	ESM043	RSM019	PCM015
Age	61	61	65	75	54	57	50	69	47	49	74
Gender	Female	Male	Male	Female	Male	Female	Female	Female	Male	Female	Male
Diagnosis	Rectum	Rectum	Colon	Colon	Colon	Colon	Colon	Rectum	Colon	Rectum	Rectum
Time Since Diagnosis	4 to 5 years	3 to 4 years	1 to 2 years	3 to 4 years	4 to 5 years	3 to 4 years	1 to 2 years	3 to 4 years	4 to 5 years	1 to 2 years	3 to 4 years
Insurance Status	Public	Public	Private	Private	Public	Private	Private	Public	Public	Public	Private
Disease Status	Active	Remission	Remission	Remission	Remission	Remission	Remission	Remission	Remission	Remission	Remission
Continuity of Care	Less Satisfied	Less Satisfied	More Satisfied	More Satisfied	Less Satisfied	More Satisfied	Less Satisfied	More Satisfied	Less Satisfied	More Satisfied	More Satisfied
Use of Cancer Support	No	Yes	No	No	No	No	Yes	No	Yes	No	No
Social Difficulties	No	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	No
FACT-C	Lower	Lower	Lower	Lower	Higher	Lower	Higher	Lower	Lower	Lower	Lower
Regression Model Fit	No	No*	No	No	No	No	No	No	No*	No	Contrary[1]

Table 7.2 Characteristics of colorectal cancer survivors participating in the qualitative interviews

Variable	ESM003	RSM027	ESM005	PCM026	PCM012	PCM031	PCM018	ESM006	ESM087	ESM121	RCM049
Age	65	64	56	70	70	73	70	68	50	78	71
Gender	Male	Male	Male	Female	Male	Female	Male	Male	Female	Female	Male
Diagnosis	Colon	Colon	Colon	Colon	Rectum	Colon	Colon	Colon	Rectum	Rectum	Rectum
Time Since Diagnosis	2 to 3 years	4 to 5 years	4 to 5 years	1 to 2 years	3 to 4 years	<1	<1	2 to 3	2 to 3 years	1 to 2 years	4 to 5 years
Insurance Status	Public	Public	Private	Private	Private	Private	Private	Private	Private	Private	Public
Disease Status	Remission	Remission	Remission	Remission	Remission	Active	Remission	Remission	Remission	Remission	Remission
Continuity of Care	Less Satisfied	More Satisfied	More Satisfied	Less Satisfied	More Satisfied	Less Satisfied	More Satisfied	More Satisfied	Less Satisfied	More Satisfied	Less Satisfied
Use of Cancer Support	No	No	No	No	No	No	No	No	Yes	No	No
Social Difficulties	No	No	No	No	No	No	No	No	No	No	No
FACT-C	Lower	Lower	Higher	Higher	Higher	Lower	Higher	Higher	Higher	Higher	Lower
Regression Model Fit	No	No	Yes	No	Yes	No	Yes	Yes	No	Yes	No

*Cases meeting all criteria for model fit except Disease Status; [1]Contrary Case

Table 7.2 (Continued) Characteristics of colorectal cancer survivors participating in the qualitative interviews

Interview participants were selected using a maximum variation sampling strategy (Section 5.3.3.2). This strategy ensured variables of interest were adequately represented, particularly the variables of the logistic regression model (Table 6.43). Five interviewees' survey responses aligned with the positive regression model (i.e. survivors who reported higher quality of life [FACT-C >116] and whose responses on *Insurance Status, Disease Status, Satisfaction with Continuity of Care, Use of Cancer Support* and *Social Difficulties* matched responses predicting better quality of life). Section 6.6.7 showed that survivors living with recurrent or metastatic disease were more likely to experience poorer quality of life. However, it was difficult to recruit participants whose survey responses fit the negative regression model as many may have succumbed to their disease or were too ill to participate in interviews. The negative model refers to survivors who reported lower quality of life (FACT-C ≤116) and whose responses on *Insurance Status, Disease Status, Satisfaction with Continuity of Care, Use of Cancer Support* and *Social Difficulties* matched responses predicting lower quality of life. Two survivors who reported active disease were selected to ensure the experiences of this group were explored. Otherwise, two participants met all criteria meeting the negative model. One participant was a contrary case, in other words, his responses did not fit within the model at all (Table 7.2).

7.3 Recollections of Quality of Life in the Acute Stages of Cancer Survivorship

Although the qualitative phase of the study intended to explore colorectal cancer survivors' quality of life and healthcare experiences at the time of the study, it was evident that survivors' well-being was heavily influenced by their experiences and *Recollections of Quality of Life* during diagnosis and treatment. When asked about their quality of life, survivors offered lengthy accounts of anxiety, depression and the physical effects experienced during diagnosis and treatment. However, many described the importance of retaining power and normality despite their disease. This assisted some interviewees to reframe their experiences of illness positively, emerging from illness as a stronger person. These descriptions are represented in the themes: *The Shock of Diagnosis*, *The Interminable Challenges of Treatment* and *Keeping up Appearances*.

7.3.1 The Shock of Diagnosis

Anxiety was described as a response to confrontation with cancer, but not necessarily at the point of diagnosis. Confrontation with the disease was a consequence of the disease becoming visible, which may have occurred prior to diagnosis, shortly after diagnosis, or at some point during treatment or survivorship. Pre-diagnosis visibility occurred when survivors saw the malignancy in their bowel during colonoscopy or experienced rectal bleeding or changes in bowel habit.

> *"When the colonoscopy was going on I asked the doctor could I see … what was happening, everything was pink for a while, and then of a sudden there was black, so I knew straight*

> *away then it was only a matter of how we'd get it out and get on with it." [PCM018, Interview]*

Peri-diagnosis visibility occurred where the survivor sought information about the disease and treatment processes. Two survivors described searching for videos and images of the surgery, so they could see what their bodies would be subjected to.

> *"I Googled it, you know, so I sort of knew what area I was looking at. So, yes, I did a bit of self-teaching, or research so to speak." [RSM048, Interview]*

Those whose disease became visible before or shortly after diagnosis seemed to experience lower levels of anxiety; they adopted confrontive coping mechanisms, describing intentions to fight or overcome their disease. On the other hand, some survivors did not consider themselves '*unwell*' at the time of diagnosis and were capable of continuing with life as normal during treatment. The absence of symptoms or the invisibility of disease fostered evasive coping mechanisms, challenged only when the disease or experience was made visible to them. Post-diagnosis visibility arose as a result of encounters with other cancer patients or developing disease- or treatment-related symptoms. Where evasive coping strategies were used, post-diagnosis disease confrontation triggered substantial anxiety:

> *"I was very fit and running around. So whilst the diagnosis is shocking, it's a little bit abstract because there was no physical [symptoms]. I didn't have a big lump coming out of my face, you know I couldn't see it or feel it … and then three weeks into the six weeks I had an allergic reaction, and then that was [like] being thrown off the ship into the middle of the sea. From that moment, absolutely, I was developing anxiety right from that moment, because I was put into a ward with extremely sick people." [ESM043, Interview]*

In the aftermath of diagnosis, worries and concerns are both individual and shared by survivors. Initial worries surrounded the extent of disease during the uncertain period of investigation. Most survivors were mindful that the possibility of successful treatment was highest if the disease was confined to the bowel. Survivors who were not experiencing symptoms, or whose diagnosis was discovered incidentally did not experience anxiety during the period of disease work-up, as they were confident about their prognosis:

> *"The funny thing is my husband was twice as worried as I was … I felt I was in very good health and that if it was far gone, I think I would have had some symptoms before that." [ESM121, Interview]*

Following diagnosis, worries for the family were related to the psychosocial well-being of the family unit, rather than the physical health of offspring and siblings. These concerns were especially prevalent among younger survivors, as they described fear and guilt at the possibility of leaving dependent children:

> *"The other thing as well that really came home to me was the kids, that they were really young, and I'd be gone, and they wouldn't have a father, that came into my mind a lot as well … it just dawned on me that if I die now, they won't have a father, and it'll be awful; I'll have kind of let them down I suppose, you know." [ESM005, Interview]*

These concerns were not shared by older participants, as they believed their children were now reared. However, older survivors were apprehensive about potentially passing the disease to their offspring. One survivor contrasted her worries for her young son during her treatment for cervical cancer 20 years previously, with her concerns for him as an adult since she had been diagnosed with colorectal cancer. At the time of her cervical cancer diagnosis, she expressed the fear that she could have left her son at a vulnerable age in his life:

> *"I didn't want to leave my son, who had just turned thirteen, they couldn't tell me before the operation how extensive the cancer was, they didn't know what they were going to find." [PCM026, Interview]*

Now in her seventies, diagnosed as a carrier of the hereditary nonpolyposis colorectal cancer gene and her son now an adult, her priorities and worries had changed. She described being more comfortable with her mortality. Although she was concerned for her son's welfare as a carrier of the hereditary nonpolyposis colorectal cancer gene, she was confident that any malignancy resulting from the genetic mutation would be identified early through routine surveillance:

> *"I haven't any immediate worries about [my son]. Okay, I wasn't happy when he was diagnosed with the gene, that wasn't good news obviously. But, as I say, he was called in very quickly and had a battery of tests … I've had cancer twice, I possibly will get it again and it possibly will kill me, but something is going to, so there's no point in worrying about it … I have my funeral all planned, so long as I go first I don't care." [PCM026, Interview]*

7.3.2 The Interminable Challenges of Treatment

Several survivors described themselves as '*sailing through*' chemo-radiotherapy, with few side-effects. However, those who underwent adjuvant chemotherapy for more advanced disease described contrasting experiences. Fatigue, insomnia, nausea, alterations in taste, appetite changes, skin irritations, diarrhoea, abdominal pain and neuropathic pain characterised the adjuvant treatment period. Survivors described difficulty determining which effects were a direct consequence of treatment and which were a consequence of medications used to manage treatment side-effects. Two participants described becoming disillusioned by the volume of medications they needed to take, which in turn affected compliance with medications for co-morbid conditions and anti-emetic regimes:

> *"The biggest physical [effect] of the chemo is the sickening feeling, I can taste it, the chemotherapy, you know, it's like a feeling inside your mouth, and it goes all the way down, right to your toes, and it's not nice, you know… if you keep taking the anti-sickness, you don't get the effect out of them. Now, I take them more or less when I really need them." [RSM027, Interview]*

Survivors spoke of being well-prepared for acute effects of chemotherapy; many had formal or informal meetings with an oncology nurse where the acute side-effects of treatment were outlined and supported by information leaflets. However, many did not believe they were well-prepared for long-term consequences of chemotherapy. Several participants described being well-prepared for the long-term implications of colorectal cancer surgery, including ostomy formation and bowel dysfunction. Only a few survivors highlighted a lack of preparation for the potential pain and trauma following surgery:

> *"[With the chemotherapy], they told me that this [neuropathy] may happen, and it might happen earlier, or it might happen later. It might never happen. So, it wasn't a surprise. Whereas with the surgery, they didn't tell me 'By the way, the next time we're seeing each other, you're going to be in a mess'. So, coming out of the anaesthetic was a total shock. I was shocked at the state of myself … it was extraordinarily traumatic; it was very painful." [ESM043, Interview]*

Depression was spoken of in the past tense by survivors. For many, depression was a *'low'* during treatment, a response to diagnosis, or difficulty coping with the acute effects of treatment. For some, the treatment schedule was '*interminable*', even those who began their treatment with optimism described a gradual physical and psychological '*wearing down*' during treatment. Some participants described a peak in depression in the days following chemotherapy, compounded by a sense of misery arising from nausea, fatigue and pain. Several survivors questioned their reasons for engaging with the treatment process, as they believed the acute adverse effects of treatment outweighed the benefit of remission. Two survivors described struggles with suicidal ideation during and shortly after treatment, suggesting they may have been better off if they allowed their cancer to take its natural course. However, both described how good days, when they felt well, and symptoms were successfully managed, reminded them that they could overcome treatment and could eventually resume their normal life:

> *"There was another thing that happened during the treatment, depression. Serious, serious depression … Like I mean at that time when I was going through, I had to go to bed everyday, I'd no energy, and you're in the bed so long that you're not sleeping, and then your mind is racing and depression sets in, and it's worse than alcoholic depression, I can tell you that. It is mind-numbing, you just feel like putting the gun in your mouth and pulling the trigger at times. Not that it would ever happen, I like life too much … but it was a sense of despair, you're saying to yourself, with all the side-effects of going through the chemo it's not worth it … and it'd be better if you hadn't even started it. It's worse than the disease … but then you'd wake up another morning, and you'd feel great, two or three days after the chemotherapy you'd sort of come back to yourself, and you'd be grand until the next dose." [ESM006, Interview]*

Family members, particularly spouses, were instrumental to survivors overcoming depression and suicidal thoughts. These participants felt family support was preferential to support from healthcare professionals or cancer support services:

> *"I'd say [my wife] was a great help to me; to keep me [going] … if I was living on my own or something, I don't think I could have coped; I'd probably be in a home or something." [RSM018, Interview]*

Overcoming depression at any point in the cancer journey required a variety of coping and self-management strategies. Some survivors took solace in the fact that the challenges of malignant illness and depression had strengthened them as a person:

> *"I think when you've come through an awful lot … of illness and whatever in your life, I think you become … a stronger person." [RSM048, Interview]*

7.3.3 Keeping Up Appearances

Survivors spoke about body image primarily in relation to the acute treatment period, focusing on hair loss and ostomy formation. Although eight participants discussed alopecia during interviews, only one actually experienced alopecia. Similarly, 18 survivors referred to ostomy formation, of whom five had never had an ostomy. Survivors who discussed ostomy or alopecia, but who had not experienced it, described themselves as having a lucky escape:

> *"I had the complete response to treatment and didn't have to have the follow-up chemotherapy; I would have lost my hair, I would have had serious side-effects to that, I was blessed in many ways." [ESM036, Interview]*
>
> *"It's great really because I never had any colostomy bag, I didn't have to go through all of that, you know that's huge … so it is easier for me to adjust, my little things are only small." [ESM158, Interview]*

For the single participant who suffered alopecia as a result of a chemotherapy regime designed to stabilise her metastatic disease, the psychological impact of alopecia was greater than she could have anticipated:

> *"The one thing which I think affected me more than I thought it would, was losing my hair, because I had invested a lot of time, sitting on a chair in the hospital using the cold cap. I was the poster-girl for the cold cap … I used it very, very successfully through twelve sessions of chemotherapy and it was great, my hair thinned a little bit, but it wasn't noticeable, and that makes you feel normal." [RCM001, Interview]*

Appearance was very important to both male and female interviewees. Several alluded to the stereotypical image of a cancer patient, appearing frail with alopecia and weight loss, describing how this helped them to reframe the seriousness of their illness:

> *"A lot of the ladies in [treatment] with me were in desperate bad shape. They had all lost their hair, and they were vomiting and constantly sick and all the rest of it. Whereas my chemotherapy; everything is relative, I think that made me feel even better about the chemotherapy … I kind of convinced myself then that I had a very mild form of chemotherapy." [ESM005, Interview]*

Many of the survivors felt they did not embody the appearance of a cancer patient, which gave them power and allowed them to retain control over an uncontrollable situation. Control lay in the survivor's ability to disclose their diagnosis on their own terms. Several described how retaining a normal appearance facilitated their projection of themselves as healthy and well, even during terminal illness. This meant that others in their social circles did not pity nor treat them differently, facilitating a semblance of normal life. This theme echoed throughout the trajectory of survivorship for many survivors.

> *"I was lucky enough not to be excessively ill throughout the chemotherapy … if you meet [neighbours and friends] with a gloomy face, they nearly cross the road to avoid you because they are sort of thinking to themselves 'Oh, things mustn't be good'. Whereas when they see you and go 'You are looking well', you think 'Thanks a million! It's great; I feel grand.' [Participant laughs] … so nobody is any the wiser really." [RCM001, Interview]*
>
> *"I didn't lose my hair, which was really very big, because I felt a bit more in control then, that I could tell people that I was sick, rather than people having that awkward feeling,*

> *coming over and not knowing what to say, because they knew when they'd see me, if I'd lost my hair. So that gave me a little bit of – that I still had a little bit of power if you like because at a time like that you're feeling very low." [ESM158, Interview]*

7.3.4 Theme Summary: Recollections of Quality of Life in the Acute Stages of Cancer Survivorship

This theme describes survivors' recollections of the early phases of cancer survivorship, from the shock of diagnosis to the interminable process of treatment. The findings of this theme extend the results of the first quantitative phase of the study, highlighting how recollections of diagnosis and treatment frame survivors' experiences of survivorship. Although survivors spoke of anxiety for their well-being in this phase of survivorship, this anxiety could be mediated by their belief that they had received an early diagnosis or had achieved disease visibility by coincidence or intent. It was evident in interviews that fears for the family eclipsed fear for the self in the initial stages of survivorship, as parents worried about leaving children at a vulnerable time in their lives or passing on the legacy of genetic cancer risk.

In the course of treatment, survivors described a paradox between extensive preparation for acute chemotherapy side-effects and long-term surgical side-effects, but a lack of preparation for chronic chemotherapy effects and the trauma experienced during the initial recovery from surgery. Treatment was an interminable process associated with a gradual waning of optimism and resolve. For some, this decline resulted in depression, exacerbated by the acute toxicities of treatment. Overcoming depression required a variety of coping strategies and support; family members were instrumental in this process.

Reframing the experience of illness was important within this theme. Many survivors described how surmounting the physical and psychological challenges of diagnosis and treatment could render them a stronger person. Appearance was critical to the process of reframing. Many survivors concluded their experiences could have been worse and other cancer survivors had more significant effects to contend with, such as alopecia, nausea, vomiting or an ostomy. Maintaining a normal appearance gave survivors power and a semblance of normality, as they retained control over who knew about their illness and in turn, how they were treated in society.

7.4 Quality of Life in Colorectal Cancer Survivorship

7.4.1 The Vestiges of Colorectal Cancer

The Vestiges of Colorectal Cancer describes the lasting physical effects of treatment and their psychosocial implications. During the interviews, ostomy formation, bowel dysfunction and neurological symptoms were the predominant and most impactful physical issues discussed by the sample and are dealt with within the sub-themes *Losing Control*, *Striving to Regain and Maintain Control* and *Losing Touch.* Smaller numbers of survivors also discussed ongoing challenges with fatigue, sleep disturbance and sexual function. Although these issues impacted upon survivors' quality of life and interfered with daily activities and intimate relationships, they were not given the same level of attention by survivors during interviews. It appeared the implications of bowel dysfunction and peripheral neuropathy were more pressing, as they affected quality of life in all domains. Therefore, the challenges of fatigue, sleep disturbance and sexual dysfunction are discussed within the sub-theme *The Vestiges of Colorectal Cancer Considered Within the Ageing Process*.

7.4.1.1 Losing Control

Losing Control referred to the changed bowel post-operatively and was discussed by ostomates and non-ostomates. Loss of control referred to the unpredictability of bowel function, whether the result of an ostomy or altered function of the bowel arising from treatment.

Ostomy was a much-feared outcome post-operatively. Although concerns voiced about ostomies were largely aesthetic and social, survivors also worried about the process of learning and mastering the skills required to live with the ostomy. Many survivors were prepared for the possibility of a temporary ostomy following surgery. Several described how their first act upon recovery from the anaesthetic was checking their body for an ostomy. Some survivors described trauma or devastation when they discovered their ostomy. Others believed the ostomy, whether permanent or temporary, was a price to pay for being alive:

> *"That was a dread … how you're going to clean it, how you're going to empty it. How you're going to cope with it?" [PCM012, Interview]*
>
> *"When I woke up after they took my tumour, the first thing I did was pull back the blanket, saw the bag and I lost it." [RSM019, Interview]*
>
> *"It's permanent … [I told myself], it's the bag or the box, so when it's that choice, of course, you choose life." [ESM087, Interview]*

Although most survivors with ostomies eventually became experts in managing their ostomy, many relayed struggles learning to manage the ostomy following surgery. Some used imagery of returning to childhood, as they learned the mechanics of their shortened bowel. This imagery was reinforced by the struggles of equipment failures, accidents and loss of bowel control:

> *"I had no sensation … you don't realise you're going to the toilet. I had an ileostomy, as they call it, which is very high up and you don't actually realise half the time that you're going … I could wake up in the morning, and you're a baby again, it might have come away." [ESM036, Interview]*

Several female survivors described being worried about others seeing the ostomy under their clothing, or overhearing noises from the ostomy. These concerns were often associated with a fear of embarrassment. Many of these survivors required reassurance from close friends or family members that the ostomy was concealed and that only those the survivor chose to inform were aware of its presence. However, herniation at the ostomy site hindered concealment of the ostomy:

> *"I'm always conscious of it because it's very obvious. No matter what I wear, I feel I can't hide the stoma, especially if I'm wearing something lighter than this. You can actually see*

> *the ridge of the stoma, the opening because it's actually sitting up on top of the hernia … so ascetically it would bother me a little bit." [RCM001, Interview]*

The majority of those who struggled to accept their ostomy had temporary ostomies; reversal of the ostomy was a much-anticipated event for many of this group. However, many were disappointed that the timeframe to reversal was often underestimated by healthcare professionals and expressed frustration at postponements of the procedure. Many who had their ostomy reversed were shocked by continuing loss of bowel control which affected some from the moment they woke following the reversal. This loss of control was also relayed by a small number of survivors who never had an ostomy. Bowel dysfunction symptoms discussed included urgency, frequency, incomplete evacuation and incontinence due to loss of sensation in the bowel. Many survivors described how they lived with constipation, diarrhoea, or a combination of both. Two survivors experienced bowel obstructions due to constipation in the years following treatment. Pain associated with bowel dysfunction was related to abdominal cramps and perianal pain arising from haemorrhoids and skin excoriation.

> *"I had no control over the bowel movement … my rear end got very excoriated, which was a big problem really to me, even to walk and wearing pads was one thing, but even that wasn't able to control nothing for me really … I really couldn't go anywhere because even in the shower or out of the shower the movement would come … it was very, very liquid and it was more like acid, it just really made my rear end rather, rather bad." [RCM049, Interview]*

A small group of survivors described how bowel dysfunction settled down over time. However, many interviewees relayed ongoing issues, in some cases intermittent, but almost daily for two. Of those who continued to experience difficulties, six described hiding away from society to ensure they were near a toilet or to avoid the embarrassment of incontinence. Hiding away encompassed narratives of social isolation and disruption of social events due to faecal urgency, frequency or incontinence. In two cases, hiding away manifested as social isolation and was associated with depression and sleep disturbance:

> *"I have constant diarrhoea, I would have five, six, maybe even seven bowel movements a day, so I never like to be too far from a toilet … and that has affected my confidence in going out, it would make me more inclined to stay in … I'm not down about it, but I would say I am probably giving up on a social life sooner than I should be." [RSM028, Interview]*

Loss of control was not limited to bowel dysfunction; two interviewees discussed the impact of urinary incontinence resulting from surgery. Another attributed urinary incontinence to the progression of Parkinson's disease. Urinary incontinence also necessitated use of pads and caused skin irritation and embarrassment:

> *"I had collateral damage to my bladder, and I only have about a third capacity. As the time has gone on, I don't have any sensation that I need to go, so I have to wear pads all the time. They irritate me. I'm always conscious that they might smell. I find if I'm going out with my friends I would like to think that the loo would be on the ground floor or I'd be near it, it would be the first thing I'd seek out when I'd go anywhere." [RCM001, Interview]*

7.4.1.2 Striving to Regain and Maintain Control

Normality was important to ostomates and non-ostomates, and several accounts suggested survivors' beliefs about normality heavily influenced their psychosocial well-being. Three survivors questioned whether they would ever be '*normal*' again. Although these survivors discussed the importance of diet in regaining control of their bowel, they described significant continuing anxiety and social isolation due to bowel dysfunction. On the other hand, a substantial proportion alluded to the '*new normal*' of bowel dysfunction. There was a sense these survivors had grown to accept the challenges of their bowel:

> *"You're completely different; your bowel is completely different, it now rules the roost." [ESM036, Interview]*

Survivors living a '*new normal*', devised a system of strategies to manage and live with bowel dysfunction. These participants described '*trial and error*' processes to identify patterns of bowel function and foods triggering altered bowel habit. Some survivors acknowledged the role of information from healthcare professionals in this process. Although some survivors believed the implications of diet for bowel dysfunction were highly individualised, most deemed the information conveyed by healthcare professionals insufficient and desired more assistance in this area from oncology nurses and dieticians. Only two survivors discussed pelvic floor exercises to retrain the bowel in the aftermath of treatment:

> *"I have to manage that [diet] myself, on a trial of hit and miss. There's been no shortage of effort in [Hospital] to assist me on that. But the knowledge basis is very shallow, I would say … the individualisation of treatment seems to be a recurring theme." [ESM043, Interview]*

Unfortunately, the process of regaining control was not successful for a number of survivors who continued to experience intermittent bowel dysfunction. One survivor required an ileostomy to be reinstated permanently as he failed to regain any control of his bowel two years following ostomy reversal:

> *"Before it was reversed to what I have now [ileostomy], that was a strenuous time, because it wasn't getting any better no matter what was [done] food wise … I was fighting so much with my body to not have to get that done … but I had to understand myself; I wasn't going to have any quality of life at all, I'd never be able to go out in any sense." [RCM049, Interview]*

A number of survivors stated that they missed their ostomy, as they had been able to engage in leisure pursuits such as swimming, fishing or hiking without worrying about the location of a toilet. Toilet mapping, planning ahead and menu shopping were now important strategies for these survivors, as they could not predict the time or place where they would need to relieve themselves:

> *"My specialist subject is all accessible toilets within an hour's walk of my home. I know all the toilets in town, anywhere I go, even subconsciously at this stage." [ESM036, Interview]*

7.4.1.3 Losing Touch

Peripheral neuropathy was a treatment side-effect discussed by 14 interviewees. For some, it began as a transient effect during treatment, usually resolving within 24 hours. As treatment progressed, the symptoms became more intense and more long-lasting. For others, peripheral neuropathy only developed after adjuvant chemotherapy, by which time, there was no way to prevent the symptoms. Only one survivor spoke about the discontinuation of treatment when peripheral neuropathy arose and by the time of the interview, two years post-diagnosis, symptoms associated with her peripheral neuropathy had resolved. Seven other survivors discussed neuropathic symptoms experienced during treatment, but stated they completed the full course of adjuvant chemotherapy:

> *"Near the end of it, I was getting very bad pins and needles in my hands, and they were locking. So, the last month of my chemo they put me on the [chemotherapy] tablets." [RSM019, Interview]*

Although the experience of peripheral neuropathy was shared, the manifestations and triggers exacerbating the symptoms varied between survivors. Most described characteristic numbness, pins and needles in the hands and feet and sensitivity to cold. However, a number of survivors also described sensitivity to heat or burning of the peripheries. For some, peripheral neuropathy was a frustrating, rapid fluctuation between freezing and burning sensations, making it difficult to alleviate symptoms. Although hands and feet were most affected by peripheral neuropathy, a small group discussed orofacial symptoms which were most intense during treatment, but persisted beyond the end of treatment to a lesser extent:

> *"The very first day as I was leaving the hospital, walking out of the building, I thought it was drizzling on my face. We walked over to the covered car park in [Hospital], and I walked in under shelter, and I'm continuing to get this feeling as if drizzle, rain is drizzling on my face and thought 'Oh, it must be just the air,' because I had been told to expect pins and needles. I went to the car, I touched the handle of the car, and it was agony it was pins, and needles like I never got before. Like, static electric shock but hundreds of them all at the one time in each finger." [RCM013, Interview]*
>
> *"I can go to bed, and my feet are ice cold, and twenty minutes later I'm sticking them outside because they're burning." [ESM006, Interview]*
>
> *"The soles of the feet, it's not pain or anything, it's just a sort of a numbness." [PCM018, Interview]*

Perceptions surrounding functional limitations arising from peripheral neuropathy varied between the treatment and post-treatment periods. In the treatment phase, neuropathic symptoms were an expected anomaly; survivors did not attribute changes in physical and social function to neuropathy at this time, but rather to the expected course of cancer treatment. One survivor described neuropathy as a reassuring side-effect, signalling the power and effectiveness of chemotherapy:

> *"I could feel what they said I was going to feel, tingling in the fingers. So, I knew that this was coming on and it was more a novelty to begin with … As the cycles increased, the*

> *tingling became more intense, and the effects lasted … It didn't overly bother me that I couldn't hold a pen … I was actually in some shape or form reassured that if the drugs were doing that to me, they must be working." [ESM043, Interview]*

However, many who discussed ongoing limitations as a result of peripheral neuropathy indicated they were not aware of its potentially chronic, irreversible nature. A substantial proportion of this group had significant daily challenges in their home, work and social lives. In some cases, peripheral neuropathy placed the survivor at higher risk of more serious injury. The loss of fine finger movement and grip affected survivors' abilities to close buttons, sew and type. Alterations to locomotory function of the lower limbs created difficulties walking, running, climbing stairs and driving. Several survivors described frequent tripping and falls due to loss of sensation and coordination of the legs. Survivors whose work involved manual labour were at particular risk of injury should they fall from a height or injure themselves with equipment:

> *"I have very finicky work, small bolts and nuts or in awkward places … when it is cold, I have to make doubly sure, be careful, don't drop this, because it would drop somewhere, it might never again be found … if I am hammering or something … if you hit your thumb, then for weeks the nerves are all over the place." [RSM048, Interview]*
>
> *"I could fall over easily if my foot catches in anything at all. If there's a stone up, a rock maybe, above the level of the ground and I just catch it, I could go off balance and fall. I'm falling all over the place here … every time I go out into the garden unless I'm careful." [PCM015, Interview]*

Co-morbidities became harder to manage for those with peripheral neuropathy. Diabetic survivors discussed heightened awareness of their feet and fears of injuries which could cause foot ulcers. One survivor described how he continued to exercise with a torn calf muscle, as he did not feel pain until the injury had progressed to a point requiring surgery:

> *"I have an injury that's directly related to the neuropathy … it's a calf tear that was perhaps a lot worse than I thought it was. So, I ran on it because I couldn't feel it, thus exacerbating the calf tear." [ESM043, Interview]*

Although survivors who had neurological co-morbidities acknowledged new and exacerbated neurological symptoms following chemotherapy, they described difficulty ascertaining whether symptoms were a result of natural disease progression or chemotherapy. One survivor who had pre-existing otosclerosis experienced significant deterioration in her hearing during chemotherapy, which necessitated the fitting of hearing aids. Another described the challenges of differentiating between symptoms of peripheral neuropathy and Parkinson's disease and the difficulty their co-existence created for symptom management:

> *"I always had otosclerosis … but the hearing really was affected by [the chemotherapy], after that, so that's … why I had to get the hearing aids." [ESM158, Interview]*
>
> *"Once the chemotherapy had finished, I realised there were other things going on, like the restless legs which I suffer from, seemed to be exacerbated. I would have to get up in the night and walk around … like a nervousness in the nerve ends or something, causing pain and discomfort, but I think that would partly be the Parkinson's too." [PCM031, Interview]*

Several survivors mentioned minor challenges using pedals while driving. Most overcame these challenges with time. However, one survivor described how she was no longer able to drive. She became reliant upon her husband to assist her with household and social activities and was distressed by her loss of independence. She described how peripheral neuropathy contributed to her withdrawal from social and family activities, as she was unable to tolerate her pain if she had to sit or stand for too long:

> *"I can't drive anymore, which I really miss … I feel my whole independence is gone and that's the saddest thing for me anyway. [My husband] is great … he drives me everywhere, he brings me to all my appointments, and we do the shopping together, things that he has never had to do … but he does everything now you see … anytime I go off for a wedding I'll be gone before the night is even half-finished, I'd stay for the meal … my legs would be paining me under the table and [my husband], he'd just take me home, because it's just not worth it. So, all that is kind of stopped … It makes you feel that you're being left behind [Participant becoming upset]." [ESM073, Interview]*

7.4.1.4 The Vestiges of Colorectal Cancer Considered Within the Ageing Process

Ageing processes occur parallel to recovery in survivorship. Several interview and survey participants described a gradual physical decline after treatment which they attributed to ageing or co-morbidity. Fatigue, changes in cognitive function and sexual dysfunction were most often linked to age or co-morbidity, in particular among survivors over the age of sixty-five:

> *"I find I can't take things in as well as before. It takes me longer if I've to read a complicated report now … I'm a bit more forgetful, but sure that's probably age." [ESM005, Interview]*

Fatigue and sleep disturbance were frequently discussed together. Three survivors described overcoming fatigue experienced during treatment, while five indicated it was an ongoing problem several years after treatment. Fatigue was described as an extreme and overwhelming slump; survivors used imagery of dragging themselves out of bed and through their daily tasks. However, many attributed ongoing fatigue to ageing, chronic illness or coping with stressful life events, including grieving the death of a parent. Ongoing sleep disturbance was frequently linked to anxiety or stress, which could exacerbate fatigue:

> *"Well there is, yes, a slight, a loss of energy but a certain amount of that is down to age too, I'm going to be seventy now in two months, so you have to accept that you're not as fit as you were when you were twenty-five." [ESM006, Interview]*
>
> *"When I was undergoing the chemo, I had problems sleeping, so I would spend a lot of time down in the kitchen. I baked a lot of bread at four o'clock in the morning, and four o'clock in the morning is still a time when I'd wake up … maybe half the nights of the week and I'm back in the kitchen shall we say. I'm not physically in the kitchen, but mentally I can feel that chill, those cold thoughts." [ESM043, Interview]*

Eighteen survey participants (six males and 12 females) made comments about sexual difficulties. Eighteen of 24 survey comments about sexual function stated that the questions did not apply to them due to age or marital status. Three survey comments elaborated upon reasons for sexual difficulties; each described declining sexual activity since surgery; one male survivor stated this was upsetting, as medical interventions to improve sexual function were unsuccessful. A female survivor indicated she had identified other ways to participate in sexual activities with her partner. It was of interest that two of the survivors who commented upon sexual function within the survey did not make any comment about the issue in their interview. For the two male survivors who discussed sexual dysfunction during interviews, both described the frustrations of erectile dysfunction and the lack of credence given to sexual function during the post-treatment period:

> *"Sexual function would be affected … that could've been more addressed … when I needed help, I think I brought it up … I just thought it was a little bit Irish to me, in the way it was done, to be perfectly honest with you … Drug assistance is definitely required from time to time. Being in a long-term relationship absolutely helped the situation immeasurably in terms of understanding and re-learning and re-functioning and all of that, and everything that goes with it. If I was dating, I wouldn't like to imagine that situation." [ESM043, Interview]*

7.4.2 The Shadow of Colorectal Cancer

The Shadow of Colorectal Cancer comprised of the psychological consequences of diagnosis and treatment. A *Cycle of Fear and Anxiety* and *Fear of Recurrence* were key issues described by colorectal cancer survivors. Many spoke of the heightened state of alert in which they existed, as they sought to *Live a Vigilant Life*, to identify early signs of recurrence. The final sub-theme discusses the *Recognition and Action* taken by survivors to identify and manage anxieties arising from the uncertainty of survivorship and fear of recurrence.

7.4.2.1 The Cycle of Fear and Anxiety

Survivors' accounts of the post-treatment period suggest that fear and anxiety were inextricably linked in a cyclical relationship. In the period of diagnosis and treatment, anxiety was more prevalent, perpetuating fear of an unknown, uncertain future. As participants transitioned from treatment to survivorship, fear overtook anxiety as the dominant emotion, as survivors worried about future events beyond their control. It was evident cancer was a shadow never far from the survivor's mind:

> *"I've gone through this thing, but like, do you ever go through it? No, you're still going through it … It's always there, so the cancer thing is always there." [ESM043, Interview]*

A small number of survivors described uneventful passages through diagnosis and treatment, with minimal anxiety. Rapid pace, task-orientation and reassurance from healthcare professionals during treatment prevented survivors contemplating the possibility of negative outcomes. For others, significant life events including the death or illness of a relative, or employment issues took precedence. Such occurrences resulted in a delayed self-recognition of psychological distress. Delayed recognition occurred after treatment when survivors felt they had no one to turn to, as they were attending the hospital less frequently. Some believed they were no longer a cancer patient and felt they were not eligible to attend cancer support centres. Loneliness further aggravated the anxiety experienced, as the survivor's social circles now believed them to be recovered and no longer in need of their support:

> *"The biggest low probably was when the treatment was finished. I felt quite low after that for quite a bit, and it's like 'You're done now and there you go, off you go,' and that was not only hospital but outside; family, everyone saying 'Oh isn't it great now you're finished, isn't it brilliant?' But I really needed a lot of support at that stage." [ESM158, Interview]*

7.4.2.2 Fear of Recurrence

The possibility of recurrence was the most dominant fear in the aftermath of treatment. Survivors categorised this as a fear of the known; survivors had experienced the symptoms of disease, the shock of diagnosis and the challenges of treatment and were aware of the implications of disease recurrence. Survivors' stories suggest fear of recurrence was not just about mortality, but of reliving physical and psychological lows of treatment and intensifying chronic effects including peripheral neuropathy and bowel dysfunction:

> *"I'd probably end up in a wheelchair if I got more chemo. So that's my biggest worry that it would come back, and I couldn't have treatment." [ESM073, Interview]*

Fear of recurrence resulted in a heightened state of alert among survivors. For many, the physical symptoms experienced during and after treatment were reminiscent of those preceding diagnosis:

> *"While I had no symptoms of bowel cancer before the surgery, I have had all the symptoms that you are told to look out for since the surgery. That is, I have constant diarrhoea, I would have maybe five, six, maybe even seven bowel movements a day." [RSM028, Interview]*

It followed that negligible changes in symptoms arising from colorectal cancer or co-morbid conditions were magnified, triggering further anxieties and greater vigilance among survivors:

> *"You'll never have a headache again; it'll be a brain tumour … you'll think worst case scenario, and that is me, I have turned into that person … you wake in the morning, how am I? … Am I okay? … Is that different from one I've had before? … Which of the symptoms is that now? Which thing is that now?" [ESM036, Interview]*

Several factors sustained fear of recurrence, preventing survivors moving on and overcoming fear. In particular, shorter time since treatment, presence of genetic risk factors and awareness of friends or family members' diagnosis or death from cancer:

> *"I can't believe it's four years [since my treatment] and I do feel a bit more confident. But then when my brother has been called back, every time I feel 'God will I be called back? Will I be called back?' So that's a worry I suppose, but everybody would have that worry, wouldn't they? When it's in your family. My brother that died, his death had an awful effect on me because he had a terrible death." [ESM073, Interview]*

7.4.2.3 Living a Vigilant Life

Fear and anxiety have significant implications for cancer survivors' physical and social well-being and create additional anxieties around use of the healthcare system. Vigilance mediated colorectal cancer survivors' fear of recurrence and mortality, through routine surveillance and self-awareness. Each tread a fine line between facilitators and barriers to overcoming fear and anxiety. Routine surveillance was reassuring as healthcare professionals actively monitored for disease, enhancing the possibility of early detection. However, routine surveillance could also trigger anxiety, as hospital appointments were a reminder of the disease they had overcome:

> *“Every time it comes up that you’ve to go back for a scan or a colonoscopy, or whatever, you worry a little bit that they're going to find something again. You see somebody who’s never had cancer doesn’t have that worry, but once you’ve had it you have that worry all the time that they're going to find something else, that it's going to appear again or its spread somewhere else.” [ESM006, Interview]*

Self-awareness related to the heightened state of alert surrounding symptoms. Several survivors described how changes in symptoms were noted and quickly acted upon. This active monitoring empowered the survivor, as they took control of monitoring for recurrence:

> *“I’m certainly more keen on maintaining a position where perhaps the symptom might come up, and you notice very early … and not doubting myself … I’m making a note of something and make sure that I am seeing somebody.” [ESM043, Interview]*

However, survivors worried that self-empowerment could be misinterpreted as paranoia or hypochondria by healthcare professionals and may result in the survivor becoming disenfranchised were they thought to ‘*cry wolf*’:

> *“You can get a bit paranoid and then you start thinking you’re bothering people. Ringing up the nurses to get my bloods done … just to check, all that kind of thing.” [ESM043, Interview]*

Self-empowerment and a heightened state of awareness also had financial implications, as survivors sought investigation of symptoms via private healthcare resources where the public healthcare system could or would not serve them. Unfortunately, such steps did not always allay survivors’ fears:

> *“I've spent a fortune on consultants, my doctor is fed up listening to me, and it just turns you into someone like that.” [ESM036, Interview]*

7.4.2.4 Recognition and Action

Recognition and action were important behaviours to address anxiety and fear. Recognition of anxiety or fear may come from the survivor, or others surrounding the survivor (family, friends, or healthcare professionals). However, recognition was only helpful if the survivor could take action to manage anxiety or fear. Taking action could be interrupted by a desire to achieve particular milestones in recovery (stopping medications, managing or overcoming side-effects). Actions taken by survivors included retreating from day-to-day demands to foster psychological well-being (holiday, yoga, meditation), taking preventative measures (adopting healthy behaviours) or planning for the future (preparing a will, planning one’s funeral). Although some survivors were more successful than others in using these activities as mediation tools, there was a sense that trying to take action to deal with recognised fear and anxiety was helpful, even where these emotions persisted:

> *“The obvious is the biggest worry. Hopefully, it won’t come back; I don’t want it to come back. So that would be the biggest worry. Just to do everything I can to be healthy. I suppose exercise, diet, just trying to keep stress reasonably under control.” [ESM087, Interview]*

One survivor acknowledged the importance of psychological disposition in mediating fear of recurrence. He placed a high priority on diet and physical activity in managing the physical and psychological consequences of cancer and preventing recurrence. Like others, he felt lifestyle behaviours could only do so much to prevent disease recurrence and that his version of taking action to facilitate early recognition and prevent recurrence may actually be a distraction to his overcoming the psychological experience of cancer:

> *"Certainly, I would have adapted my diet to rule out the stuff that might contribute to colon cancer … but there's a degree of bolting the stable after the horse has bolted shall we say? … How much am I pretending? And how much is actually working? … Am I on a subconscious level running to stand still? Am I doing all of these exercises to convince myself? … There's a baseline of anxiety, that must be why I wake up in the middle of the night … There'd be swampy areas I'd be wary of going close to, [I'm] concentrating on what I'm doing on a day-to-day basis, although because of my ailments I do have to concentrate, like the food diary and the exercises that I do." [ESM043, Interview]*

7.4.3 Returning to "Normal"

The social implications of colorectal cancer survivorship are addressed within the theme *Returning to "Normal"*. To return to *"normal"*, survivors must *Overcome the Financial Challenges of Cancer* and transition to retirement or *Return to Employment*. Survivors recounted strategies they used to ease this transition and helpful and unhelpful behaviours within the workplace during this time. Understandably, the experience of survivorship impacted significantly upon the *Family Unit* and *Social Networks*. Within these sub-themes, survivors discuss the support of and concerns for their families and friends since their diagnosis. Survivors employed a range of coping strategies; these are discussed within the theme *Living with a New Normal*.

7.4.3.1 Overcoming the Financial Challenges of Cancer

The diagnosis of colorectal cancer precluded many from remaining in active employment due to the scheduling demands of treatment and its physical effects. A small number of survivors' employers facilitated long-term sick leave with social welfare top-ups or contributions to salary protection schemes. Several who were self-employed chose to continue working during treatment with a reduced workload. Many survivors described financial implications of cancer, particularly the cost of transport and parking at the hospital for appointments. Survivors who relied solely on social welfare benefits described how the payment of €188 per week failed to meet the mounting costs of treatment and day-to-day living. Survivors from higher socio-economic groups described buying premium food produce and nutritionally balanced convenience meals. Meanwhile, those from more disadvantaged backgrounds described foregoing '*anti-cancer*' organic diets prescribed by popular media, as they struggled daily to make ends meet:

> *"[Social welfare] is €188 whether you like it or not and then you've to do the juggling … I need €25 of electric, I need €25 worth of gas, I need €10 on the bin to be collected, I have to pay €50 a week rent. And that is reality … it's like your diet, people saying eat organic meat … change my diet … I can't afford it." [RSM027, Interview]*

A number of survivors felt social welfare payments were inadequate and systemic bureaucracy could exacerbate financial hardships:

> *“The financial help available from the state is also inadequate … the only reason I coped financially was from the help of my parents.” [ONL002, Survey]*
>
> *“Applying for disability benefit (pension) was a nightmare. Mountains of paperwork, difficult communication (office is in town) and a processing time of about three months added a lot of unnecessary stress and worry.” [RCM016, Survey]*

Over the longer-term, some survivors discussed how financial challenges and associated psychosocial difficulties were intensified by retirement. Survivors described being unable to continue with hobbies and holidays they were accustomed to due to financial concerns and the persistent physical effects of their treatment. Despite regret at these losses, one survivor described the discovery of new opportunities, interests and social outlets:

> *“I miss my long-haul holidays … there's the money side of the social life as well and the holidays … since I did the course and starting [teaching], I've a new group of friends … so that’s a whole new thing that’s going to open. Now I joined the library, I never joined a library before in my life.” [ESM036, Interview]*

7.4.3.2 Returning to Employment

After treatment, concerns about return to work were prevalent. At the time of the interview, nine participants remained in full or part-time employment, while four had retired since diagnosis. For some, returning to work was a critical milestone in recovery:

> *“I suppose… one of my fears when I was diagnosed with cancer was ‘Oh my god, will I get back to work or…?’ It’s all ‘Will I? Will I? Will I?’ So, I was delighted to get back to work, absolutely thrilled to get back to work.” [ESM087, Interview]*
>
> *“I don’t know if somebody said it to you, there's nearly an unwritten thing, don’t let it make you leave work, go back, don’t leave work because of it, go back and let it be your decision … and I did go back, and I decided, I was absolutely wrecked, I couldn’t keep it up anyway, I just couldn’t.” [ESM036, Interview]*

A number of interviewees placed high importance upon not returning to work until fully recovered and returning to full-time employment gradually. This helped survivors to manage post-treatment fatigue and acclimate to a new daily routine. General practitioners were important advisors in the decision-making processes of returning to work. Several survivors talked about return to work interviews with their line managers and one described meeting with an occupational health advisor:

> *“I went back to work maybe two days a week, I finished my treatment in March, and I didn’t go back to work until August … [My] local doctor advised me strongly to take as much time off as I could because once you were back at work, you were back at work.” [ESM005, Interview]*

However, some survivors disregarded advice to delay return to work. Many described boredom motivating them to return to work. Regrettably, two survivors described returning to work while still experiencing profound treatment-related side-effects, particularly fatigue, which eventually lead to a voluntary or involuntary departure from the workforce. One survivor described how reduced work productivity caused by his symptoms resulted in wrongful termination of his employment and he was now participating in legal mediation.

> *"I was coming home, I would have my dinner, I'd go to bed, and I'd drag myself out of the bed in the morning, so I just couldn't hack it." [ESM036, Interview]*

These stories symbolise supportive and unsupportive characteristics in the work environments of colorectal cancer survivors. Many survivors described employers who were highly supportive, respectful and responsive to their needs. Such employers were morally supportive during treatment. They did not place survivors under pressure to return to work quickly following treatment and facilitated an incremental return to a full working week, with flexible working hours:

> *"Now as [my employer] said, 'At any time that you don't feel that you're able to cope, you ring us, and we'll lighten your load, but don't stress over it.'" [RSM019, Interview]*

On the other hand, unsupportive employers created stressful working environments, placing unrealistic expectations upon the survivor. Unrealistic expectations included overtime work, placing the survivor in departments where they felt uncomfortable working and comparing the work productivity of the survivor with their colleagues'.

> *"I had one obstacle put in my way, prior to getting sick, I worked in quite a difficult area … [It] provoke[d] a lot of anxiety and a lot of stress … It was an area that I'd a lot of experience in and my employer wasn't too happy with my decision [to work in a different area upon my return] and pushed me a bit. So, I did go to occupational [health] … and they said … 'take as much time as you want.'" [ESM087, Interview]*

One survivor speculated that an employers' first- or second-hand experience of cancer might influence their behaviour toward cancer survivors returning to work:

> *"I think somebody that has been affected by cancer somewhere closer to them and have part-lived what the family is going through, let it be their father, or mother, or brother, or maybe a cousin even, they would understand better." [RSM048, Interview]*

7.4.3.3 Cancer Survivorship and the Family Unit

Many interviewees discussed the impact of cancer on the family unit. Many survivors believed their family members experienced greater distress at the time of diagnosis than the survivor. Several speculated that their spouses attempted to be supportive by hiding their anxiety. As a result, some survivors were unaware of their partner's distress:

> *"I only heard afterwards that [my husband] was very worried. And my children, they think I'm invincible and the idea of it, they were so shocked." [ESM121, Interview]*

One survivor, whose brother had been treated for colorectal cancer, speculated that family members may worry about the individual with cancer more than the person with cancer would do for themselves. She attributed these concerns to her own experience of cancer as a lonely journey and her experience of her brother's illness when she was unable to understand how he was feeling or how to help him feel better:

> *"I tell you cancer is a very lonely place because no matter how many people are around you and want to help you're in it on your own … When you're sick yourself you know how you're getting along, you know how you're feeling, you know that you just need to rest …*

> *You don't know how the other person is; you don't know if they're feeling stronger today or they're feeling weaker today or what you can do to help them. Now my brother is like me, 'Go away, don't bother me,' when I'm sick I really want to be on my own … but I found I worried much more about him." [PCM026, Interview]*

Indeed, spouses, and sometimes children, carried the burden of cancer, vicariously suffering the survivor's disease. Family members assumed new roles, becoming advocates, caregivers and homemakers while maintaining their previous roles within the family as breadwinner, husband, wife or child. The shadow created by cancer meant many survivors feared becoming a burden on their family if they became ill again or required informal care in the home:

> *"[It] affected [my partner] as well in that sense, everything was evolving around the hospital and doctors and check-ups and more check-ups … she was as much a part of this whole process." [RSM048, Interview]*
>
> *"Probably the lack of understanding from some professionals. Also, the feeling of being discharged and being alone and the feeling of being just one of many who had cancer. The complete lack of acknowledgement from professionals of my partner in the whole process, who I believe carries the burden for both myself and the whole family." [RSM014, Survey]*

Most interviewees revealed how healthcare professionals encouraged survivors to have their siblings participate in bowel screening via regular colonoscopies. When asked about their concerns for biological family members, concerns were often associated with the hospital waiting lists for colonoscopies:

> *"One of my daughters is booked in for colonoscopy, but she is a long time waiting for it now even though she has [private health insurance] … If colonoscopy was easy to have, the two boys would go and have it, but this idea of going on a waiting list, and not wondering whether they would be available to go the day it comes up." [RSM028, Interview]*

A common response to this line of questioning was a denial of any cancer-related concerns for family members. Survivors described how they advocated for healthy living and vigilance of colorectal cancer risk rather than panic among their children. Survivors who had been diagnosed with or were under investigation for family risk factors believed their worries were counteracted by confidence in family risk programmes available to first degree relatives of those with genetic mutations:

> *"It will give me peace of mind, that if it's a gene that is in the family, that my own children can be tested early, and they can look after themselves, and when they get to a certain age they keep going and have colonoscopies and be tested for it." [ESM073, Interview]*

Two interviewees living with terminal disease spoke of concerns for their children's psychological well-being. Both described how their sons endeavoured to help within the household or advocate on their behalf when required. One survivor's son refused to discuss her impending death; another survivor's son took full responsibility for this knowledge as his father did not want to know his prognosis. This created difficult interactions with healthcare professionals and led to anxiety and depression among the children of these survivors:

> *“[My son] doesn’t even talk about it … He had a bit of a breakdown last year … accumulation of this and accumulation of that and [it] boiled over … that’s the most frightening thing ever.” [RSM027, Interview]*

Despite the challenges that cancer imposed upon the family unit, these and other survivors described how the experience of cancer had strengthened their relationships with their family members:

> *“[My son] is philosophical, he's a realist, he tells you how it is and he's more or less my confidante, he gets me through.” [RSM027, Interview]*
>
> *“It just made us all closer.” [RCM013, Interview]*

However, one survivor’s relationship with her partner came to an end following her treatment. Although she had a strong support network of family and friends, she alluded to concerns about meeting another partner in the future.

> *“[I] don’t have a partner anymore, [I’m] single and not really into the whole dating thing, I don’t know if that’s got anything to do with cancer and the stoma, I don’t know, maybe?” [ESM087, Interview]*

These sentiments were reflected by the hypothetical concerns of a young man:

> *“Fortunately, I’m in a long-term relationship. Again, if I was younger, and perhaps was dating, I’m not quite sure how I’d handle that.” [ESM043, Interview]*

7.4.3.4 Cancer Survivorship and Social Networks

Similar to relationships within the family unit, several survivors spoke of positive growth in close friendships. For survivors who lived alone, friends, neighbours and work colleagues were an extension of the family unit, providing essential practical, psychological and social support during treatment. Some survivors described how this support extended beyond treatment, as their friends remained cognisant of chronic treatment effects:

> *“They tend to be a bit more minding of me or something … We’ve been away and shared houses, and I end up with the best room … with ensuites and bathrooms, they’re all very [minding].” [ESM087, Interview]*

However, some survivors described how interactions with their social networks were limited by the physical consequences of treatments, causing varying degrees of social isolation:

> *“On the golf scene, I’m taking a buggy … the lads I used to play with walk, they don’t want to be sitting on a buggy. So, you’re kind of messed up that way … you’re finding it hard to play with the lads you want to play with.” [PCM015, Interview]*

The power that survivors derived from their relatively healthy appearance during treatment seemed to create a barrier to recovery. Three factors exacerbated these obstacles and created significant psychological distress for survivors. Firstly, survivors appeared ‘*well*’, but the lasting effects of treatment were invisible to those who did not know better:

> *“When people look at you, they think ‘Oh god look at your feet, your feet look perfect,’ and you’d say [it’s peripheral neuropathy], and they can’t understand, they think it’s all in your head.” [ESM073, Interview]*

Secondly, survivors believed it was important to present a strong persona to the world. Many loathed to be pitied:

> *"It's just the look in their eye as if to say, 'Ah, you poor thing.' … I'm not that type of a person; I don't wallow in self-pity … maybe there is some people like that, but I'm not. I prefer to get up and go." [RSM019, Interview]*

Finally, the societal stigma attached to faeces and bowel function disguised chronic issues. Survivors alluded to difficulty created by such stigmas, as bowel dysfunction was a core component of their '*new normal*':

> *"If you hurt or break your arm … you can freely talk about it, but to start talking to people, even people that are very close to you, about your bowel movement or whatever, nobody wants to know because the toilet is a place that's just for one at a time." [RCM049, Interview]*

Survivors' encounters with cancer within their social circle were particularly illuminating. Several survivors spoke of the increasing prevalence of cancer within their social networks as they grew older. Stories of friends' or family members' cancer diagnoses caused survivors distress, as they worried for the individual and were reminded of their mortality. However, these survivors were often upheld as models for positive behaviour and adjustment to be emulated.

> *"He's had [cancer] twice … his attitude was 'I'm not putting up with this, it's not going to be the same' … [he was] doing laps of [Hospital] all day long, he was determined to get his strength back and when I was going in [for my surgery] … I was afraid to lie there for more than a half a minute!" [PCM026, Interview]*

While many survivors commented upon positive adjustment and behaviours among cancer survivors in their social circles, many more identified negative adaption or coping strategies which they endeavoured to avoid:

> *"[My neighbour] was [a patient] with me in oncology and I met him, [I said] 'Have a bit of faith,' [he said] 'Ah f**k that oul' faith,' … Now [he] more or less came home after being in the hospital … After three weeks [he] was buried. He more or less took to the bed and died … So, I feel that no, I keep motoring and I won't go there." [RSM027, Interview]*

7.4.3.5 Living with a New Normal

Living with a new normal required significant adaption and coping mechanisms. All survivors spoke about coping mechanisms used in the course of diagnosis, treatment and survivorship. These strategies reflected the eight coping styles of Jalowiec (2003) (Table 7.3). Many survivors used a combination of coping strategies; only one failed to describe any coping strategies. Optimistic, palliative and confrontive coping strategies were the most popular coping styles described by survivors.

Optimistic coping strategies were important during the diagnosis, treatment and after-treatment periods. Survivors who described optimistic coping strategies embodied the ideal of *Living with and in Spite of Colorectal Cancer Side-Effects*; their stories suggested more mature coping mechanisms, minimising the impact of chronic effects upon quality of life. Examples of optimistic coping strategies included reframing side-effects as less burdensome than those of another, expressing

Coping style	Description	Coding example
Confrontive (n=17)	*Face up to the problem*	Figure out ways to handle the problem
Evasive (n=8)	*Avoid the problem*	Try to get away from the problem
Optimistic (n=20)	*Positive thinking*	Try to think positively
Fatalistic (n=4)	*Pessimistic thinking*	Expect the worst that could happen
Emotive (n=0)	*Release emotions*	Get mad and let off steam
Palliative (n=17)	*Make yourself feel better*	Take medications to reduce stress
Supportant (n=4)	*Use of support systems*	Discuss problems with family/friends
Self-reliant (n=5)	*Depend on yourself*	Feel you can handle things yourself
Source adapted from Jalowiec A. (2003) Jalowiec Coping Scale. In *Measurement of Nursing Outcomes, Volume 3: Self Care and Coping, 2nd edn.* (Strickland O.L. & Dilorio C., eds.), Springer, New York, pp. 71-87; p.76.		

Table 7.3 Jalowiec Coping Styles (2003)

appreciation for life, living for the moment, keeping positive or using humour. Despite the significant psychological and social effects of bowel dysfunction and peripheral neuropathy, a small number seemed to reframe their experiences. Several survivors who reported high levels of difficulty with bowel dysfunction or tingling in the hands or feet in the survey spoke of reframing their circumstances and feeling gratitude for their lives rather than dwelling upon the negative implications of chronic effects:

> *"I don't know how it affects other people, there was a woman down the road there, she's dead now, God rest her, but she got neuropathy after cancer, she could hardly walk, she got it really bad. I'm counting my blessings; it's not stopping me getting around." [PCM015, Interview]*

Confrontive coping strategies were most common during diagnosis and treatment. Acceptance was an important confrontive strategy, fostering attitudes to do what needed to be done to overcome and understand illness. Several survivors described battle imagery and a fighting spirit in response to their diagnosis. For some, confrontive strategies encompassed factors fostering power, such as maintaining a healthy appearance. For others, confrontive action in the post-treatment period was about moving on from the psychological turmoil and uncertainty of diagnosis and treatment. This notion intersected with the optimistic strategy of gratitude for life and reframing:

> *"I didn't mind [the diagnosis], didn't faze me in the slightest. There were two student nurses there and … they were watching my reaction, was I going to 'Oh no! Why me?' That wasn't the case at all; it's just 'Let's get it on, get it done.'" [ESM003, Interview]*

Palliative coping strategies encompassed self-care strategies and setting goals for recovery. Narratives derived from this code were most commonly directed towards regaining health and fitness. Survivors discussed using diet to maintain the function of the bowel and to be '*healthy*'. Reducing red meat consumption and increasing fruit and vegetable intake were commonly cited by survivors. Physical activities such as walking, jogging and swimming were important to survivors in regaining and maintaining health and for management of physical (bowel function, peripheral neuropathy) and psychological (depression, anxiety) consequences:

> *"Walking is great for the head, apart from anything else, I found it amazing. I walk an awful lot which helps, and I drink a lot of water which helps [my bowel] … I have to watch what I eat; I have to eat sensibly, I eat to go to the toilet basically." [ESM036, Interview]*

Goal setting was important for survivors who were unable to engage in physical activity to the degree they desired, or whose diets were not as healthy as they wished:

> *"When you were sick and after [you have] recover[ed] from things, well, I had to learn how to walk again and be more confident. But you had a determination to walk, with a frame first, and then on a stick, and then every step was a step toward getting better." [RCM049, Interview]*

Survivors described a variety of strategies to avoid triggering peripheral neuropathy. Strategies included wearing additional clothing when handling cold items or outdoors (gloves, hats, scarves), avoiding heavy or tight footwear, avoiding walking on textured surfaces barefoot (tiles, carpet, grass, sand) and physical exercise (fine finger movements, stretching exercises and running):

> *"I sometimes have to warm my gloves, three times in the morning before I get any bit of heat into them because I just can't feel it." [RSM048, Interview]*
>
> *"I would never take painkillers because I feel that my feet were sore, I'd be more likely to massage them or do something like that, walk or take my shoes off and walk in my bare feet, I'd be more likely to do that." [ESM087, Interview]*

Few survivors described fatalistic or evasive coping strategies. Eleven survivors used one or both of these strategies. However, these were used in combination with confrontive, optimistic or palliative strategies. Evasive strategies were more often associated with superstition surrounding the use of the word '*cancer*' or '*survivor*', rather than denial of their diagnosis:

> *"I'd be very conscious; I hate using the term 'I survived cancer.' I was very conscious; I don't like saying that. I feel that's tempting fate." [ESM005, Interview]*

Of the four survivors who discussed fatalistic coping strategies, each spoke at length about anxiety and continued struggles with limiting physical side-effects. Although slight, there was a sense of hope that they would eventually overcome physical effects with the help of medical advances:

> *"Just waiting for your life to start [and] get back to where you were. Sometimes you think you're never going to get there, there is nothing that's going to take this away from you … I have to have hope and then [my husband] gives me great hope, he keeps saying 'there will, there'll be something that will come on the market that will help.'" [ESM073, Interview]*

Fatalist coping strategies were also associated with an inherent awareness of one's mortality. One survivor living with metastatic colorectal cancer did not want to be told of his prognosis. He consented to his family members meeting with his oncology team to be updated on his condition. This man was fully aware he was living with a terminal illness, but he believed if he were to know the full extent of his disease that he would give up hope and hasten his death:

> *"I don't want to know nothing, I said 'Tell [my son], talk to him and don't tell me anything, I don't want to know nothing'. I just live today, I feel good … I'm not saying I will live to be one hundred and eight, but I'm not ready yet." [RSM027, Interview]*

Self-reliant and supportant coping strategies were each associated with confrontive coping strategies, but no survivor discussed using both self-reliant and supportant strategies. Survivors who used supportant strategies placed importance upon the support of family, friends, healthcare professionals and cancer advocacy organisations. Those who used self-reliant strategies expressed the desire to deal with the experiences in their own way. Although the importance of healthcare professionals was acknowledged by members of this group, these survivors were more pragmatic in learning to live with and beyond their disease:

> *"I think that if I had had somebody coming around to do the changing of the bag for me all the time I'd have developed a poor me attitude. I reckon that it was better for me that I was left to do it myself." [RCM013, Interview]*

7.4.4 Deriving Benefit from the Experience of Colorectal Cancer

Despite the overwhelming challenges of colorectal cancer survivorship, many survivors seemed able to derive benefit from the experience. Survivors' appreciation of their lives and strengthening of relationships fit within this theme and have been discussed in relation to psychological and social well-being. The most prominent benefits discussed by survivors were a desire to help others and give back to the services that helped them. This altruism was evident in survivors' descriptions of informally meeting other colorectal cancer survivors within their local community, to provide support, information and advice about colorectal cancer and survivorship.

> *"I do some unofficial home visits to neighbours and friends who are diagnosed with colorectal cancer and use a stoma. I tell them what works for me and keep the chat very upbeat and positive. I tell them they can ask me anything and they do because we can be empathetic." [RCM001, Survey]*

Several survivors made themselves available to healthcare professionals as a point of contact for newly diagnosed patients:

> *"I did put the word out in the oncology ward, I told them in there … that if anybody wanted to talk about it or was due to go through it and wanted to talk about it on a one-to-one basis that I would be quite willing to do that." [RCM013, Interview]*

Others described a desire to assist by participating in research. However, where the benefit of the research was not clearly evident, survivors described frustration and a desire to withdraw:

> *"I'm thrilled that you're doing the research and that other people are doing research and that research is being done … I'm delighted to help with any research or whatever." [ESM121, Interview]*
>
> *"It was for research I suppose, but it wasn't doing me any favours … and if I thought it was helping someone, but I mean they've no cure for it, it's a nerve damaged … there's no coming back from it." [PCM015, Interview]*

Raising awareness of colorectal cancer was the most popular form of altruism discussed by interviewees. Several lamented the poor uptake of the colorectal cancer screening service. Many described encouraging eligible friends and family members to partake in the screening initiative, as they believed it could save lives:

> *"I have told all of my friends, a lot of whom were invited [to BowelScreen] but hadn't bothered filling in the form … so I've been advocating to every one of the age to make sure that they do that." [PCM018, Interview]*

7.4.5 Theme Summary: Quality of Life in Colorectal Cancer Survivorship

The Vestiges of Colorectal Cancer encompass the lasting physical effects of colorectal cancer treatment and their psychosocial consequences. The unpredictability of bowel function following treatment is illustrated within the sub-theme, *Losing Control*. *Losing Control* was embarrassing and isolating, as survivors struggled to live with pain, constipation, diarrhoea, faecal urgency, frequency, incomplete evacuation or incontinence. Survivors hid away in an effort to conceal the ostomy and avoid the embarrassment of incontinence in public spaces, contributing to social isolation for some. *Striving to Regain and Maintain Control* discusses survivors' approaches to managing their bowel dysfunction. Diet was a particularly important component in the suite of bowel management strategies. However, dietary triggers were highly individualised, meaning information and support from healthcare professionals in this area was limited. Other bowel management strategies included toilet mapping, planning ahead and menu shopping, which facilitated and enhanced survivors' ability to engage in social activities.

Peripheral neuropathy was a widely discussed and highly distressing consequence of chemotherapy, explored within the sub-theme *Losing Touch*. Although survivors acknowledge they were informed of the risk of peripheral neuropathy during chemotherapy, few were aware that it could be a lasting effect in the years after treatment. The pain and loss of sensation brought about by peripheral neuropathy significantly impacted survivors' daily lives and ability to participate in work and household chores. For some, peripheral neuropathy enhanced the risk of secondary injuries resulting from falls or loss of coordination in manual tasks. Although many survivors continued in their normal activities despite these risks, those who accepted their limitations were distressed by their loss of independence and inability to fully participate in family and social life. Finally, in the course of interviews, it was evident many survivors attributed a selection of symptoms to ageing and co-morbidity including fatigue, sleep disturbance and sexual dysfunction, often these *Vestiges of Colorectal Cancer* were framed by discussions of the *Ageing Process*.

The psychological challenges of living after colorectal cancer are encompassed in *The Shadow of Colorectal Cancer*. Many survivors spoke highly of the reassurance healthcare professionals provided during treatment. However, after treatment, this support was less apparent when anxiety and *Fear of Recurrence* and the unknown became issues for some. In many cases, the recognition of *Fear and Anxiety* was delayed due to the task-orientation of diagnosis and treatment. The chronic effects of treatment resembled the symptoms of colorectal cancer itself, creating a heightened state of alert and *Vigilance* among survivors. Survivors spoke of a paradox within surveillance activities, as they were reassured by healthcare professionals' attention to the disease, but such appointments were a regular reminder of the disease they had overcome and its ongoing threat to their well-being. Few survivors who experienced anxiety successfully overcame it. Instead, they spoke of their strategies to *Recognise* and take *Action* to mediate anxiety.

Returning to "Normal" examines the social difficulties experienced by colorectal cancer survivors. Survivors frequently discussed the financial burden of cancer and the inadequacy of social welfare support. For a small cohort, *Returning to Employment* was a milestone in recovery; support from the survivor's general practitioner and employer were instrumental in the transition back to work. Unfortunately, not all survivors were able to sustain work following their return. The physical consequences of treatment, including fatigue, pain and peripheral neuropathy meant some survivors withdrew from the workforce voluntarily or involuntarily. For some, this exacerbated the *Financial Challenges of Cancer* and resulted in a tapering of hobbies and routine activities.

Unsurprisingly, the diagnosis of colorectal cancer impacted survivors' *Family* and wider *Social Circle*. Many survivors described concerns for the physical and psychological well-being of their family members following diagnosis. Family members experienced anxiety and distress due to the uncertainty of the disease and assumed new roles as advocates, caregivers and homemakers to support the survivor. For most, the experience of cancer may strengthen family relationships. However, for a small number, the burden may prove too much, contributing to the breakdown of the spousal unit. Although friends are an excellent source of support for many survivors, they do not always have an insight into the extent of the lasting consequences of cancer. Physical limitations including peripheral neuropathy and bowel dysfunction may result in significant social isolation for some survivors, as bowel dysfunction is a taboo topic of conversation. To come to terms with the *New Normal* of their lives, survivors adopted a variety of positive and negative coping and self-management strategies to adapt to and live with their diagnosis and the physical, psychological and social issues which persisted beyond the end of treatment. Social comparison and reframing were common, and, in some cases, survivors succeeded in finding benefits in their experience of illness; developing altruistic behaviours to assist other cancer survivors or raise awareness of the disease.

7.5 The Healthcare Experiences of Colorectal Cancer Survivors

7.5.1 Reflections Upon Acute Healthcare Experiences

Colorectal cancer survivors described mostly positive experiences of healthcare at the time of their diagnosis and treatment. Many survivors identified healthcare professionals who went above and beyond their duty of care to support, comfort and rehabilitate them. Survivors used such comments to validate positive evaluations of overall healthcare. However, this overall experience was underpinned by a continuum of positive and negative care incidents along the pathway of care. This continuum was illustrated in specific excerpts describing interactions with healthcare professionals, successes and failures of the healthcare system and incidents where survivors' needs were met or unmet. These experiences are discussed within the themes *Securing Access to the Oncology Healthcare System, The Power of Interactions with Healthcare Staff, The Role of Primary Care Services in Colorectal Cancer Care* and *Reflections Upon Preparation for Transition to Survivorship.*

7.5.1.1 Securing Access to the Oncology Healthcare System

The speed of progression from the first awareness of symptoms to the onset of treatment was keenly discussed by survivors. In most cases, the general practitioner was the gatekeeper of oncological care. The general practitioner's responsiveness to the survivor's initial symptoms was instrumental to diagnosis and survivors praised their diligence in arranging prompt investigation.

> *"I had a spot of blood there one evening … so I went to the local [general practitioner]. He took blood tests, and he got in touch with me, a week after that and sent me to … a more senior man … it was all that quick … [He] wasn't taking any chances when I first discovered it." [PCM015, Interview]*

On the other hand, dismissal of malignant symptoms caused survivors distress and required repeated visits to the general practitioner before investigations commenced:

> *"I returned to my general practitioner twice with symptoms [bleeding], before she sent me for a colonoscopy - which <u>then</u> discovered the cancer. I had been given prescriptions for haemorrhoids twice before that. It was very upsetting for me." [ESM122, Survey]*

Three survivors described systemic failures which lead to delayed or incorrect diagnosis. Two survivors hypothesised that the delay in reaching a correct diagnosis resulted in the progression of disease to a terminal stage. One terminally ill survivor described the horror of inadvertently discovering her diagnosis during a chance phone call with an unknown consultant:

> *"I was initially told I had diverticulitis … My surgery was in mid-December, it had been cancelled twice prior to that, and when I left, there were no results … as if the HSE closes down for Christmas. In the post, a few days after Christmas, I got a letter from [Hospital] to ask me to attend my surgeon's clinic at the end of March, so I'm thinking to myself 'This is great, there mustn't have been any cause for concern because he doesn't want to see me until the end of March.' But as it turned out the radiation oncologist goes to the joint meetings in [Hospital], and my case had been discussed and she thought, 'take the ball on hop' [calling me to come in for an appointment that day], but she didn't realise that while they all knew about it and she knew about it, I didn't know about it. So, the first we knew, well we suspected, was when she told us." [RCM001, Interview]*

Insider information was an asset to accelerate the pace of investigations or secure access to allied health services which eluded survivors. Sources of insider information were concerned hospital employees, family members or friends who understood the healthcare system. These survivors explained how the persistence of the insider prevented delayed diagnosis. Many described gratitude for their conscientiousness:

> *"I got an appointment for an ultrasound for September, which was [six] or seven months down the road. So, a friend of mine got me an ultrasound the next day … and within about a month … I was contacted and told 'Go to [Hospital] … and tell them you're not well … 'It's your way into the system; it's a back-door entry, go in there and just tell them you're not well … you will come into the system, and that's where it all starts.'" [RSM027, Interview]*

After diagnosis, many survivors commended the rapid access to radiotherapy, chemotherapy and surgery. A small number experienced delays beyond the control of healthcare professionals, as they tried to resolve the risks of existing co-morbidities and surgical interventions. Those who had private health insurance expressed concern for uninsured patients in the public health system, as they believed they were more likely to have late diagnoses and delays in treatment and investigations. For the most part, these concerns did not reflect the experiences of survivors engaged with public health systems, and many praised the care and efficiency of the public health system:

> *"In general, I would say that I never felt that ... because I'm a public patient, I didn't feel I was getting any lesser treatment." [RCM001, Interview]*

Indeed, some privately insured survivors preferred the sense of security created by having immediate access to a suite of healthcare professionals in the public health system:

> *"I think possibly you get a lot more in the public hospital and I think that is one of the downsides of the private hospitals, there is a team, but it's not quite the same team as in the public." [PCM031, Interview]*

However, several uninsured survivors believed the challenge of the public healthcare system was gaining access:

> *"Once you get into the system, you're well looked after; it's to get into that system, to get onto the track is the problem." [RSM027, Interview]*

7.5.1.2 The Power of Interactions with Healthcare Staff

Although some survivors may suspect malignancy prior to diagnosis, the manner of diagnostic disclosure could positively or negatively influence the survivor's psychological distress. Factors contributing to negative, inappropriate diagnosis included encounters with healthcare professionals lacking empathy, or failure to ensure privacy and familial support at the moment of diagnosis:

> *"I was in a ward [with] two other people … We were having the operation on the same day … and there's only a curtain separating you in the public ward … I could hear [the colorectal cancer nurse] talking to the man next to me and saying, 'Oh fantastic; you're totally clear' … When she was finished with him, she came to me and said, 'The team will be up to you now shortly.' I'll never forget that moment, now that was really badly done, you should be told in a [private] room … that was so traumatic and impactful, it actually overshadows [everything else]." [ESM043, Interview]*
>
> *"There is a kind of a privacy issue there because there is a big long ward, two [patients beside each other]. It's a fairly new hospital, I was surprised at that. I mean everybody's diagnosis, from one end of the ward to the other, is for everybody to hear … I probably would have liked a bit more privacy … not somebody coming to the end of the bed." [PCM031, Interview]*

On the other hand, healthcare professionals who were empathetic fostered hope and reassured the patient in the uncertain period of diagnosis. Such healthcare professionals presented the bad news of diagnosis with a positive outlook and emphasised their intention to return the survivor to health. They ensured the survivor was informed of all treatment options and aware of the implications of such treatment options for their prognosis and physical well-being. Above all, survivors described the empathy of interactions with such doctors and nurses, demonstrated despite the competing demands of their workloads:

> *"I think the attitude and the professionalism; it's something to be admired where somebody is efficient and professional and sympathetic all in the same go, and that's what underscored everything." [RCM013, Interview]*

As survivors progressed into treatment, healthcare professionals' diligence and empathy remained central to survivors' physical, psychological and social well-being. Survivors' narratives revealed the importance of dignity, respect, autonomy and ensuring confidentiality of care in therapeutic relationships. Discussions surrounding violation of these principles were associated with tearful accounts emphasising the lasting impact of such occurrences:

> *"I had no problem with sitting and waiting, I had passed the letter in. The door of the unit was open and all I could hear from inside was – 'We're <u>so</u> busy today', and it was sort of like – 'Why don't <u>these people</u> ring?' You really would want to be deaf … eventually, the clinical nurse manager came out and sat down beside me and proceeded to hold the consultation in the waiting room [participant becomes upset] … I had been thinking myself, are you so diminished by all of this that you're not able to stand up for yourself? … There are actually two or three consultant rooms … there's a bucket room, there's a sluice room, any of those we could have stood behind … it was insulting." [RCM001, Interview]*

Equally, survivors discussed the comfort of feeling known and supported by healthcare professionals. Many survivors described relationships with healthcare professionals characterised by egality and comradery which facilitated open communication, understanding and autonomy. Survivors expressed appreciation for medical and nursing staff who enquired about their psychosocial well-being and offered support:

> *"You get the best of treatment and up there … all they're short of is wearing wings, angels … they're all in tune … the nurses, it's as if they're only looking after you … it's very personal and you're treated with the best up there in oncology, the nurses there are next to none." [RSM027, Interview]*

The responsiveness of medical and nursing staff to issues arising during treatment was also discussed, framed by the sense of security it brought the survivor:

> *"I had some sort of a scan … and then I went upstairs to get ready for the treatment and apparently there was a tiny little clot showing on the scan, and the young doctor was ready to give me this stuff … I was very heartened that everything was watched that carefully." [PCM012, Interview]*

Even in circumstances where healthcare professionals could not relieve treatment side-effects, their acknowledgement of the symptom and in some cases, tactful reframing of the symptom were appreciated gestures:

> *"One thing I did have was hiccups and one day it went on for about twenty-four hours or longer … and when I was in with [Consultant Medical Oncologist] … he said there really wasn't a great deal that [he could do], it was more to do with the steroids I was on … and his comment, which really woke me up, was, 'You should have been here ten years ago and see what people had to put up with before those things were there.' And I took his point on that." [PCM018, Interview]*

Safeguarding survivors' dignity was not limited to medical, nursing and allied health professionals. In the course of interviews, it was evident that every member of hospital staff could contribute to cancer survivors' well-being. A sharp contrast was drawn by two survivors' interactions with auxiliary hospital staff. In the first story, the survivor's tone of voice and body language conveyed the lasting embarrassment of the post-operative interaction. In the second, the survivor praised the emotional and clinical awareness of auxiliary staff in another hospital:

> *"On the reversal operation I remember waking up, all I wanted to do was go to the toilet … Every fifteen minutes … and it was pure diarrhoea, and one of the cleaners got on to me, [as] I was dripping as I was going along, and she said, 'I'm after washing that,' I said, 'Well I can't help it,' She said, 'You should have got something to hold it.'" [RSM018, Interview]*

> *"Everyone was so clued in, even the lady who came in to clean the place was completely clued in because there was a lady across from me who was in the later stages of Alzheimer's, they had to put up the sides of the bed [or] she'd be gone. It wasn't up to myself or another patient to be dealing with it … we'd ring for the nurse, but even the lady who was cleaning knew what to do in the situation … I just found everybody so clued in." [ESM036, Interview]*

The final aspect of *The Power of Interactions with Healthcare Professionals* reflected survivors' desire to be a good, compliant patient, while also being recognised and respected as an expert on their own experiences. Being a good, compliant patient meant following healthcare professionals' instructions and not '*bothering*' healthcare professionals unnecessarily. On the other hand, many survivors believed they had expert knowledge of their condition and self-management strategies fostered through lengthy periods of trial and error. In many ways, the expert patient could facilitate the behaviours of a good patient, as such survivors endeavoured to self-manage their problems insofar as possible. When survivors' expertise was recognised, this enhanced their confidence and fostered willingness to question their care. This was a characteristic of egalitarian clinician-patient relationships described by one participant in her survey comments:

> *"I always felt as if I was part of [the healthcare] team and they would move heaven and earth to get me well, which they did, thank God. I am particularly impressed with how they all carried out their duties with professionalism and humanity. The patient always comes first." [ESM036, Survey]*

She expanded upon these sentiments with an example of such care during the interview:

> *"I was in Accident & Emergency, and the doctor there, I'd met him before, a lovely fella, but he was a rock of sense too because he knows my history, the bowel history, I thought because I was in so much pain that maybe I needed an antibiotic. [The] doctor … said, 'I'm not inclined to put you on one, but someone in your boat usually knows what to do for yourself,' as in what to eat, what to drink … He left it to me, as in, 'you've dealt with this for so long now that you know yourself what you should and shouldn't be doing and how to get around this.'" [ESM036, Interview]*

However, the good patient persona required the survivor to be agreeable and somewhat submissive to healthcare professionals. This submissiveness and the power imbalance of clinician-patient relationships disempowered survivors' ability to question and self-advocate, resulting in healthcare professionals overlooking survivors' expertise. This contrasted strongly with egalitarian relationships fostering support and confidence in survivorship. These struggles caused survivors' anxiety, depression and in one case resulted in an adverse event:

> *"From my previous surgery I knew I went home with staples in and the district nurse came every couple of days and she removed them, and there wasn't a bit of trouble. [Before discharge] I said this to the registrar, and he said, 'No, they come out now'. Now, the sister on ward who was an extremely experienced nurse agreed with me, and she said 'I'm really sorry, there's nothing I can do, I have to obey orders' … As soon as she took every third stitch out it just broke down, and the registrar had to come up and stitch me in the bed on the ward, where I don't know what anybody else had, but I was very concerned for airborne germs or infections. I was most upset at not being valued as a patient and a person because he wouldn't listen to what my previous experience had been." [RCM001, Interview]*

Moreover, a number of survivors believed they were dependent on healthcare professionals in the hospital and community for care. The above case demonstrates how survivors may feel bullied into receiving care they disagree with. Several narratives described survivors as victims of healthcare professionals' power. A second interviewee described two incidences where her general practitioner prescribed inappropriate interventions for acute and chronic conditions. In both cases, she sought a second opinion from healthcare professionals in hospital settings. After one of these incidences she was hospitalised, and upon discharge, her general practitioner verbally assaulted her, as a hospital doctor criticised his negligence of the survivor. The power imbalances of the clinician-patient relationship meant that in these and other cases, survivors are hesitant to make complaints about malpractice or inappropriate behaviour, even where family members or other members of the multidisciplinary team encourage it as an appropriate course of action:

> *"[My daughter] said to the secretary 'The doctor in [Hospital] was not impressed with the antibiotic that [the general practitioner] put my mother on, he thought it wasn't strong enough.' So, [the secretary] sent for me the next morning … I [was] very sick, hardly able to get my head up off the pillow … she said, 'He just wants you here straight away.' So, I got up out of bed, and I went on up, and he absolutely read me from a height, about what my daughter had said … He absolutely had me in floods of tears … I was fierce upset … so I said to [my husband], 'I don't mind what the rest of you do, but I am not going back.' … he had treated me so badly … I felt I was elderly and I deserved a little bit better than that … at seventy-four, seventy-five you don't really need to be changing doctors, it would have been the last thing I would have done in ordinary circumstances." [RSM028, Interview]*

> *"When [my husband] told the [general practitioner] about it he said, 'Did she complain?' [participant becomes upset]. He said 'no', and [the general practitioner] said 'Why didn't she?' And [my husband said] 'Well ... she has to go back there for however much longer, and she doesn't want to create an atmosphere.'" [RCM001, Interview]*

7.5.1.3 The Role of Primary Care Services in Colorectal Cancer Care

The general practitioner held an important role in the pre-diagnosis phase. However, most interviewees felt that they were not involved in the treatment process:

> *"Once [my general practitioner] sent me into [hospital], I was out of her care altogether, I never went near her, because I was dealing with [the hospital]." [PCM012, Interview]*

Whilst some survivors felt the general practitioner had no role in their treatment-related care, several believed they had a major role to play in psychological care and return to work. Two described how their general practitioner rose to these expectations, responding to acute distress associated with anxiety and depression during treatment:

> *"I had never gone to our doctor as somebody who had a mental health issue, and on that day, he was very kind. He just sat there he wasn't looking at the screen, he was doing nothing, he just swivelled his chair around, and he said, '[Your husband] is worried about you. You don't want to have him worried about you, tell me what happened.'" [RCM001, Interview]*

However, not all survivors benefited from such positive responses. Indeed, one felt demoralised by her general practitioner's failure to enquire of her well-being or act upon her reports of anxiety during and after treatment. This led to her avoiding the practice with other health concerns following treatment:

> *"One place where I got no support, and it really hurt me a lot, was my local [general practitioner]. I really felt that. I was shocked, so much so, that I just haven't the heart to go back there. So, I'm in limbo now, because I don't know where to go [about my fatigue]." [ESM158, Interview]*

Most survivors believed their general practitioners were kept abreast of their cancer-related care in communications from the hospital. However, a number of survivors, particularly those who were terminally ill, believed they must be responsible for communication of their treatment plan, as communication from hospitals could be slow or insufficient:

> *"I think there is a very bad disconnect between hospital and home … Very often I find that I am telling [my general practitioner] what's going on in the hospital long before he gets that information from the hospital. So, his records aren't always as up to date." [RCM001, Interview]*

An added concern among survivors was the belief that the general practitioner was not sufficiently skilled in oncology and believed it was more appropriate to direct their concerns to oncology professionals. Most survivors believed their general practitioner did what they could to support them with physical, psychological or social issues following treatment and responded to oncology-related concerns within their scope of practice:

> *"Over Christmas, the stoma got very, very sore and I went to the doctor, and he didn't know much about it, he said 'I could give you stuff, but I'm not 100% sure. So, I rang the stoma nurse, and she was out with me within an hour." [RSM019, Interview]*

Several survivors who travelled a distance to receive chemotherapy commended the actions of their general practitioner or local public health nurse to upskill in the care of central lines and disposal of chemotherapy. These actions saved survivors time and energy, avoiding weekly visits to the oncology unit between cycles of chemotherapy:

> *"I was really lucky in that there was a nurse with my doctor in town, who then could … syringe the line into my chest. So, I didn't have to go back, I only had to go to the hospital once a fortnight, which was great. That was fabulous, having the local person being able to do it for me was terrific." [ESM005, Interview]*

The public health nurse was mentioned by several survivors with functional limitations due to metastatic disease or co-morbidities. Interview data suggested public health nursing services were underutilised resource for colorectal cancer survivors. One survivor described suffering with anorectal pain and lymphedema impairing her mobility. Her referral to the public health nurse came about after intervention from her general practitioner. She explained how the public health nurse was able to provide aids to support her in the home and alleviate her discomfort. A small number of survey participants felt public health nurses avoided caring for them due to a lack of confidence with oncology issues.

> *"When the nurse came she was shocked, so she said, 'Do you mean to say you don't have a ring cushion?' There was so much that she could have done." [RCM001, Interview]*
>
> *"I wasn't aware that there was a health centre down there that I could have been going down to every day to get my dressing changed because I used to make appointments with my doctor. Now, [my general practitioner] saw me, there was never a problem but … it could have cost me a lot of money apart from anything else." [ESM036, Interview]*

7.5.1.4 Reflections Upon Preparation for Transition to Survivorship

Accounts of transition to survivorship were closely related to survivors' views about information and support needs. For many, this was the first interface with the cancer services. Some commented on their naivety regarding the procedures and trajectories of cancer treatment. However, many described the consideration and delivery of information about surgery, radiotherapy and chemotherapy. Survivors described how information about side-effects and treatment outcomes were supported by visual, written and oral information. An example was the illustration of the section of bowel removed during surgery, a description of the function of that section of bowel and what the implications of removal were for post-operative bowel function. Recommendations for treatment were supported by statistics of prognostic benefit, particularly for adjuvant chemotherapy regimens:

> *"I was getting the chemo done then, that was a belt and braces job, they told me I didn't necessarily have to have it, but they do out these statistics and calculations and things, and I think I always had this feeling that I've been lucky." [ESM005, Interview]*

Hospital and community stoma nurses were a highly valuable point of contact before and after discharge from the hospital. Survivors described their attentiveness and care when learning how to manage the ostomy, providing a wealth of written and oral information about products, skin care and dietary management. All survivors spoke very positively of their interactions with stoma nurses:

> *"Now the [Stoma Nurse] was absolutely brilliant, she was just fantastic because she showed me how to use the bag and then she gave me a belt to put around it that would hold it in." [RSM019, Interview]*

Unlike the consensus regarding preparation for the acute effects of adjuvant treatment, a substantial number of interviewees believed they were insufficiently prepared for potential chronic complications of treatment, particularly peripheral neuropathy, bowel dysfunction and sexual dysfunction. Many survivors expressed a desire for greater information about pre-emptive self-management strategies for complications of treatment and disease prevention activities, such as diet and physical activity. Quite a few survivors believed dietetic consultation should be an integral component of colorectal cancer care, which could prevent lengthy trial and error processes:

> *"I think the side-effects should have been explained better. I feel they weren't explained at all now, and I think that's missing out of it. As for the rest of the treatment, I can't fault it, except the information end of it." [ESM006, Interview]*
>
> *"I should have been sent to a dietician to see what food you could eat and what food you couldn't eat … It doesn't matter what I do [I can't control my bowel], and the only thing I said about the food, I should have been able to go to a dietician for that particular thing." [RSM018, Interview]*

Many survivors were offered formal psycho-oncology consultations during treatment but declined them as they believed they were coping with their diagnosis. However, the psychological implications of cancer survivorship only became apparent after treatment for many. These survivors described worsening anxiety, fear and loneliness since the end of treatment and believed they could benefit from ongoing access to a psycho-oncologist or voluntary cancer support service. However, most felt these services were not available to them as they were no longer acutely ill and were unaware of alternative services:

> *"In terms of the psychological follow-up, I think [it] was very important. But it was very treatment-centric … access to the psychologist was only available for the duration [of treatment] … There wasn't any follow-up … I was going to the person once every two weeks … and then when [treatment] ended, that was it, 'You're done now,' there was no … 'I'll contact you in six months and see if you want to come back in, just to look back on the last six months.'" [ESM043, Interview]*

Survivors desired greater information about social issues during treatment and after discharge. Recurring concerns in interview and survey data were need for information about medical cards, managing financial difficulty, social welfare and pension entitlements and guidance about returning to work. Information about social issues was usually provided by social workers within the hospital, but these consultations were not routinely provided, or often came too late during treatment when survivors had already endured significant financial burden:

> *"A social worker comes in, she tells you about the car park facilities and all of that, but it was a little bit through [the treatment], so financially I had missed out a little bit." [ESM158, Interview]*

Some survivors linked shortcomings in survivorship information to being overwhelmed by information at the time of diagnosis. A number described a lack of closure at the end of treatment and felt cast out into the world unprepared for survivorship. These survivors believed the end of treatment was an opportunity to relay survivorship information and reinforce information given at diagnosis. Such reflections were prominent among survivors who lived with chronic physical and psychological effects following treatment:

> *"They gave me practically no information as to what would happen after the chemotherapy the way I would feel … I remember thinking the last day I walked out … 'Gosh, I don't know anything now, what's going to happen now?' … I just felt, I suppose, 'You're done now, we've done with you,' … I remember walking out that door, and it was*

> *like 'Oh, bye!' and there were waves and that was the end, there was no closure." [ESM158, Interview]*

Many survivors who shared these sentiments suggested support from other cancer survivors or peers could have assisted their preparation for physical and psychosocial survivorship issues. This theme was particularly strong among survivors who had used their own experiences to informally advise and assist other cancer patients and survivors in their communities. During treatment, nurses offered survivors the opportunity to meet post-treatment cancer survivors, yet the services were never arranged, despite the interviewee's enthusiasm. Several survivors suggested a concluding consultation or follow-up phone call from a nurse or cancer survivor to prevent a sense of unfinished business or lack of closure on the milestone of completing treatment:

> *"I think that's one of the very few things really that I think that they fell down on. They could've sent, maybe somebody along apart from a doctor, or a surgeon, but somebody that would understand from other patients [what to expect after treatment] … Who you'd have in the hospital to deal with something like that … That would be able to sit down with you and maybe bring some leaflets." [RSM048, Interview]*

The few survivors who felt well-prepared for survivorship spoke of receiving copies of their discharge letter with self-care instructions. Others talked about receiving information in an informal '*drip-fed*' manner, during radiotherapy or chemotherapy. Although they did not understand the meaning of this information at the time, they believed when side-effects occurred, they were prepared for them:

> *"He would let me know how other patients fared afterwards and it was only a while later I realised he's trying to tell me what life's going to be like after this, which was amazing and he did it so well and so nicely … I remember most of what he told me, but a lot of things happened, and I wasn't surprised when they happened." [ESM036, Interview]*

7.5.2 Healthcare After Colorectal Cancer

The models of follow-up and surveillance care for colorectal cancer survivors reflected the culture of the organisation where the survivor was treated and the survivor's disease status. Within the centre of excellence and regional centre, survivors received nurse-led surgical follow-up (*n*=15), regardless of insurance status. In the private centre, colorectal cancer survivors were engaged in consultant-led shared-care between medical oncology and surgery (*n*=5). Survivors with metastatic disease were under the care of consultant-led medical oncology services (*n*=2). Colorectal cancer survivors' experiences of post-treatment healthcare are represented within the sub-themes *Navigating the Schedule of Surveillance for Colorectal Cancer*, *Relationships with Healthcare Professionals in Follow-Up* and *Healthcare Professionals' Response to Survivors' Needs*.

7.5.2.1 Navigating the Schedule of Surveillance for Colorectal Cancer

Colorectal cancer survivors spoke positively of interactions with healthcare services since completing treatment. The majority had a very clear understanding of their post-treatment surveillance protocol, with many outlining the intervals of scans, colonoscopies and clinical consultations. Many described post-treatment surveillance as a '*finely tuned machine*', as appointments for routine investigations were arranged six months in advance, allowing survivors' time to plan for care:

> *"I'll see the nurses in September and then in 2017 I'll have another CT scan, and the nurses and all that, and then in 2018 I'll have another colonoscopy … I can plan my life … because the appointment is made so far in advance." [ESM121, Interview]*

When the sequencing of these appointments was incorrect, survivors took responsibility to ensure surveillance was efficient, minimising unnecessary clinical visits and delays to themselves and healthcare professionals. Examples of this were illustrated by survivors who initiated contact with healthcare professionals to reschedule clinical consultations if blood tests or scans were not completed. Those who described such events indicated that healthcare professionals welcomed survivors engaging with the process in this way:

> *"I keep an appointment diary; it allows me to call the hospital to reschedule dates if tests or bloods are out of sync with consultant appointments. This empowers me and means my appointments are of maximum benefit." [RCM001, Survey]*
>
> *"They schedule an appointment for the consultant … and then I ring her, I said … 'I'm going to the hospital seeing the surgeon and no bloods done' … and [they will] reschedule it … you have to watch yourself, because … you'd be twice the amount of [time] in a hospital." [RCM048, Interview]*

7.5.2.2 Relationships with Healthcare Professionals in Follow-Up

Survivors commended the accessibility of healthcare professionals responsible for their care. This accessibility facilitated survivors engaging with surveillance planning and provided reassurance to survivors when new, unexpected symptoms arose. In such situations, healthcare professionals recommended appropriate services to attend to investigate their symptoms, whether that was the general practitioner, Emergency Department, or an expedited appointment in the follow-up clinic. Several survivors described how doctors and nurses overseeing follow-up would bring scheduled investigations forward if there was any change in their symptoms. Furthermore, healthcare professionals were willing to relay results of investigations over the phone when they were available to alleviate survivors' anxiety:

> *"Recently when I [was] really, really sick with [constipation], I rang [Clinical Nurse Specialist] … my doctor had put me on stuff, but then when I rang [her] she took me off some of it … giving me natural things to do … I was due a scan, she got that brought forward so that I wouldn't have to wait, just to see was there anything, and … [she] rang me [with the results], just to tell me everything was fine." [ESM036, Interview]*

Survivors' positive evaluations of follow-up care were underpinned by the relationships developed with the healthcare professionals responsible for their care. Survivors described familiarity with doctors and nurses and open communication which fostered continuity in their care. Several described how healthcare professionals, particularly nurses, took time to get to know them. Survivors equated such endeavours to healthcare professionals' empathy and willingness to care for them. Feeling known on a personal level encompassed healthcare professionals' knowledge of the survivor's social and family life:

> *"But if either of [the Colorectal Cancer Clinical Nurse Specialists] happen to pass, they'd see me, come down and [ask] 'How is everyone in [Town]?' … She knows exactly who we are … How she can remember everybody I don't know, because I mean hundreds have gone through, even since me." [ESM121, Interview]*

On a medical level, feeling known incorporated healthcare professionals taking time to gain a thorough knowledge of their medical history, including co-morbidities. In some cases, feeling known and cared for extended to include their oncology specialists advocating for the survivor with other medical specialties about co-morbidities which were not related to colorectal cancer:

> *"I've utter respect and trust in them, that they know what they're doing, anything … regardless of what it is, [they] straighten [it] out for me … you can see that they are caring, anything that you have to do, they're right here, they're right behind you, so it's very good, I'm glad." [ESM003, Interview]*

7.5.2.3 Healthcare Professionals' Response to Survivors' Needs

Survivors felt cared for by healthcare professionals during follow-up, but highlighted specific areas where care needed to improve. As already outlined, survivors felt secure in surveillance programmes. However, analysis of interview data and survey comments suggested healthcare professionals' responses to cancer-related physical, psychological and social issues varied within and between hospitals. Some survivors described how healthcare professionals were responsive to quality of life issues raised. Others described oversight of quality of life issues or less than satisfactory engagement from healthcare professionals on such matters.

In several cases, survivors' narratives suggested their satisfaction with healthcare professionals' engagement with their physical and psychosocial issues were a legacy of their preparation for transition to survivorship (or lack thereof). Peripheral neuropathy was a survivorship issue many survivors were unprepared for. For many, it followed that they received poor counsel regarding management strategies, specialist assessment and interventions. Two survivors were discharged from medical oncology following chemotherapy, after which time, peripheral neuropathy symptoms intensified. Each described feeling disregarded by medical oncology staff when they reported symptoms:

> *"[The peripheral neuropathy symptoms] would come and go and I got a severe attack of it shortly after [treatment]. I got no support in the Oncology Ward with that. I kept ringing them up because I had spent three weeks literally with no sleep … They just said 'Oh, it may come, it may never go, sometimes it does, and sometimes it doesn't.' So that was it, that wasn't great support." [ESM158, Interview]*

These survivors described how surgical follow-up services acknowledged their concerns but were ill-equipped to manage neurological issues as they lacked expertise and experience with peripheral neuropathy. Three survivors were referred to neurology for evaluation of severe peripheral neuropathy. Although one survivor had a favourable outcome relieving the carpal tunnel syndrome exacerbating her symptoms, two described frustration as they returned for neurological consultations, receiving the same interventions repeatedly, with no subjective improvement in their symptoms:

> *"For the neuropathy, I felt I was just being pushed from one to another, I'd come out after being in the clinic, and there was nothing at the end of it … she tests your legs and tests your feet, and then that's it, for another six months … and I'd have to wait another six months, just to go back again and still nothing. And four years down the line, there's still nothing. And that's very distressing." [ESM073, Interview]*

Despite these frustrations, survivors described how nurses remained cognisant of their ongoing challenges with peripheral neuropathy, were willing to discuss it and provide reassurance. This fostered hope among this group of interviewees, even where they understood symptom relief might be impossible. This hope was mirrored in a male survivor's description of healthcare professionals' response to bowel dysfunction:

> *"They sent me to a stomach specialist … he'd be looking for different things than the surgeon … I'm hoping and praying that he comes up with something that can be fixed and then I won't have the problems … The stoma nurse … did everything she could to try and ease the situation." [RSM018, Interview]*

Several survivors' narratives suggested healthcare professionals failed to refer them to appropriate allied health services for lymphoedema (lymphoedema nurse), peripheral neuropathy (physiotherapy) and bowel dysfunction (dietician). In two of these cases, survivors described how they fought to gain referrals through a combination of persistence, insider knowledge and acquired knowledge:

> *"I said to [the nurse in treating hospital] 'Is there a lymphedema nurse here?' I had already found out that there wasn't, but I thought maybe they had a secret one somewhere. I'm very, very good at ferreting out things … She said 'No, we don't have such a thing here, I do know there's one in [Oncology Hospital]'. Now by coincidence, my best friend is a radiographer in [Oncology Hospital] … she was able to tell me that the lymphedema specialist nurse had actually been removed from that post and sent back to the wards when the cutbacks took place … [Eventually], it turned out that there was this palliative care doctor in [treating hospital] who has a physiotherapist on his team, who I believe does this manual lymph drainage … At no stage had I been told that this consultant existed, [I called his secretary], then about ten days later, an appointment arrived for me ... nearly a month after my initial [symptoms] … I can't understand why they were keeping this man a secret … You're really depending on the professionals to say, 'this is available, and we think it might be useful for you.' I certainly don't want to be grabbing at everything just because it's there." [RCM001, Interview]*

In most cases, survivors suggested that healthcare professionals leading follow-up responded to questions or issues when raised. However, many survivors believed they needed to drive discussions of chronic treatment effects. A small number commented that both the clinician and survivor were preoccupied with discussion of surveillance results during follow-up, to the detriment of symptoms assessment and management:

> *"I think [sexual dysfunction] is something that should be brought up … It's not feeling [un]comfortable [discussing it], it just never came up, I've no problem bringing it up if I can*

> *remember when I meet them, but then there's so few times that you meet them … [sexual dysfunction] doesn't seem to have any priority whatsoever in follow-up." [ESM006, Interview]*

7.5.3 Systemic Barriers to Healthcare Across the Spectrum of Colorectal Cancer

In previous sections, colorectal cancer survivors relayed a variety of unmet information and supportive care needs, particularly for enduring physical and psychological effects. Factors contributing to ongoing unmet needs discussed thus far include:

- Shortcomings in interdisciplinary communication and interpersonal skills,
- Power imbalances in the therapeutic relationship,
- Systematic errors creating delays in diagnosis or treatment,
- Underutilisation of community resources,
- Healthcare professionals' lack of expertise in the management of particular symptoms, and
- Oversight of the potentially chronic nature of treatment toxicities.

Although these are barriers to healthcare in themselves, survivors suggested these were largely individual-level problems arising from the inaction or oversight of a single healthcare professional. Survivors theorised these problems were encouraged by political and organisational motives and cultures, including staffing shortages and professionalisation of nursing. Since 2008, there was an embargo on staff recruitment in public hospitals due to the economic recession. Survivors who received care in public hospitals commented on the impact of reduced nurse-patient ratios on their care. While many survivors were sympathetic to the workloads of nursing staff in surgical, medical and radiation oncology settings, some felt the increasing workloads of healthcare professionals created unsafe conditions for patients. As a result, one interviewee took a more active role in their care during treatment, collaborating with nursing staff to check the sequencing of chemotherapy drugs. Some survivors felt nursing tasks were neglected following surgery, particularly if the survivor was able to self-care:

> *"I was so debilitated from the surgery; I couldn't actually do it myself … Like any nursing service, it's a situation that they're understaffed. No two ways about that … I can understand that's just the way it is. But sometimes there wasn't a staff member there to change the bag when it needed to be changed, so it burst a couple of times." [ESM043, Interview]*

One survivor implied that the professionalisation of nursing was contributing to a greater orientation towards advanced practice roles and documentation of care, resulting in oversight of basic nursing care. Ultimately, survivors' awareness of healthcare professionals' competing demands meant they may be less willing to pursue information needs as they did not want to disenfranchise other patients or the healthcare professional:

> *"I noticed initially when I was diagnosed and maybe in the first or two or three years that, the nurses did have time to chat to you about anything … [but] laterally it was just sort of,*

> *put the line in, connect your port and that was it, they were gone, so there was very little point of contact and you sort of felt, if I delay them now, it's delaying everybody else." [RCM001, Interview]*

Staffing shortages may also have contributed to survivors being cared for in general surgical wards, with patients who did not understand the nature of the survivor's surgery, creating embarrassment for the survivor as they adjusted to the placement of an ostomy or altered bowel function:

> *"I was on the medical card anyway, there was six people in the [ward], and you had to go through all this, and some of them weren't in for [colorectal cancer]. In fact, the first time I was in, I was in a ward where they put in joints, hips and that, and I was running to the toilet every five minutes." [RSM018, Interview]*

In interviews and surveys, survivors in younger age groups described how colorectal cancer was more typically a cancer diagnosed in those over the age of 60. Younger survivors felt there was a failure to tailor care to their age-related needs. Younger survivors described challenges of continuing and returning to work and support for family members, including parents, spouses and dependent children. One survivor felt there was a failure to address the psychological implications of a colorectal cancer diagnosis as a young man in his forties:

> *"Most people with colon cancer are a lot older than me. They're not going to be turning around complaining, 'this is affecting my athletic performance' … There was a definite willingness [among healthcare professionals] to engage, [but] there was certainly a failure of experience and infrastructure and support groups, for somebody specifically of my age." [RSM043, Interview]*

7.5.4 Theme Summary: The Healthcare Experiences of Colorectal Cancer Survivors

Colorectal cancer survivors' experiences of healthcare during diagnosis, treatment and follow-up were largely positive. For the most part, the doctors and nurses encountered were considerate, knowledgeable and efficient providers of care, often surpassing the expectations of the clinician-patient relationship to foster continuity, support and reassurance. However, there was an undercurrent of both positive and negative care events punctuating the processes of care. Systemic failures, poor interpersonal skills and under-utilisation of primary care resources characterised negative experiences. Survivors were vulnerable within the clinician-patient relationship, as *Power* imbalances and disregard of the survivor's knowledge and expertise of their condition could cause distress and contribute to negative healthcare outcomes. One of the most concerning findings within this theme was survivors' lack of *Preparation for Survivorship* and shortcomings in access to psychological support following treatment. Several survivors felt the end of treatment was marked by a lack of closure; a missed opportunity to provide education about the long-term implications of a cancer diagnosis. A substantial proportion of survivors lamented the insufficient *Response* from healthcare professionals to the physical and psychosocial challenges which continued to burden survivors after the end of treatment. This theme has highlighted the variety of individual, organisational and political barriers to healthcare, including staffing shortages and a lack of individualisation of care which allows survivors' unmet needs to flourish. The next section will describe the systems and supports colorectal cancer use survivors to address these unmet needs.

7.6 Bridging the Gap of Unmet Need: Navigating the Network of Support Beyond the Healthcare System

Section 7.5 illuminated a variety of unmet information and supportive care needs experienced by survivors in the aftermath of colorectal cancer. A final theme emerged from the data highlighting the resources and resourcefulness of survivors in overcoming unmet healthcare needs. Many survivors identified alternative sources of information and support beyond the healthcare service. These are discussed within the sub-themes *Family and Social Networks, Peers in Cancer Survivorship, Voluntary Cancer Support Services* and *Sourcing Information Beyond the Healthcare Network*.

7.6.1 Family and Social Networks

Unsurprisingly, family members were the most enduring source of support, sharing the experience of cancer with the survivor. Family members had the greatest insight into the survivor's physical and psychosocial difficulties and were willing to assist the survivor to overcome the limitations and challenges of survivorship. Family members knew the survivor best and knew how to respond to their needs in a way they were receptive and appreciative of:

> *"My wife was fantastic, and even the kids were great … because they kept bringing you back to reality … making life easier for me … I got this huge supportive feeling from [my wife], she was always there; I always had somebody." [ESM005, Interview]*

Friends and members of the community formed a significant network of support for survivors who lived alone or did not have family. However, unlike family, social networks were not always sensitive to or aware of cancer survivorship issues. In the absence of survivorship awareness within social networks, survivors felt isolated, lonely and needed to '*plan ahead*' for social occasions to avoid embarrassment. Also, members of social networks could be unhelpful in the process of recovery. Firstly, by making inappropriate suggestions about the survivor's care, and secondly, by suggesting unhelpful self-management strategies:

> *"I'd like to think I learn quick … but I know other people don't, but then I think people interfere with them. It's a nuisance that someone says [negative things about healthcare and recovery]. They haven't experienced it to say those words. They think negative, not positive and you have to try and think that by yourself, with a positive attitude to it." [RCM049, Interview]*

On the other hand, a small number of survivors described how close friends and those who had familial experiences of cancer were aware of survivorship issues. Such friends were compassionate, empathetic and available to support survivors in times of psychosocial distress. Examples of friends' supportive behaviours included providing emotional support, assisting with domestic chores and ensuring survivors had access to appropriate dietary options and toilet facilities in social situations:

> *"I've wonderful neighbours, they were knocking on the door constantly, 'Do you need anything from the shop?' 'Have you got enough milk?' – it makes such a difference and [I felt] the offers were all genuine offers." [PCM026, Interview]*

Family members and friends who worked in the healthcare service were the greatest sources of insider knowledge, assisting survivors to navigate the system more competently and efficiently. In addition, family and friends were important resources when attending hospital appointments, as they were available to take notes on clinical consultations, assist decision-making processes and advocate for the survivor where the survivor felt unable to do so:

> *"Have a friend or somebody to listen at any consultation; it is very important to have somebody because when you're there worried, you're waiting for the bad news or you're only half listening to the detail. Whereas the other person is listening." [ESM121, Interview]*

7.6.2 Peers in Cancer Survivorship

Survivors believed cancer survivor peer supporters could be a useful source of information and support for survivors at transitionary periods of the cancer trajectory. Survivors described informal peer support during chemotherapy, radiotherapy and surgical admissions. Many survivors built relationships with other survivors as treatment schedules overlapped. These relationships were a source of emotional and practical support, as survivors were united by shared life experiences. These relationships offered access to information about self-management strategies, shared humour as a coping mechanism and facilitated social comparison to reframe individual experiences:

> *"[There was a] young lad in [Ward] diagnosed with Crohn's disease, which you can imagine has some effect on the man's life, a young fella. When we were talking about Crohn's disease, you're talking about life-changing afterwards. Well, then I think that my life-changing experiences are pretty minor in comparison." [RSM048, Interview]*

Beyond the hospital, cancer survivors identified peers within their social networks who were beacons of information about practical self-management strategies to cope with side-effects:

> *"My daughter-in-law, her aunt has terminal cancer, and they'd been treating her for a number of years … She gave [my son] loads of tips … And the one thing I can remember, and do you know it really was necessary, wear gloves at the fridge or the freezer. I wouldn't have thought of that in a fit, but I really needed them." [PCM026, Interview]*

7.6.3 Voluntary Cancer Support Services

Few survey participants used voluntary cancer support services (Section 6.4.3.3). Many interview and survey participants explained they did not require such support in surveys and interviews as they were coping, had a wish to move on or had adequate support from family, friends and healthcare professionals. However, a proportion of survivors were unaware of voluntary support services or did not have access to such organisations due to distance or lack of local availability:

> *"They did tell me there were meetings … but I didn't attend them now … It would be fifteen or sixteen miles away from me at least. We have lost a bus service … and it would make it a bit more awkward that way." [RCM049, Interview]*

Several survivors highlighted potential benefits of hospital-based support groups, lamenting this gap in care:

> *"I initially said in oncology, was there any group of cancer sufferers, a support group, where … people like me, not knowing exactly what was going to happen, just to have a chat, just a workgroup, just chat like. And as far as I can remember, she said, 'No, not really,' But, she said she'd take a note of it, that I would be willing to talk to other patients if the other patients so wishes. But unfortunately, that never came off the ground." [RSM048, Interview]*

As already discussed, some survivors stigmatised discussion of bowel-related symptoms. Survivors were unaware of colorectal cancer-specific support groups and felt it inappropriate to attend generic cancer support groups. The idea of discussing bowel-related symptoms with survivors who would not understand or share their experiences embarrassed many survivors:

> *"I suppose if I looked it up, there was groups I could join, there was plenty of groups for breast cancer and stuff like that, but not for bowel. I probably didn't look enough, and I'm not that good at mixing with a group of people that I didn't know. With the symptoms I was having, it would be better because you'd have someone else who might have the same system or might have found some way to cope with that … I think every cancer would be different ... With breast cancer, you wouldn't have the side-effects that I'm having." [RSM018, Interview]*

For others, support groups were too personal; several feared being labelled or defined by their disease. Others feared taking on the problems of others and avoided group support. One survivor described how his previous experience of a cancer bereavement support group was unhelpful:

> *"I don't have an awful lot of faith in support groups. My first wife died of ovarian cancer … The [Hospital] had a support group [I attended] after she had died. I said never again … [the people] I spoke to weren't interested in helping anybody else, they were looking for help for themselves, so I didn't go back." [ESM006, Interview]*

Despite these challenges, a number of survivors discovered that cancer support centres offered more extensive services than originally realised. Survivors who shunned group support found they could receive support for physical, psychological and social well-being issues. Some of these survivors discovered they could access individual counselling services, nursing services, complementary therapies, advocacy services, lectures and information sessions. Male survivors were more likely to discuss accessing advocacy or information services, while female survivors spoke about psychological support and complementary therapies:

> *"[Cancer Support Centre] were just fantastic while I was going through [treatment] ... I did support groups; I did art therapy … I had reflexology; I had nutritional and diet information. They started a stoma support group, so it was a little group of people with similar experiences … It's the whole notion of… you're not on your own … Even some of the people giving the lectures or talks would have been service users at one stage; I found it helpful to see people get through this all the time." [ESM087, Interview]*

7.6.4 Sourcing Information Beyond the Healthcare Network

Survivors used various information sources to supplement the advice of healthcare professionals, including cancer information leaflets, cancer support centres, cancer helplines, and most commonly, the internet. Many survivors were averse to using the internet to gain information about prognosis or treatment, as it yielded '*horror stories*'. However, some survivors admitted '*Googling*' information about their disease to prepare for treatment or determine whether changing symptoms were related to colorectal cancer or another co-morbidity. Many of these survivors felt there was a need to be selective of the websites used to garner information, to ensure they were getting accurate information. Websites such as www.macmillan.org.uk, www.livestrong.org and www.patient.co.uk were specific examples of '*good*' websites described by cancer survivors:

> *"Macmillan, I think one of the nurses said 'Okay, if you must Google, Google them.' Also, the Lance Armstrong one … One of the good things about the Lance Armstrong site was [that] it was full of positive stories. I found it very beneficial … it was a pretty comprehensive website, and there was information on there, for sports people about neuropathy, one of the few cancer resources that actually had sports-specific information on it that was relatively modern." [ESM043, Interview]*

Few spoke of corroborating information acquired from the internet with healthcare professionals. Among those who did, it was considered important, given unverified claims of successes in the management of side-effects on some websites:

> *"I looked it up on the web one time, and you've all these Americans telling you how they have a cure for [peripheral neuropathy] and everything. But, I spoke with the [general practitioner], and he said … you can't force [the nerves] to grow, they grow at their own speed." [ESM006, Interview]*

Despite this, the internet could be a source of hope for survivors, as they endeavoured to remain abreast of advances in pharmacological and non-pharmacological management strategies of chronic symptoms, particularly peripheral neuropathy and bowel dysfunction:

> *"[My husband] gives me great hope, he keeps saying, 'There'll be something that will come on the market that will help [my peripheral neuropathy]' … he's always looking up the internet to see if there are any new drugs." [ESM073, Interview]*

One survivor described how the internet led to him make contact with a research group specialising in the management of peripheral neuropathy in America. As he compared the information he received from the research group with that from healthcare professionals responsible for his care, he concluded that healthcare professionals in Ireland were not aware of the most recent research in the field. He felt he was receiving conflicting information from healthcare professionals and the research group:

> *"I suppose we're lucky in this day and age; we've got Google, so you can do a lot of research on Google. My experience is that the science and research of peripheral neuropathy is evolving at a rate of knots … and it's my understanding that there isn't really anyone in Ireland who's tapping into this … I got in touch with a doctor [in America] who's doing a study group with Charcot-Marie-Tooth people because one of their symptoms is neuropathy … These people are running … The overwhelming advice I got from anyone I saw, in this country was to not run, because of the danger of causing irreparable damage in the joints." [ESM043, Interview]*

7.6.5 Theme Summary: Bridging the Gap of Unmet Need: Navigating the Network of Support Beyond the Healthcare System

Sections 7.4 and 7.5 illustrate the significant implications of colorectal cancer for long-term physical, psychological and social health. Although survivors rated their experience of healthcare positively, many experienced a variety of information and supportive care needs. Thus, survivors sought alternative resources to *Bridge the Gap of Unmet Need*. *Family Members* were a consistent and appreciated source of support, doing their utmost to provide psychosocial support for the survivor. Where survivors lived alone and did not have the assistance of immediate family members, *Social Networks* often filled this void. However, friends and acquaintances may lack awareness and understanding of cancer survivorship issues. As a result, well-meaning friends could offer inappropriate or unhelpful advice, causing the survivor unintentional distress.

Formal *Peer Support* structures were under-developed within the hospital setting, yet many survivors spoke of the benefits of shared experiences with other cancer survivors during treatment. Several survivors felt these peers were valuable sources of information and support. Although formal cancer support was available from *Voluntary Cancer Support Services*, many survivors declined to engage with such services due to challenges of access, fears of discussing specific bowel cancer concerns with mixed tumour support groups or fear of dwelling upon their disease. However, for survivors who explored the services of voluntary cancer support centres, many were surprised to discover services other than support groups, including counselling services, complementary therapies, advocacy services and information services. While online resources were an important source of information, many survivors were sceptical of the reliability of these resources. However, where computer-literate survivors felt they were not getting the most appropriate or evidence-based advice from their healthcare professionals, the internet was a gateway to secondary medical opinions beyond the Irish healthcare system.

7.7 Chapter Summary

This chapter has presented the results of the thematic analysis of qualitative data within this mixed methods study exploring the impact of healthcare experiences upon the quality of life of colorectal cancer survivors receiving follow-up care in tertiary oncology healthcare services in Ireland. The interviews provided depth and context to support and enhance interpretation of quantitative findings. The narratives of survivors provide a greater understanding of the cross-domain impact of the chronic effects of colorectal cancer upon their quality of life and the strategies which survivors use to manage and reframe the impact of these effects. The results describe the triumphs and shortcomings of the healthcare system and professionals guiding survivors from diagnosis into follow-up. Although survivors evaluated their overall experiences of care positively and believed healthcare professionals endeavour to support them as much as possible, there are areas of care which remain overlooked. The qualitative findings highlight particular unmet needs relating to survivors' preparation for survivorship. Despite feeling secure in surveillance programmes, many survivors feel unprepared and somewhat unsupported to cope with physical, psychological and social issues which manifest in the aftermath of treatment. Several interviewees point to political and organisational barriers which may exacerbate healthcare professionals' failures to respond to their symptom-related needs.

The findings of Phase 2 interviews extend understanding of Phase 1 survey results, identifying specific issues within healthcare encounters which can influence colorectal cancer survivors' lives favourably or detrimentally. The qualitative analysis suggests that there is a network of support beyond the Irish healthcare system which critically builds upon care provided by healthcare professionals (Figure 7.2). This network bridges the gap of unmet needs and in some circumstances, improves survivors' well-being, enhancing survivors' knowledge and understanding of their experience and providing support. The quantitative findings indicate that survivors rarely access voluntary support services, yet the qualitative analysis suggests that poor understanding of these services, a lack of awareness of their availability to cancer survivors and challenges surrounding access may contribute to colorectal cancer survivors' failure to engage with advocacy-led cancer support services. Chapter Eight will deal with the integration of the quantitative and qualitative results and will discuss the findings in the context of previous literature.

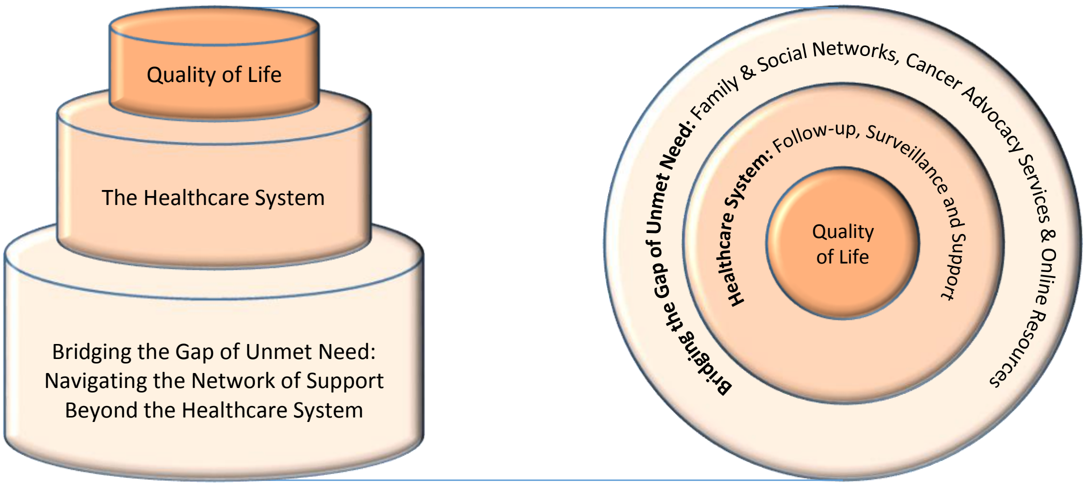

Figure 7.2 Mapping colorectal cancer survivors' formal and informal networks of support: Bridging the Gap of Unmet Need to manage ongoing quality of life concerns

Chapter Eight – Discussion and Integration of Study Findings

8.1 Introduction

The overarching aim of this mixed method study was to understand and explore the impact of healthcare experiences upon the quality of life of colorectal cancer survivors receiving follow-up care in tertiary oncology settings in the Republic of Ireland between six months and five years following diagnosis. The concept analysis (Section 2.2) and literature review (Chapter Three) highlighted a limited body of empirical literature explicitly exploring the potential relationship between colorectal cancer survivors' quality of life outcomes and healthcare experiences in tertiary oncology follow-up settings and dualist public-private models of healthcare provision. A pragmatic, mixed methods sequential explanatory design was selected to guide the conduct of the study, affording an opportunity to achieve a comprehensive understanding of the magnitude and context of the quality of life issues experienced by this sample (Chapter Four & Five). The survey phase provided key information to describe quality of life outcomes, and the socio-demographic, cancer-related and healthcare-related factors which may influence the quality of life of colorectal cancer survivors (Chapter Six). The subsequent qualitative interview phase enhanced the results of the quantitative study, providing a greater depth of understanding of the complexity and individuality of quality of life outcomes and healthcare experiences of colorectal cancer survivors (Chapter Seven).

Within this chapter, the demographic, cancer-related and quality of life characteristics of the study sample are compared with the general Irish population and the samples of previous Irish and international studies of colorectal cancer survivors (Section 8.2). The subsequent sections of this chapter are concerned with the integration, interpretation and discussion of the quantitative and qualitative study results (Sections 8.3-8.9). The results of the quantitative and qualitative phases of the study are presented and interpreted logically within the scope of the overarching mixed methods study objectives (Table 8.1). Integration of findings is achieved as the results of the

Overarching Mixed Methods Objectives (Section 2.4.1)
1. To understand colorectal cancer survivors' quality of life between six months and five years following diagnosis in Ireland (Section 8.3).
2. To establish the nature and prevalence of adverse physical, psychological and social effects following colorectal cancer treatment in Ireland (Section 8.4).
3. To explore colorectal cancer survivors' experiences of healthcare in the aftermath of treatment (Section 8.5).
4. To identify the unmet information and supportive care needs of colorectal cancer survivors (Section 8.6).
5. To determine the personal and organisational structures used by colorectal cancer survivors to address unmet information and supportive care needs (Section 8.7).
6. To ascertain the healthcare-related factors which influence colorectal cancer survivors' quality of life (Sections 8.8 and 8.9).

Table 8.1 Mixed methods objectives of The Cost of Survival Study

qualitative phase are used to interpret, explain and extend understanding of the quantitative findings, consistent with the intention of a sequential explanatory study design (Ivankova *et al.* 2006). The mixed methods results are discussed and interpreted in relation to previous empirical and theoretical literature within each section. The chapter concludes with a summary of the limitations and strengths of the current study (Section 8.10).

8.2 Sample Characteristics

As a first step in interpreting the findings, it is necessary to establish the representativeness of the sample within Irish and international contexts. Therefore, this section will compare the socio-demographic and cancer-related characteristics of the sample to equivalent Irish census data, and the characteristics of colorectal cancer survivors enrolled in previous quality of life studies conducted internationally. It is important to understand whether participants of the current study differ from other populations in any meaningful way to ascertain the potential applicability (generalisability and transferability) of the findings. Therefore, the quality of life data provided by colorectal cancer survivors in the quantitative phase of this study are compared to normative scores for 1) the general population, 2) cancer patients, and 3) cancer survivors.

8.2.1 Socio-Demographic Characteristics

The distribution of age and gender within the sample are consistent with national trends. In Ireland, fewer than 15% of all cancers are diagnosed before the age of 50; two-thirds of colorectal cancers are diagnosed in people over the age of 65, and approximately 58% of new cases arise in males (NCRI 2013a). The sample was largely of White Irish ethnicity (95.5%), which is comparable to the ethnic distribution of the Irish population, as minority ethnic groups account for just five percent of the national resident population (Central Statistics Office 2017). Compared to the Irish Census results, similar proportions of the sample resided with family members or friends in urban areas (Central Statistics Office 2017). The high number of survivors who were unable or unwilling to engage with the labour force prior to diagnosis and at the time of the survey may be explained by the age profile of the sample, as two-thirds were above the age of 65, the age of statutory retirement in Ireland. Furthermore, the proportion of survivors (38%) who left the workforce between diagnosis and the time of the survey was similar to those reported by Domati *et al.* (2011) and Hanly *et al.* (2013).

The proportion of colorectal cancer survivors who hold private health insurance (48%) is comparable to the general population (43%). However, a greater number were in possession of a medical card at the time of the study (63% versus 37%) (DoH Ireland 2016). This discrepancy may be explained by shifting social welfare policies in the Republic of Ireland over the past decade. Until January 2014, all persons over the age of 70 were automatically entitled to a medical card, granting the holder free or heavily subsidised healthcare in the Irish public health system. Since 2014, all medical card applicants are subject to a means test, regardless of age. Medical cards are granted to those whose income is below the level of state social welfare benefits or where an individual would suffer hardship due to their state of health without one (HSE 2015). Given the demographic profile of colorectal cancer patients and workforce patterns, many cancer patients are automatically granted medical cards to address ongoing health concerns.

8.2.2 Cancer-Related Characteristics

The ratio of colon to rectal cancer survivors within the sample is similar to that of previous quality of life studies which have recruited random samples of colorectal cancer survivors from cancer registries in Ireland (Thomas *et al.* 2014), Europe (Caravati-Jouvenceaux *et al.* 2011, Buffart *et al.* 2012) and internationally (Chambers *et al.* 2012b, Sisler *et al.* 2012b). Similarly, the distribution of age, gender and co-morbidity within the current sample are comparable to those of similar studies which have utilised convenience and randomised sampling techniques (Phipps *et al.* 2008, Pucciarelli *et al.* 2008, Ristvedt & Trinkaus 2009, Caravati-Jouvenceaux *et al.* 2011, Domati *et al.* 2011, Mrak *et al.* 2011, Salsman *et al.* 2011, Buffart *et al.* 2012, Kilic *et al.* 2012, Knowles *et al.* 2013, Mols *et al.* 2014, Salz *et al.* 2014, Schlesinger *et al.* 2014, Vallance *et al.* 2014). In the present study, 91% of survivors underwent surgical treatment of their colorectal cancer either alone or in combination with chemotherapy (59%) or radiotherapy (24%). These statistics are in keeping with proportions of survivors receiving each treatment modality in previous studies (Schneider *et al.* 2007, Bouvier *et al.* 2008, Peddle *et al.* 2008a, Jansen *et al.* 2011a, Lynch *et al.* 2011, Pullar *et al.* 2012, Sisler *et al.* 2012b, Schlesinger *et al.* 2014).

The concept analysis identified inconsistencies in the stages of disease and timeframe of survivorship utilised in the inclusion criteria of cancer survivorship research (Section 2.2). Although cancer survivorship begins at the moment of diagnosis and continues for the duration of the individual's life (Mullen 1985, Reuben 2004, National Coalition for Cancer Survivorship 2013), the purpose of this study was to understand colorectal cancer survivors' quality of life within the context of tertiary oncology follow-up care. Therefore, the study limited inclusion criteria to those survivors who were between six months and five years following diagnosis. Five years is acknowledged as the end of *Extended Survival* by Mullen (1985), and many quality of life studies conform with this (Fucini *et al.* 2008, Haggstrom *et al.* 2009, Ristvedt & Trinkaus 2009, Grimmett *et al.* 2011, Jansen *et al.* 2011a, Chambers *et al.* 2012b). Furthermore, the proportion of survivors who self-report recurrent or metastatic disease in the current study (11%) is similar to other studies which have included these groups of colorectal cancer survivors (Hoerske *et al.* 2010, Costrini 2011, Den Oudsten *et al.* 2012, Schlesinger *et al.* 2014).

Author (Year)	Country	Sample Size	Mobility (*n*)	Self-Care (*n*)	Usual Activities (*n*)	Pain/Discomfort (*n*)	Anxiety/Depression (*n*)	VAS Score
Current Study	Ireland	287	28.8% (85)	6.1% (18)	36.7% (108)	33.7% (98)	29.9% (88)	81.2 (16.1)
Kind et al. (1998)	UK	3395	18.4% (625)**	4.3% (146)	16.3% (553)**	33.0% (1120)	21.0% (713)**	82.8 (0.4)
*$p \leq 0.05$; **$p \leq 0.005$								

Table 8.2 Results of two-proportion Z-tests to compare the proportion of colorectal cancer survivors reporting difficulties on EuroQol 5D-5L items with population norms for the UK

Author (Year)	Country/Sample	Sample Size	FACT-G (*SD*)	PWB (*SD*)	SWB (*SD*)	EWB (*SD*)	FWB (*SD*)	CCS
Current Study	Ireland[3]	254-283	89.3 (15.5)	24.6 (4.3)	23.3 (5.4)	20.1 (3.9)	21.2 (6.6)	22.1 (5.0)
Brucker et al. (2005)	United States[1]	1075	80.1 (18.1)**	22.7 (5.4)**	19.1 (6.8)**	19.9 (4.8)	18.5 (6.8)**	Not Available
Brucker et al. (2005)	United States[2]	2236	80.9 (17.0)**	21.3 (6.0)**	22.1 (5.3)**	18.7 (4.5)**	18.9 (6.8)**	Not Available
Holzner et al. (2004)	Austria[1]	926	86.5 (15.2)*	24.9 (4.1)	20.2 (5.8)**	19.5 (4.5)*	21.4 (5.5)*	Not Available
Holzner et al. (2001)	Austria[3] (Breast)	30	82.3 (14.5)*	25.0 (3.9)	17.5 (6.1)**	18.7 (3.7)	21.1 (6.4)*	Not Available
Holzner et al. (2001)	Austria[3] (Breast)	28	91.1 (9.2)	26.4 (2.6)**	20.4 (3.4)**	20.5 (2.7)	23.4 (3.3)	Not Available
Kopp et al. (1998)	Austria[3] (BMT[4])	41	89.2 (13.9)	23.4 (5.0)	20.6 (5.1)**	16.9 (2.9)**	21.3 (5.0)	Not Available
*$p \leq 0.05$; **$p \leq 0.005$; [1]General Population Normative Scores; [2]Cancer Patients; [3]Cancer Survivors; [4]BMT: Bone Marrow Transplant								

Table 8.3 Results of two-sample t-tests to compare Functional Assessment of Cancer Therapy-General (FACT-G) scores in the current sample with normative scores for general populations and cancer patients internationally

Author (Year)	Country	Sample Size	FACT-C (*SD*)	PWB (*SD*)	SWB (*SD*)	EWB (*SD*)	FWB (*SD*)	CCS (SD)
Current Study	Ireland	251-283	111.9 (18.8)	24.6 (4.3)	23.3 (5.4)	20.1 (3.9)	21.2 (6.6)	22.1 (5.0)
Austin et al. (2010)	Australia	37	107.3 (15.1)	23.7 (4.2)	21.1 (6.1)*	20.6 (4.2)	20.7 (5.3)	21.1 (3.3)
Austin et al. (2010)	Australia	15	106.4 (20.3)	22.7 (4.3)	23.6 (4.6)	20.3 (3.6)	18.9 (7.4)	20.9 (3.9)
Chambers et al. (2012b)	Australia	740	113.8 (15.4)	24.2 (4.7)	22.7 (4.8)	21.7 (2.9)**	22.2 (5.2)*	23.0 (3.8)*
Chambers et al. (2012b)	Australia	740	118.0 (14.6)**	25.8 (3.7)**	23.2 (4.4)	22.2 (2.7)**	23.2 (4.9)**	23.7 (3.6)**
Costrini (2011)	USA	39	103.4 (23.9)*	21.5 (6.1)**	22.0 (5.1)	19.6 (4.7)	19.8 (6.6)	20.6 (5.0)
Lynch et al. (2007b)	Australia	1966	111.5 (16.4)	23.6 (5.2)**	22.4 (4.8)*	21.3 (3.3)**	21.5 (5.6)	22.7 (4.0)
Lynch et al. (2011)	Australia	1966	111.0 (16.0)	24.0 (5.0)*	22.0 (5.0)**	21.0 (3.0)**	21.0 (6.0)	23.0 (4.0)**
Lynch et al. (2011)	Australia	1657	116.0 (15.0)**	25.0 (4.0)	23.0 (5.0)	22.0 (3.0)**	23.0 (4.0)**	23.0 (4.0)**
Lynch et al. (2011)	Australia	1474	117.0 (16.0)**	25.0 (4.0)	23.0 (5.0)	22.0 (3.0)**	23.0 (5.0)**	23.0 (4.0)**
Lynch et al. (2011)	Australia	1266	118.0 (14.0)**	26.0 (4.0)**	23.0 (4.0)	22.0 (3.0)**	23.0 (4.0)**	24.0 (4.0)**
Peddle et al. (2008a)	Canada	413	110.3 (17.0)	24.3 (5.0)	20.6 (4.0)**	19.9 (4.0)	23.1 (5.0)**	22.2 (4.0)
Vallance et al. (2014)	Canada/Australia	178	110.8 (17.5)					23.0 (4.0)*
*$p \leq 0.05$; **$p \leq 0.005$								

Table 8.4 Results of two-sample t-tests to compare Functional Assessment of Cancer Therapy-Colorectal (FACT-C) scores in the current sample with those of previous international studies of colorectal cancer survivors

8.2.3 Quality of Life Scores

This section seeks to compare the quality of life scores for the current sample to normative population scores and previous samples of colorectal cancer survivors. Unfortunately, normative data for the EuroQol 5D-5L, FACT-C and SDI are not available for Ireland; therefore, results are compared to normative population scores for the UK, USA and Austria. In a positive finding, colorectal cancer survivors' ratings of health on the EuroQol 5D-5L scale were similar to normative general population scores in the UK (Table 8.2). However, survivors in the current study were more likely to experience challenges with mobility (Z=-3.83, $p \leq 0.0005$), usual activities (Z=-7.09, $p \leq 0.0005$) and anxiety/depression (Z=-2.89, p=0.004). In all cases, subscale and overall scores for the FACT-G were significantly better in the current sample than those of American and Austrian normative populations and samples of heterogeneous cancer survivors (all $p \leq 0.05$; Table 8.3). The FACT-C scores of this sample were largely comparable to previous cross-sectional and longitudinal studies of colorectal cancer survivors (Table 8.4). However, participants of a longitudinal Australian study were more likely to report more positive overall quality of life, emotional well-being and functional well-being, and fewer colorectal cancer concerns between one and five years following treatment (all $p \leq 0.05$; Table 8.4) (Lynch *et al.* 2011, Chambers *et al.* 2012b). These differences are most likely explained by differences in the time points of survivorship examined, as these studies examined survivors' quality of life longitudinally year by year, from diagnosis, rather than collectively, as in the current study. Despite the high proportions of colorectal cancer survivors who reported negative responses to Social Well-being items in this study, the mean SWB score of the sample was relatively high (Figure 6.3; Figure 6.5). Furthermore, the present sample have reported some of the highest social well-being scores compared to normative populations and previous studies of cancer patients and survivors (Table 8.4). Finally, SDI scores for the current sample are comparable to those of heterogeneous cancer survivors up to three years following diagnosis in the UK (Ashley *et al.* 2013) (Table 8.5).

Author (Year)	**Country**	**Sample Size**	**Everyday Living (*SD*)**	**Money Matters (*SD*)**	**Self and Others (*SD*)**	**SD-16 (*SD*)**
Current Study	Ireland	253-281	1.7 (2.9)	1.1 (2.2)	1.2 (2.1)	3.8 (5.7)
***Ashley et al. (2013)*[1]**	UK	111	1.7 (2.9)	1.2 (2.1)	1.6 (2.1)	4.5 (6.2)
***Ashley et al. (2013)*[2]**	UK	111	1.6 (2.8)	1.1 (2.0)	1.6 (2.3)	4.2 (6.1)

*$p \leq 0.05$; **$p \leq 0.005$

[1] Adult cancer patients – mixed diagnosis – electronic responses

[2] Adult cancer patients – mixed diagnosis – paper responses

Table 8.5 Comparison of SDI Subscale Scores with those of cancer survivors in the UK

8.3 Objective 1: Quality of Life

The first objective of this study was to establish an understanding of colorectal cancer survivors' quality of life up to five years after diagnosis in Ireland. On average, survivors scores on the EuroQol VAS and FACT-C were comparable to or better than normative populations (Table 8.2; Table 8.3). Despite these positive mean scores, more than half of survivors were dissatisfied with their quality of life on the FACT-C item "*I Am Content with the Quality of My Life Right Now*" (54%). It is evident from the quantitative and qualitative findings that the experience of colorectal cancer can have profound and lasting effects on domain-specific quality of life. Between 74% and 88% of participants reported one or more physical, functional, social or emotional concerns. The qualitative phase of the study helped to explain this disparity. Similar to theoretical and empirical literature in cancer survivorship and chronic illness, the interview data suggests many survivors engage in activities to reframe their experiences of illness and expectations of quality of life to adapt to their newfound situation as a cancer survivor (Carr *et al.* 2001, DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Foster & Fenlon 2011, McCaughan *et al.* 2012). In the current study, use of optimistic coping strategies and social comparison with other cancer patients or survivors allowed participants to re-imagine their functional limitations as '*small things*' to live with or overcome. Several suggested physical, psychological and social symptoms were a trade-off for survival, no matter their level of interference. The price to pay for being alive was used to provide context for survivors' gratitude and positive evaluations of quality of life. The prevalence and impact of these symptoms upon survivors' well-being in each domain is discussed further in Section 8.4.

8.4 Objective 2: The Nature and Prevalence of Chronic Physical, Psychological and Social Side-Effects

The second objective of this study was to establish the nature and prevalence of adverse physical, psychological and social effects following colorectal cancer treatment in Ireland. The prevalence of side-effects experienced by colorectal cancer survivors in this study are interpreted and compared to the variable prevalence rates reported within previous studies (Section 3.4). Between-item disparity for sexual dysfunction and body image was identified within the current study due to overlap between some items on the EuroQol 5D-5L, FACT-C and SDI questionnaires. However, this reflects the substantial variation in the prevalence of chronic side-effects reported within the colorectal cancer survivorship literature (Table 8.6). The disparity may be explained by the varying timeframes examined by each instrument, ranging between one day (EuroQol 5D-5L), one week (FACT-C) and one month (SDI). In addition, the structure of items within each survey is different. For example, the FACT-C asks the participant to rate their agreement with statements on a five-point Likert scale (e.g. *I Like the Appearance of my Body*), while the SDI asks the participant to respond to questions on a four-point Likert scale (e.g. *Have You Had Any Difficulty Concerning Your*

Effect	Prevalence		References
	Current Study	Previous Studies	
Negative Body Image	74%[2] 28%[3]	14-47%	(Schneider *et al.* 2007, Phipps *et al.* 2008, Sisler *et al.* 2012b, Bailey *et al.* 2015)
Sexual Dysfunction	66%[2] 29%[3]	29-67%	(Di Fabio *et al.* 2008, Phipps *et al.* 2008, Domati *et al.* 2011, Au *et al.* 2012a, Sisler *et al.* 2012b, Milbury *et al.* 2013, Rees *et al.* 2014, Bailey *et al.* 2015)
Fatigue	64%[2]	3-83%	(Schneider *et al.* 2007, Phipps *et al.* 2008, Buffart *et al.* 2012, Chambers *et al.* 2012b, Sisler *et al.* 2012b, Thong *et al.* 2013, Rees *et al.* 2014, Schlesinger *et al.* 2014, Thomas *et al.* 2014)
Fear of Recurrence	60%[4]	7-75%	(Nikoletti *et al.* 2008, Phipps *et al.* 2008)
Insomnia	59%[2]	3-56%	(Di Fabio *et al.* 2008, Phipps *et al.* 2008, Johnson *et al.* 2009, Knowles *et al.* 2013, Lowery *et al.* 2013, Abu-Helalah *et al.* 2014, Rees *et al.* 2014, Schlesinger *et al.* 2014, Thomas *et al.* 2014)
Bowel Dysfunction	28-57%[2]	4-100%	(Phipps *et al.* 2008, Hoerske *et al.* 2010, Ball *et al.* 2013, Bailey *et al.* 2015)
Worries About Health	51%[2]	24-94%	(Schneider *et al.* 2007, Knowles *et al.* 2013)
Peripheral Neuropathy	47%[4]	9-100%	(Bennett *et al.* 2012, Kidwell *et al.* 2012, Lowery *et al.* 2013, Mols *et al.* 2013, Tofthagen *et al.* 2013a, Rees *et al.* 2014)
Diarrhoea	41%[2]	3-39%	(Schneider *et al.* 2007, Nikoletti *et al.* 2008, Phipps *et al.* 2008, Serpentini *et al.* 2011, Knowles *et al.* 2013, Rees *et al.* 2014, Thomas *et al.* 2014)
Constipation	37%[4]	0-37%	(Schneider *et al.* 2007, Nikoletti *et al.* 2008, Phipps *et al.* 2008, Serpentini *et al.* 2011, Knowles *et al.* 2013, Abu-Helalah *et al.* 2014, Rees *et al.* 2014, Thomas *et al.* 2014, Bailey *et al.* 2015)
Pain	34%[1] 30%[2]	2-46%	(Di Fabio *et al.* 2008, Phipps *et al.* 2008, Johnson *et al.* 2009, Lowery *et al.* 2013, Abu-Helalah *et al.* 2014, Rees *et al.* 2014, Schlesinger *et al.* 2014, Thomas *et al.* 2014)
Urinary Dysfunction	18-34%[2]	3-26%	(Gosselink *et al.* 2006, Liu *et al.* 2010, Bailey *et al.* 2015)
Anxiety / Depression	30%[1]	2-28% / 7-40%	(Esplen *et al.* 2007, Lynch *et al.* 2008a, Krouse *et al.* 2009, Shun *et al.* 2011, Buffart *et al.* 2012, Chambers *et al.* 2012b, Andrykowski *et al.* 2013, Mols *et al.* 2013, Thong *et al.* 2013, Abu-Helalah *et al.* 2014, Rees *et al.* 2014, Bailey *et al.* 2015)
Cramps / Swelling	28%[2]	3-33%	(Schneider *et al.* 2007, Nikoletti *et al.* 2008, Lowery *et al.* 2013, Rees *et al.* 2014, Bailey *et al.* 2015)
Financial Difficulties	25%[3]	6-40%	(Abu-Helalah *et al.* 2014, Rees *et al.* 2014, Thomas *et al.* 2014)
Inadequate Family Support	23%[2]	10-27%	(Phipps *et al.* 2008, Domati *et al.* 2011)
Nausea	13%[2]	3-29%	(Nikoletti *et al.* 2008, Chambers *et al.* 2012b, Rees *et al.* 2014, Thomas *et al.* 2014)
Weight Loss	18%[2]	13%	(Knowles *et al.* 2013)

[1] EuroQol 5D-5L (On the day of participation in the survey)

[2] Functional Assessment of Cancer Therapy (FACT-C) (Week preceding participation in the survey)

[3] Social Difficulties Inventory (SDI) (Month preceding participation in the survey)

[4] National Cancer Institute Common Terminology Criteria for Adverse Event V4.03 (Week preceding participation in the survey)

Table 8.6 Comparison of prevalence rates for physical, psychological and social effects in the current study and previous studies

Appearance or Body Image?). The varying terminology used to describe the attributes of quality of life means the validity of cross-cultural comparison is difficult to evaluate. However, the prevalence rates of physical and psychosocial effects within this study are broadly similar to those identified in international studies (Table 8.6).

This study has provided insight into the prevalence, nature and impact of physical, psychological and social symptoms experienced by colorectal cancer survivors in Ireland up to five years following diagnosis. Negative body image (74%), sexual dysfunction (66%) and fatigue (64%) were the most common issues reported by survivors on the FACT-C questionnaire (Table 8.6). However, interview findings suggest the most prevalent symptoms were not necessarily the most impactful. Rather, symptoms which influenced quality of life in multiple domains were discussed in greater detail during follow-up interviews. For example, bowel dysfunction and peripheral neuropathy were discussed at length as they affected survivors' physical, psychological and social well-being. Meanwhile, more common side-effects such as fatigue and sexual dysfunction received less attention in interviews as many survivors suggested that these effects were related to ageing processes or co-morbidity, in keeping with previous literature (e.g. Ramirez *et al.* 2009, McCaughan *et al.* 2012). Considering these findings, the following sections discuss the key findings relating to physical, psychological and social well-being of colorectal cancer survivors.

8.4.1 Physical Consequences of Colorectal Cancer

Following treatment for colorectal cancer, survivors experience an array of physical, psychological, and social issues which may persist for years following treatment. These consequences are heavily interlinked, stemming from the experience of disease and daily struggles with the physical vestiges which characterise survival and triumph over the disease. Lack of energy, dissatisfaction with sexual activities and sleep disturbance were the most prevalent physical effects, affecting over three in five survey participants. However, interviewees described less prominent symptoms such as bowel dysfunction and peripheral neuropathy as having the greatest impact upon their quality of life. Therefore, this sub-section will focus on discussion of these issues.

8.4.1.1 Bowel Dysfunction

The frequency of bowel dysfunction symptoms such as diarrhoea (41%), constipation (37%) and difficulties with bowel control (43%) or ostomy care (44%) in the current study are consistent with previous literature (Table 8.6). Loss of control was a particularly challenging aspect of bowel dysfunction for many survivors, with some describing imagery of returning to childhood to emphasise the regressive impact of faecal incontinence and urgency. As in previous studies, survivors were compelled to adopt trial and error approaches to self-management to overcome altered bowel function, with varying degrees of success. The erratic nature of survivors' bowel habits resulted in many becoming isolated and avoiding social activities to avoid embarrassment, similar to earlier studies (McMullen *et al.* 2008, Krouse *et al.* 2009, Ramirez *et al.* 2009, Hamilton *et al.* 2010, Grant *et al.* 2011, Bains *et al.* 2012, McCaughan *et al.* 2012, Palmer *et al.* 2013). For some, the public availability of restaurant menus and dietary information facilitated the planning required for social outings, ensuring survivors avoided triggers of bowel dysfunction. Nevertheless, access to toilet facilities remained a barrier to daily activities and social events. Many survivors spoke of toilet mapping, but this was not always feasible. It is possible a map of publicly accessible toilets similar to those available in Australia and the UK may address an unmet social need for colorectal cancer survivors, assisting them to plan trips and social outings (Knight & Bichard 2011, DoH Australia 2013, Royal College of Art 2017). However, further empirical work is necessary to ascertain the potential impact of such public services upon colorectal cancer survivors' well-being. The implications of bowel dysfunction for survivors' psychological and social well-being will be discussed further in Sections 8.4.2 and 8.4.3.

8.4.1.2 Peripheral Neuropathy

Almost half of the current sample reported experiencing tingling in the hands or feet (47%) (Table 8.6). Several survey instruments examine the suite of peripheral neuropathy symptoms in cancer patients (Cella *et al.* 2003, Shimozuma *et al.* 2009, Smith *et al.* 2010, Tofthagen *et al.* 2011, Lavoie Smith *et al.* 2013, Vasquez *et al.* 2014). However, it was beyond the scope of this study to investigate a specific symptom in this manner. Admittedly, tingling in the hands or feet is not a comprehensive assessment of peripheral neuropathy, but it is an acceptable means to estimate the prevalence of this prominent, classic symptom of peripheral neuropathy (Bennett *et al.* 2012, Kidwell *et al.* 2012, Mols *et al.* 2013, Tofthagen *et al.* 2013a). Qualitative data suggest peripheral neuropathy was often an expected anomaly during treatment, in one case, reassuring a survivor of the effectiveness of chemotherapy. It became clear within the interviews that survivors were largely unprepared for the lasting impact of peripheral neuropathy and its associated effect on functional, psychological and social well-being as they transitioned to post-treatment follow-up.

Consistent with previous literature, peripheral neuropathy encompassed symptoms of numbness, burning, freezing, pins and needles and sensitivity to temperature changes in the hands, feet and orofacial area, with a small number describing challenges with mobility and driving (Bennett *et al.* 2012, Kidwell *et al.* 2012, Mols *et al.* 2013, Tofthagen *et al.* 2013a). This study extends understanding of the implications of peripheral neuropathy for colorectal cancer survivors. Firstly, describing risks to survivors' personal safety arising from compromised sensory and motor function, increasing the risk of falls and secondary injuries. Secondly, the social impact of functional limitations on colorectal cancer survivors contributed to a loss of independence, greater reliance upon others and reduced engagement with social activities beyond the home. Finally, survivors described frustration at the oversight of peripheral neuropathy during follow-up and the apparent futility of neurological assessments and interventions in the absence of an effective treatment for peripheral neuropathy. Although these issues have not been raised within the colorectal cancer survivorship literature previously, they are reflective of studies of heterogeneous cancer survivors (Tofthagen 2010a, Tofthagen *et al.* 2012, Tanay *et al.* 2017). Indeed, the meta-synthesis by Tanay *et al.* (2017) highlighted a lack of empirical understanding of cancer survivors' experiences of peripheral neuropathy in European contexts, as previous studies have largely employed mixed tumour groups drawn from North American populations. The qualitative results of this study make an important contribution to this literature, enhancing the understanding of colorectal cancer survivors' experience of peripheral neuropathy and the potential impact of healthcare professionals' response to symptom assessment and management.

8.4.2 Psychological Consequences of Colorectal Cancer

In line with previous research, colorectal cancer survivors reported a range of psychological effects following colorectal cancer treatment. More than half of survey participants reported negative body image (74%), fear of recurrence (60%) or metastasis (51%) or worries about deteriorating health (51%) in the seven days preceding the survey. Furthermore, two in five survivors described difficulties coping with illness (44%) or the possibility of death (44%). Yet, fewer than one-third of survivors described difficulties with anxiety or depression (30%), coinciding with findings of previous literature (Esplen *et al.* 2007, Schneider *et al.* 2007, Lynch *et al.* 2008a, Krouse *et al.* 2009, Chambers *et al.* 2012b, Andrykowski *et al.* 2013, Bailey *et al.* 2015). Interviewees suggested psychological consequences were related to the physical symptoms experienced and had implications for their social well-being. Consistent with the quantitative phase of the study, body image, anxiety and fear of recurrence were the most frequently discussed psychological issues; therefore, this section will focus on discussion of these findings.

8.4.2.1 Body Image

This study has reported the highest incidence of self-perceived negative body image among colorectal cancer survivors in the reviewed literature (74%) (Table 8.6). However, body image interfered with daily life in less than one-third of colorectal cancer survivors in the past month (28%), consistent with findings of Schneider *et al.* (2007), and Bailey *et al.* (2015). Interviewees described body image with reference to bowel dysfunction and the ostomy. Specifically, the embarrassment and distress of incontinence and the visibility of bowel dysfunction and the ostomy. These discussions resonate with the '*Mortification and Contradiction of Surface Appearances*' described by Charmaz & Rosenfeld (2006, p.41). Loss of control was a regressive event, discordant with societal expectations of bodily control in adulthood. Charmaz & Rosenfeld (2006) hypothesise that individuals may avoid social environments where loss of control could be witnessed. However, participants of this study seemed to strive to regain and maintain control over their bowel function and live life with, and in spite of, chronic symptoms. It appeared that family members and close friends assisted survivors with this process, providing reassurance and supporting survivors to discreetly manage bowel dysfunction. Interviewees spoke of the impact of their '*healthy*' appearance, which was discordant with societal expectations of the appearance of a cancer patient or survivor. As the theme was frequently related to social well-being, it will be discussed within the Social Consequences of Colorectal Cancer (Section 8.4.3.3).

8.4.2.2 Anxiety and Fear of Recurrence

Fear and anxiety characterised the experience of cancer from diagnosis to survivorship. Anxiety and depression were reported by one-third of survey participants, with more than half reporting fears relating to recurrence, metastases or deteriorating health. Contextualising these findings, the interview data suggested that the sources of fear and anxiety varied as survivors moved through each stage of treatment but were inherently linked to the uncertainties and unknowns of the disease and their future. This study extends the understanding of fear of recurrence, as interviewees suggested fear of recurrence in the aftermath of treatment was as much to do with fears of re-experiencing acute physical and psychological effects of treatment, as the implications for their mortality. In keeping with DeSnoo & Faithfull (2006) and McCaughan *et al.* (2012), physical symptoms and routine surveillance were regular reminders of potential recurrence, triggering a heightened state of alert. During periods of heightened alert, additional coping mechanisms were required to mediate fear. Survivors engaged in a process of recognition and action, which embodied elements of "*Guarding Against Recurrence*" (Taylor *et al.* 2011). Guarding in the current sample encompassed activities of monitoring for recurrence ('*Body Monitoring'*), reducing the risk of recurrence through diet and lifestyle behaviours (*'Managing Risk'*), and seeking reassurance from healthcare professionals ('*Seeking Reassurance'*) (Taylor *et al.* 2011, p.246). Recognition and taking action in the current study went beyond '*Guarding'*, as interviewees recognised the manifestation of anxiety itself, rather than the cause of anxiety alone (risk and fear of recurrence). Among this sample, survivors took action to reduce anxiety by fostering psychological well-being, retreating from day-to-day demands, engaging in the activities of guarding, seeking prompt investigation of any new symptoms suggestive of recurrence and planning for the future by preparing a will or their funeral.

8.4.3 Social Consequences of Colorectal Cancer

Social well-being is a product of the individual's relationship with and experience of their social environment. The quantitative phase of the study revealed the prevalence of social concerns (FACT-C) and social difficulties (SDI) among colorectal cancer survivors during the week and month preceding the survey, respectively. The qualitative data enhanced understanding of social well-being outcomes and experience of social difficulties, as survivors described physical and psychological effects hindering recovery of their social well-being following treatment. Although this sample reported some of the most positive social well-being scores on the FACT-C instrument in the reviewed literature (Table 8.4), substantial numbers of survey and interview participants experienced challenges relating to work, financial difficulties and social expectations of illness. Therefore, this section will interpret the integrated results of survey and interview data relating to these issues and explore their meaning in relation to the cancer survivorship literature.

8.4.3.1 Returning to Employment

Work is important to cancer survivors' functional, psychological and social well-being, as it provides financial security and represents an important component of self-actualisation, self-identity and self-esteem (Wells *et al.* 2013, Beesley *et al.* 2017). The most common social challenges for participants of this study were remaining in employment (57%) and gaining fulfilment from one's work (57%). Between diagnosis and the time of the survey, the proportion of survivors who were not engaged in the workforce rose from 60% to 75%. Although it cannot be confirmed that departures from the workforce were directly related to the experience of colorectal cancer, the results echo findings of an Irish study by Hanly *et al.* (2013), in which almost two-fifths of employed cancer survivors left the workforce due to retirement, illness or transition to being a homemaker. Although the age groups most commonly affected by colorectal cancer are those who are approaching or past the age of retirement, the growing incidence of colorectal cancer among those under the age of 50 will have significant implications for workforce planning, pension contributions and social welfare provision in Ireland and internationally (Siegel *et al.* 2017).

During interviews, reasons for disengaging from the workforce included difficulty coping with the physical effects of disease within the workplace. Survivors who remained in employment described employers who were supportive and understanding of treatment consequences, facilitating gradual re-acclimation to full-time employment. Nevertheless, a small number worked in environments which placed unrealistic expectations on survivors upon their return to work, causing stress. This finding is inconsistent with Amir *et al.* (2010), which suggested employers had low expectations of cancer survivors to meet workplace demands in the UK. The results of this study suggest that employers and occupational health advisors try to support cancer survivors in their return to work and return to work experiences were largely positive for survivors who were willing and able to return to work. However, some employers are not aware of the implications of returning to work as a cancer survivor. There is a need to consider strategies to ensure all survivors have the opportunity to remain in the workforce if they wish to. In Ireland, further research is required to understand both employers and cancer survivors' experiences of returning to work after cancer in Ireland, so that the needs of each may be identified and strategies to assist survivors in this transition may be developed. Wells *et al.* (2013) suggest cancer survivors may be supported at the juncture of returning to work through the adoption of person-centred interventions which consider the meaning and importance of work to the individual cancer survivor. Occupational health advisors may be an important source of support for survivors when returning to work. However, Amir *et al.* (2009, 2010) suggest that greater information, training and support are necessary to foster awareness and facilitation of cancer survivorship issues among employers and occupational health consultants in the UK.

8.4.3.2 Financial Difficulties

The financial implications of a cancer diagnosis and the inadequacy of social welfare payments were prominent qualitative themes. As in previous Irish studies, attendance at the hospital for treatment or follow-up was a costly endeavour (Hanly *et al.* 2013, Thomas *et al.* 2014, O'Ceilleachair *et al.* 2017). Access to financial support was hindered by delayed provision of information about existing initiatives during treatment, reflecting findings of Corner *et al.* (2013). One-quarter of survivors in the current study described financial difficulty in the past month, similar to studies conducted in Saudi Arabia and Ireland (Abu-Helalah *et al.* 2014, Thomas *et al.* 2014). As would be expected, a greater proportion of those who transitioned out of the workforce reported financial difficulty or welfare-related difficulties than those who remained, keeping with the results of a recent Irish study (O'Ceilleachair *et al.* 2017). Social welfare benefits were disparaged in interviews and survey comments due to the bureaucracy of applications and their failure to adequately respond to the increased financial burden associated with cancer. Survivors' accounts of the financial implications of a cancer diagnosis in the current study reflect the results of studies by the ICS and NCRI, including loss of income and increases in household expenditure relating to medical expenses and household bills such as heating, childcare and domestic support (Sharp & Timmons 2010, Milward Brown 2015, O'Ceilleachair *et al.* 2017). Furthermore, British and American research has highlighted the psychological impact of financial difficulties attributed to a cancer diagnosis (Corner *et al.* 2013, Fenn *et al.* 2014, Kale & Carroll 2016). This study provides additional evidence suggesting cancer survivors may withdraw from social activities due to financial concerns, as well as physical and functional limitations, particularly survivors whose employment status changes following diagnosis. Although the ICS provide financial support to cancer patients and survivors, it was evident survivors were not aware of such supports. Therefore, initiatives are required to alleviate the financial burden of a cancer diagnosis, including strategies to enhance survivors' understanding of the variety of supports available from advocacy organisations in Ireland. This could be achieved during initial treatment information consultations, supported with written information and a point of contact within the local advocacy organisation. Social workers have an important role in survivors' access to social support services, yet interviewees suggested the information provided during these consultations often came too late to be useful. Involvement of advocacy personnel may support the role of social workers, as they may provide survivors with pertinent information and support to expedite applications for financial support in collaboration with social work staff, thereby reducing delays experienced by survivors. In addition, the Department of Social Protection and the HSE could alleviate some of the financial burden associated with a cancer diagnosis by implementing strategies which streamline and expedite the processes of medical card and social welfare applications for those who have been diagnosed with cancer.

8.4.3.3 The Impact of Appearance on Social Relationships

The theme of appearances and their impact upon the relationships of colorectal cancer survivors were unique findings of this study, offering some explanation for the poor perceptions of social well-being described by interviewees. Previous studies of heterogeneous cancer survivors suggest that changes in the dynamic of relationships with family and social networks are due to altered appearances during treatment; therefore, survivors may make significant efforts to appear healthy (Hamilton *et al.* 2010). As already discussed, social comparisons during treatment assisted survivors to reframe the gravity of their illness in the current study (Section 8.3). Many interviewees discussed the benefits of sustaining their normal appearance during treatment, rather than one of emaciation or alopecia which they witnessed in oncology units. A seemingly healthy appearance allowed survivors to retain control over others' perceptions of them, as they reserved the power to disclose their illness on their own terms. Ultimately, many survivors could project an image of health and wellness to their community, which meant they were not pitied or treated differently by society. Unlike Hamilton *et al.* (2010), interviewees suggested they did not have to make significant efforts to appear well. Yet, the advantage of a healthy appearance waned as the survivor transitioned to follow-up care and the availability of professional psychosocial support dwindled. At this time, survivors were still in need of psychological and social support to cope with the physical implications of survivorship. A lack of public understanding and awareness of the physical vestiges of colorectal cancer led members of the survivor's community and social network to believe the survivor was healthy, '*cured*' and had resumed (or continued) living a '*normal*' life, where they did not require support. These assumptions caused survivors considerable distress, particularly females, similar to previous findings among thyroid cancer survivors (Easley *et al.* 2013). Only half of survey participants described close, supportive relationships with their friends, and one-quarter experienced loneliness. These issues are much more prevalent in the current study than previously reported (Rees *et al.* 2014). The qualitative data offer partial explanation for these findings, as survivors speculated that their friends and acquaintances were not privy to the chronic physical, psychological and social burdens of survivorship, perhaps due to a lack of public awareness of these issues.

To date, research surrounding appearance and body image in cancer and cancer survivorship has focused on the impact of the lingering visible signs of cancer resulting from disease and treatment processes (McMullen *et al.* 2008, Ramirez *et al.* 2009, Grant *et al.* 2011). There is an absence of literature in the field of cancer survivorship to support the findings about the impact of survivors' appearance on the behaviours of their social networks. However, the results of this study echo the work of Charmaz & Rosenfeld (2006) in chronic illness, as the public (healthy) identity contradicts the survivor's true identity of the private (unwell) self. Disclosure of an invisible or hidden illness may fail to sensitise others to the physical, psychological and social limitations of survivorship, resulting in others underestimating the survivor's experience (Charmaz & Rosenfeld 2006). Further complicating these challenges is the societal stigma attached to bowel function, enhancing the embarrassment and fear of public accidents, and limiting survivors' ability to explain or discuss their experiences with members of their social circle (Charmaz & Rosenfeld 2006, DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Ramirez *et al.* 2009). Previous colorectal cancer survivorship literature has highlighted the importance of social networks for psychosocial support among female colorectal cancer survivors (Goldzweig *et al.* 2009, Krouse *et al.* 2009). Therefore, the discord between healthy and unwell identities and the stigma attached to the physical consequences of colorectal cancer creates a dangerous opportunity for psychosocial distress to manifest.

8.5 Objective 3: Experiences of Healthcare

The third objective of this study was to understand colorectal cancer survivors' experiences of healthcare in the aftermath of treatment. On average, continuity of care was positively evaluated, with the majority reporting access to and support from one or more named healthcare professionals and adequate support from hospital staff. Interview data support these results, providing insight into the nature of healthcare experiences which were not captured by survey instruments. However, interviewees suggested an underlying continuum of positive and negative healthcare experiences throughout investigation, diagnosis, treatment and follow-up which impacted upon their quality of life, psychological well-being and trust in the healthcare system. Within this section, results pertaining to survivors' evaluations of continuity of and access to healthcare are integrated and discussed, including the experiences of therapeutic relationships with healthcare professionals and communication between members of the multidisciplinary team.

8.5.1 Evaluations of Healthcare Experiences and Continuity Across the Cancer Trajectory

In each phase of the study, survivors rated their overall care very positively. Continuity of care scores were similar to those of colorectal cancer survivors in a previous study and better than those of medical-surgical patients in some cases (Table 8.7). Sisler *et al.* (2012b) defined satisfaction with care on the PCCQ as a score of greater than four on each subscale. According to this operationalisation, more than three-quarters of survivors in this study were satisfied with their relationships with their healthcare professionals, provision of disease-related information, management of follow-up care, and written and verbal communication between healthcare professionals. However, 36% reported inadequate continuity of care overall, with a score of four or less on one or more subscales of the PCCQ.

Author (Year)	Country	Sample Size	Information Transfer	Relationships with Healthcare Providers	Management of Forms	Management of Follow-up	Communication Among Providers
Current Study	Ireland[1]	225-277	4.4 (1.0)	4.5 (1.0)	4.4 (0.9)	4.6 (1.0)	4.5 (0.9)
Sisler et al. (2012b)	Canada[1]	95-106	4.3 (0.7)	4.4 (0.9)	4.4 (0.9)	4.4 (0.9)	4.4 (0.9)
Hadjistavropoulos et al. (2008)	Canada[2]	204	4.0 (1.1)**	4.5 (0.9)	4.6 (0.7)*	4.1 (1.1)**	4.1 (1.0)**

*$p \leq 0.05$; **$p \leq 0.005$

[1] Colorectal Cancer Survivors; [2] Orthopaedic/Family Medicine Patients

Table 8.7 Results of t-tests to compare the Patient Continuity of Care Questionnaire (PCCQ) subscale scores of the current sample with those of previous international studies

That patients rate their healthcare experiences positively is not a unique finding of this study (Aiken *et al.* 2012, Cunningham & Wells 2016). Compared to Sisler *et al.* (2012b), fewer participants of this study described insufficient continuity of care ($p=0.001$). However, the qualitative results suggest survivors experience healthcare within a continuum of positive and negative events. Vivid recollections of specific interfaces with healthcare professionals and services during diagnosis, treatment and survivorship suggested positive and negative healthcare events left lasting impressions with implications for survivors' quality of life, even if these events did not seem to influence the survivor's overall evaluation of care. At the positive end of the spectrum, survivors described interactions with healthcare professionals who went beyond the call of their healthcare duties to support, comfort and rehabilitate, akin to Appleton *et al.* (2013). On the opposite end of the spectrum, negative episodes arose from shortcomings in the health services at individual, organisational and political levels. As in previous studies, suboptimal preparation for long-term treatment effects and the prioritisation of surveillance over supportive care in survivorship were identified (Di Fabio *et al.* 2008, Phipps *et al.* 2008). Power imbalances in therapeutic relationships, care rationing due to reduced staffing levels and the increasing workload of healthcare professionals have not previously been discussed in the colorectal cancer survivorship literature. However, these issues appeared to have detrimental effects upon interviewees' quality of life and sense of security within the healthcare system. These issues are discussed further in subsequent sections of this chapter.

8.5.2 Relationships with Healthcare Professionals During Follow-up Care

Survivors believed their follow-up healthcare was managed very well, with good clinician-patient communication since transitioning to follow-up care. In both phases of the study, survivors appeared to have a good understanding of their schedule of follow-up care and the accessibility, support and familiarity of oncology-based healthcare professionals substantiated survivors' confidence in and satisfaction with continuity of care. The qualitative data endorse the positive survey findings regarding clinician-patient relationships; similar to Appleton *et al.* (2013), survivors described egalitarian relationships characterised by open communication, empathy, reassurance and comradery. These characteristics are consistent with many aspects of patient-centred communication described by McCabe (2004), including attendance, empathy, friendliness and humour. However, several interviewees also described incidents which aligned to challenge parity in the therapeutic relationship, including power imbalances, unmet needs or a lack of empathy which created significant barriers to care. An important concept identified in the qualitative data was the power wielded by healthcare professionals within the clinician-patient dyad. Survivors experienced a paradox between being a compliant, submissive patient and asserting the expertise they had acquired through trial and error approaches to self-management. In several cases, the paradox between being compliant and being an expert resulted in adverse events and psychological distress, as healthcare professionals made assumptions about the survivor's knowledge and condition. Similar to findings of McCabe (2004), these assertions of professional dominance were extremely unhelpful to colorectal cancer survivors, as their autonomy and dignity were subverted. In stark contrast, survivors whose expertise was recognised by the healthcare professional described partnerships where their autonomy was respected, confidence enhanced, and questioning of care encouraged.

The concept of the expert patient has been well-represented within chronic illness and mental health literature for almost three decades (German 1988, Vandereycken & Meermann 1988, Playle & Keeley 1998, McCabe 2004, Wilson *et al.* 2007). Expert patients who are competent in self-management and active in their care may be considered a threat to healthcare professionals (Wilson *et al.* 2006). The chronic illness literature has long urged healthcare professionals to understand the reasons for patients' noncompliance, acknowledge their expertise and enlist patients as active, rather than passive participants in care (Vandereycken & Meermann 1988, Playle & Keeley 1998, DoHUK 2001). These calls have spawned a movement to foster patient expertise and promote collaborative patient participation in care (DoHUK 2001, Squire *et al.* 2006, Squire & Hill 2006, Boylan *et al.* 2011, Job *et al.* 2016). Therefore, it is concerning that any proportion of colorectal cancer survivors should be subjected to paternalistic practices in a modern healthcare system which undermines their autonomy or removes their voice from decision-making processes regarding their care. It is possible that cases of paternalistic healthcare provision described by interviewees were isolated incidents, a result of care rationing or occupational stress. However, they may also be deeply entrenched, related to the culture of the healthcare organisation itself, making them difficult to overcome. Limited research suggests such behaviours toward patients may result from professional insecurity or fears of litigation among oncology nurses (Wilson *et al.* 2006). To keep up with international developments in survivorship care, the Irish healthcare system must ensure all cancer survivors benefit from the care and guidance of healthcare professionals who realise the survivor's expertise and respect them as equal partners within the processes of healthcare. Although difficult to achieve, gaining an understanding of the prevalence and origin of behaviour-related barriers to patient-centred care among healthcare professionals is required to begin addressing these challenges, and may contribute to the development of interventions which can support healthcare professionals in the provision of patient-centred care and empowerment of cancer survivors to be active participants in the management of their follow-up care.

8.5.3 Professional Roles and Communication in Cancer Survivorship Care

Primary care practitioners often lead or share responsibility for survivorship care in the USA and parts of Europe (Snyder *et al.* 2008b, Baravelli *et al.* 2009, Sisler *et al.* 2012b, Mols *et al.* 2014). However, follow-up care in Ireland is predominantly provided via nurse-led or consultant-led models of care in tertiary oncology healthcare settings, with no formal involvement of primary care practitioners (Section 1.5). Although the general practitioner was critical to diagnosis, most survivors did not believe they had a role to play in care once diagnostic investigations had begun. Similar to previous studies of heterogeneous groups of cancer survivors, many interviewees felt the general practitioner was not appropriately skilled in cancer-related care and expressed a preference for physician-led or nurse-led oncology services for surveillance and cancer-related issues (Hudson *et al.* 2012, Roorda *et al.* 2015, Murchie *et al.* 2016, Brandenbarg *et al.* 2017). Despite these sentiments, primary care services appeared to play a vital supplementary role during treatment and follow-up, providing support for psychosocial issues and reducing the frequency of hospital consultations by providing practical care during treatment. However, each phase of the study suggests primary care practitioners may be overlooked in the chain of interdisciplinary communication and are potentially an underutilised resource in cancer survivorship care in Ireland, as one-fifth of survivors stated general practitioners were not involved in their cancer-related care. The population of colorectal cancer survivors is predicted to increase in Ireland over the next 20 years (NCRI 2014b), placing an increasing burden on tertiary oncology services. Therefore, future research to evaluate the role of the general practitioner and community services in cancer survivorship care is necessary to optimise their formal involvement in care planning and delivery and ensure that appropriate care, delivered in an appropriate setting is achieved for survivors at all stages of the cancer trajectory.

The continuum of positive and negative events characterising survivors' healthcare experiences (Section 8.5.1) is further illustrated by the communication between interdisciplinary healthcare professionals; more than one-quarter indicated dissatisfaction in this domain of the survey. Interview narratives suggested communication among healthcare professionals was an issue at all points of the cancer trajectory. It was most saliently highlighted within the qualitative theme *Securing Access to the Oncology Healthcare System*, as it may have contributed to delayed and inappropriate delivery of diagnosis in a small number of cases. In keeping with previous literature, interviewees believed general practitioners and other community services were ill-informed of survivors' cancer-related care due to insufficient communication, which may have contributed to the large proportion of survivors who felt unsupported by these services (Krishnasamy *et al.* 2007). Roorda *et al.* (2015) emphasises the importance of good communication between oncologists and general practitioners in determining survivors' acceptance of primary care-led breast cancer follow-up. Further research is necessary to confirm this relationship in larger quantitative samples and in an Irish context, as fewer participants of this study provided negative ratings of interdisciplinary communication when compared to an American survey study of 300 breast cancer survivors (25% vs 72%) (Mao *et al.* 2009).

Interviewees suggested that inadequate communication between oncology and primary care practitioners meant survivors must develop advanced levels of health literacy to ensure continuity of communication and care throughout each stage of cancer care. However, the survey results suggest these issues are experienced by a relatively small proportion of colorectal cancer survivors, as more than four-fifths of participants described satisfaction with communication between members of the multidisciplinary team and primary care practitioners. Beyond the oncology-primary care communication interface, qualitative data suggested health literacy was particularly important during the treatment process. Ireland was particularly affected by the 2008 global economic downturn. During this recession, the government introduced cost-saving measures, including an embargo on recruitment of staff to public sector services. At the time this study was launched in October 2014, the number of whole time equivalent staff employed by the HSE had fallen by over 15,000; 14% of the total HSE staff at peak employment in 2007 (HSE 2014). The embargo on recruitment had a significant impact on nurse-patient ratios in acute care areas, including surgical and oncology units. Several interviewees described their perceptions of low nurse staffing levels in oncology units, which they described as enhancing their perceived risk of medication errors and omissions in care. Investigation of the effect of clinician-patient ratios upon healthcare experience was beyond the scope of this study. Nevertheless, the impact of nurse-patient ratios on patient outcomes is well established in general patient populations. Most significantly, increased nurse workload is associated with greater likelihood of inpatient mortality (Aiken *et al.* 2012). With increased workload, nurses may engage in care rationing, prioritising performance of tasks most critical to ensure patients' physical well-being (Ausserhofer *et al.* 2014). Care rationing may result in negligence of essential activities of nursing care, such as patient education, psychosocial care and documentation of care (Ausserhofer *et al.* 2014, Ball *et al.* 2014). Furthermore, care rationing has been associated with lower levels of patient satisfaction and greater risk of medication errors, critical incidents, falls and nosocomial infection (Schubert *et al.* 2008, Brady *et al.* 2009, Lucero *et al.* 2010, Ausserhofer *et al.* 2013).

8.5.4 Cancer Treatment Summaries and Survivorship Care Plans

Survivorship care plans and treatment summaries have been tentatively suggested as a possible solution to communication issues between primary and secondary care and the survivor (Earle 2006, IoM 2006, Baravelli *et al.* 2009, Grunfeld & Earle 2010, Appleton *et al.* 2013). While these documents are not a part of routine care in Ireland, interview data suggest discharge summaries provided to a small number of survivors following surgery contain information pertinent to diagnosis, treatment and survivorship care. Yet these documents did not appear to influence survey participants' level of satisfaction with communication of disease-related information. Although these are important findings, they should be interpreted with caution. Formal treatment summaries and survivorship care plans may support communication, dissemination of information and care coordination (Mayer *et al.* 2012, Brothers *et al.* 2013, Nicolaije *et al.* 2015). However, international randomised controlled trials and a systematic review have suggested survivorship care plans, at best, have no effect on cancer survivors' quality of life outcomes, satisfaction with care or perceptions of continuity and coordination of care (Grunfeld *et al.* 2011, Brothers *et al.* 2013, Brennan *et al.* 2014, Boekhout *et al.* 2015). At worst, survivorship care plans have been associated with greater symptom burden, illness concern and emotional distress (Nicolaije *et al.* 2015).

The implementation of survivorship care plans is a developing area of research and practice. Therefore, further evaluation of emerging evidence in the field using randomised controlled trial and systematic review approaches is warranted. The most recent National Cancer Strategy of Ireland recommends cancer treatment summaries and survivorship care plans be provided to patients and healthcare professionals involved in their care to enhance communication and integration of care (DoH Ireland 2017). Given that this recommendation will lead to the implementation of new practices in cancer survivorship care in Ireland, there is an opportunity for innovations in the design and operationalisation of cancer survivorship care plans. Most critically, the development of survivorship care plans must respond to the specific challenges of Irish cancer survivors, including issues of interdisciplinary communication and unmet information and supportive care needs, such as those identified within this study. A 'living' survivorship care plan may provide such a solution, encompassing the traditional components proposed by IoM (2006), including a treatment summary, plan of follow-up, lifestyle advice and information regarding the long-term physical, psychological and social implications of the disease. In a living survivorship care plan, the researcher proposes that the technology to generate a living care plan should be fully integrated with the cancer survivor's medical records to ensure the documents are automatically updated in real-time with actions of care, outstanding tasks and responsibility for completion of tasks. Unlike traditional care plans, the living survivorship care plan and live updates to the plan would be remotely accessible and available to update with changes in the survivor's quality of life and disease status by all members of the healthcare team, including the survivor themselves. For survivors who do not wish to engage with online platforms, changes or updates to the summary should be provided in written format following each appointment. However, the implementation of a living survivorship care plan would have significant ethical and economic implications. Therefore, further work must be undertaken to establish the feasibility of such a programme.

8.6 Objective 4: Unmet Information and Supportive Care Needs

The fourth objective of this study was to identify the unmet information and supportive care needs of colorectal cancer survivors. Unmet needs are informational and practical resources or actions which may negatively affect physical, psychological, social and spiritual domains of well-being if overlooked (Margaret 2000, Sanson-Fisher *et al.* 2000, Campbell *et al.* 2009). Of the five PCCQ subscales, communication of information was the least satisfactory aspect of continuity of care on average, as one-quarter expressed sub-optimal scores. Survey data revealed high levels of unmet needs, with two in three survivors describing one or more information needs. The interview phase corroborated and contextualised the prevalence of unmet information needs relating to physical and psychosocial survivorship issues. Despite the positive evaluations of support received from hospital and general practice staff in the survey phase, interview data suggested many survivors had unmet supportive care needs relating to the physical and psychological consequences of colorectal cancer, including bowel dysfunction, peripheral neuropathy and anxiety. Interviews provided a deeper understanding of survivors' unmet healthcare needs, identifying challenges of accessing diagnostic investigations where symptoms of colorectal cancer arose. Within this section, the findings relating to survivors' unmet information and supportive care needs are integrated and discussed in relation to previous literature.

8.6.1 Disparities in Access to the Irish Oncology Healthcare Service

Although survivors evaluated their experience of care positively and commended the speed of access to treatment once diagnosis was confirmed, initial access to the healthcare system was often difficult. In Ireland, the time between referral and colonoscopy varies substantially (O'Shea & Collins 2016). Where survivors are referred via BowelScreen following a positive faecal occult blood test, more than 80% will undergo colonoscopy within four to six weeks (National Screening Service 2017). In contrast, of those who are referred for a colonoscopy by a general practitioner, more than half will have a waiting time of more than six weeks (O'Shea & Collins 2016). For survivors with private health insurance, delays in the investigation of malignant symptoms in the public health system could be overcome by seeking private consultation, with investigations beginning in as little as two days, and 50% undergoing colonoscopy within 10 days (O'Shea & Collins 2016). Participants of the current study who did not have private health insurance were in a precarious situation, as some were expected to wait for up to six months for initial radiology or colonoscopy appointments.

In such cases, insider knowledge was essential to negotiate timely access to diagnostic procedures and navigation of the healthcare services.

Access to timely investigation was widely discussed by colorectal cancer survivors during interviews. In Ireland, elective colonoscopies in public hospitals increased by a magnitude of two-thirds between 2005 and 2012 (Health Information and Quality Authority 2014). In 2008, half of all colonoscopies conducted in Ireland were privately funded, of which almost one-third were conducted in public hospitals (Health Information and Quality Authority 2009). Meanwhile, the National Treatment Purchase Fund ensured just 15% of publicly funded colonoscopies were procured within private hospitals within its remit to reduce maximum waiting times for clinical appointments (National Treatment Purchase Fund 2017). These findings have significant implications for uninsured colorectal cancer patients outside the criteria for the BowelScreen programme in Ireland, as services which are already under strain disenfranchise those who cannot afford private health insurance, thereby contributing to delays in diagnosis. These challenges are endorsed by the literature which describes how diminished access to timely, quality healthcare is associated with more advanced stages of diagnosis and poorer quality of life among uninsured and lower socio-economic groups of cancer survivors (Richardson *et al.* 1992, van Doorslaer *et al.* 2006, Macleod *et al.* 2009, Rapiti *et al.* 2009).

This study highlights the importance of insider knowledge to assist cancer patients and survivors in overcoming administrative challenges and disparities in care which may arise within a healthcare system where public and private services co-exist. Traditionally, patient navigators have been identified as an important source of insider and navigational knowledge (Carroll *et al.* 2010). However, nurse-led patient navigation programmes in oncology have offered mixed results, ranging between no effect upon quality of life, healthcare usage or symptom experience (Skrutkowski *et al.* 2008) to improved outcomes regarding satisfaction with care and quality of life (Lee *et al.* 2011, Wagner *et al.* 2014). The 2017 National Cancer Strategy of Ireland commends the role of advocacy services in supporting patients to navigate the healthcare system (DoH Ireland 2017), yet such services are not formally available within the healthcare service due to the separation of health and advocacy care services in Ireland. With just 15% of colorectal cancer survivors accessing advocacy organisations, there is a risk that informal navigational support is not available to them. Patient navigation is a well-established field in North American healthcare settings which has tentatively demonstrated positive effects upon cancer survivors' satisfaction with care and quality of life (Hopkins & Mumber 2009, Lee *et al.* 2011, Wagner *et al.* 2014). Although it is a growing area in Europe, no formal implementation or evaluation of such roles has been undertaken in Ireland. Therefore, further research is necessary to examine the feasibility and acceptability of formal nursing and peer navigation models within the public and private oncology services in Ireland.

8.6.2 Unmet Information Needs

The prevalence of unmet generic (68%), physical (30%) and psychosocial (25%) information needs in the current study is comparable to previous studies (Krishnasamy *et al.* 2007, Nikoletti *et al.* 2008, Baravelli *et al.* 2009, Sisler *et al.* 2012b, Burg *et al.* 2015). The top three specific survey information needs were consistent with the most commonly discussed information needs during interviews. Similar to DoHUK (2012), diet and lifestyle were the most prominent unmet information needs, followed by the physical effects of living after cancer. The prevalent need for information about diet is consistent with previous international literature (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Haggstrom *et al.* 2009, Pullar *et al.* 2012, Anderson *et al.* 2013, Ho *et al.* 2015). Compared to the DoHUK (2012) sample, a greater proportion of participants in this study expressed a need for more information about diet, lifestyle and physical effects (Figure 8.1). The small proportion of survivors who expressed a desire for more information about returning to work is comparable to results of DoHUK (2012). These findings may be explained by the negative skew toward older age groups in both studies, and the distribution of employment status within each sample. In this study, more than one in five participants expressed a desire for more information about medical card entitlements, and financial assistance or social welfare benefits. During interviews, there was an overwhelming sense that information about social support was often communicated too late, and survivors were in some cases deterred or overwhelmed by the bureaucracy of application procedures, similar to previous Irish studies among cancer survivors (Sharp & Timmons 2010, Milward Brown 2015).

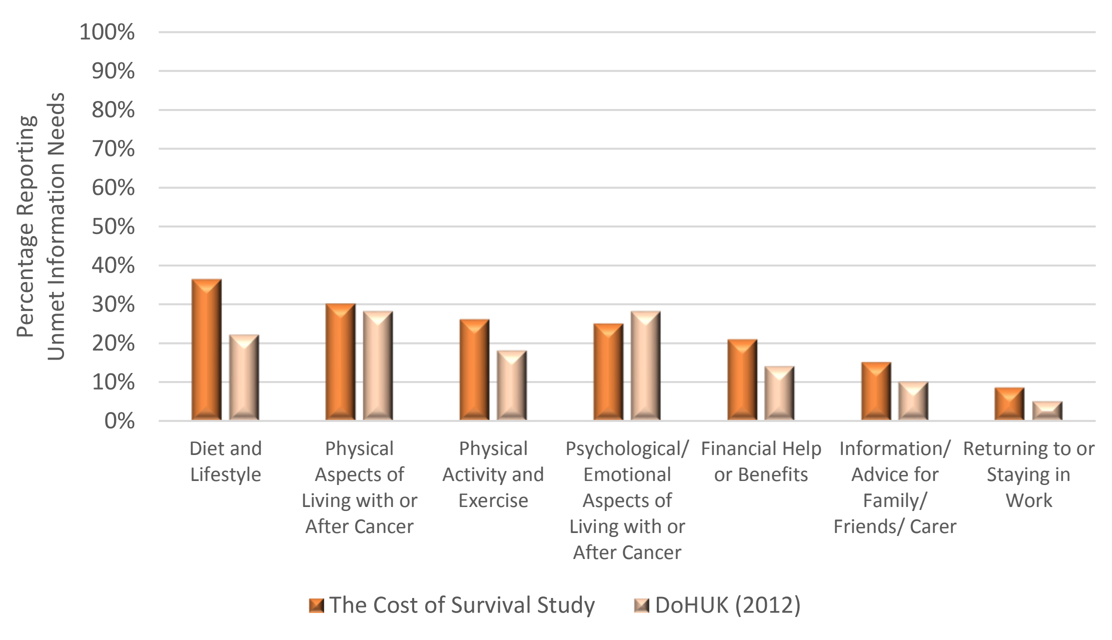

Figure 8.1 Comparison of prevalent information needs in the current study with results from DoHUK (2012)

This study identified significant unmet need around symptom awareness and self-management strategies, with rates comparable to Sisler *et al.* (2012b). As in previous studies, survivors commended the level of information about diagnosis, surgery and acute radiotherapy and chemotherapy effects (Johansson *et al.* 2014, Faller *et al.* 2016). Multi-media approaches to the delivery of information about diagnosis and treatment was commended by survivors, supporting their interpretation and understanding of information. However, as survivors reflected upon their preparation for the transition to survivorship, many lamented the lack of comparative preparation for potential chronic effects, particularly bowel dysfunction, sexual dysfunction and peripheral neuropathy. Consistent with previous research, the current sample expressed a desire for greater support and advice to develop self-management strategies, particularly bowel management, ostomy care and diet and lifestyle (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Haggstrom *et al.* 2009, Pullar *et al.* 2012, Anderson *et al.* 2013, Ho *et al.* 2015, Brown *et al.* 2016).

8.6.3 Unmet Supportive Care Needs

Further complicating survivors' lack of preparation for the physical consequences of colorectal cancer was a perceived oversight or ineffective management of chronic symptoms. Interviewees suggested that the physical symptoms that caused them the greatest difficulty were most often the issues that they believed healthcare professionals could assist them with. Prioritisation of surveillance activities by healthcare professionals and survivors was a barrier to symptom management in this study and others (Esplen *et al.* 2007, Di Fabio *et al.* 2008, Phipps *et al.* 2008, Tofthagen 2010b). Participants emphasised the responsiveness and empathy of healthcare professionals when concerns about physical effects were raised. However, survivors believed healthcare professionals were ill-equipped to manage some symptoms or lacked awareness of services which may have greater expertise. These concerns were best illustrated in relation to peripheral neuropathy, dietary management of bowel dysfunction and to a lesser extent, lymphoedema and sexual dysfunction. Lack of awareness of specialist services or self-perceived sufficiency of care resulted in siloed approaches to symptom management or delayed referral to specialist services. These issues compelled survivors to be resourceful, enlisting insider knowledge and investigative skills to overcome these barriers, albeit not always successfully. Reliance upon survivors' resourcefulness to access specialist care is a precarious practice, as a lack of confidence or vulnerability in the post-treatment period may prevent survivors' developing such skills and in turn, accessing appropriate care (Foster & Fenlon 2011).

Unmet physical and psychological symptom management needs were concerning findings of this study. Interview participants suggested initiation of discussions about ongoing treatment side-effects was a challenge during follow-up appointments due to their preoccupation with the results of surveillance during follow-up consultations. It seemed that interventions are required to prompt such clinical conversations and facilitate planning and evaluation of effective supportive care. Recent innovations in symptom assessment present a novel opportunity to facilitate cancer survivors' articulation of symptom difficulties. These interventions integrate standardised instruments with remote technology to assess survivors' symptoms and quality of life, supporting healthcare professionals to develop a plan of care (Velikova *et al.* 2010, Maguire *et al.* 2017, Nanton *et al.* 2017). Although the development and implementation of such interventions are in early stages, evaluation of their feasibility and outcomes for colorectal cancer survivors may be worthwhile in the Irish healthcare services.

The implication that unmet needs arising from colorectal cancer were related to inappropriate management of symptoms or delayed referral to specialist services suggests interventions are necessary to overcome these barriers. A collaborative approach to complex symptom management between multidisciplinary and interdisciplinary team members is essential in cancer survivorship. Guidelines and protocols which provide clear instructions for the management of complex treatment side-effects and referral pathways should be collaboratively developed by oncology healthcare professionals and members of the wider multidisciplinary team in primary, secondary and tertiary care settings to support the management of complex symptoms such as peripheral neuropathy, bowel dysfunction, lymphoedema and sexual dysfunction. Such guidance may enhance the timeliness of referral to other medical specialties which could support oncology specialists in the management of symptoms, such as neurology and physiotherapy in the case of peripheral neuropathy.

Similar to results of DoHUK (2012), almost one-quarter of survey participants expressed a desire for more information surrounding the psychological aspects of cancer survivorship. The sense of abandonment experienced by survivors following transition to follow-up care is illuminated in interviewees' descriptions of the contrast between the wealth of multidisciplinary psychological support available during treatment and the absence of support following treatment when psychological consequences became more apparent for many survivors. At this point, survivors felt they were alone and had no awareness of services which may be able to provide them support, as they were no longer under the care of acute hospital services, similar to previous research (Taylor *et al.* 2011, Beech *et al.* 2012, McCaughan *et al.* 2012, Johansson *et al.* 2014, Pisu *et al.* 2014). Consistent with Wilson *et al.* (2006, 2007), a barrier to accessing advocacy-led cancer support programmes was a lack of awareness of such services. Survivors linked their lack of preparation for survivorship issues and sense of loneliness to a lack of closure at the end of treatment. Several interview participants suggested that the end of treatment was an opportune time to engage in formal discussions of survivorship to establish the goals of care and recovery. These results suggest that greater efforts are necessary to raise awareness of the availability of cancer support services for colorectal cancer survivors during and after treatment.

That survivors may feel abandoned by healthcare professionals at the end of treatment, without access to support structures is not unique to this study (Krishnasamy *et al.* 2007, Tofthagen 2010b, Foster & Fenlon 2011, Taylor *et al.* 2011, McCaughan *et al.* 2012). According to Aiken *et al.* (2012), two-thirds of Irish general nurses do not believe their patients are equipped for self-management at the time of discharge. The prevalence of unmet information and supportive care needs among this group of colorectal cancer survivors adds weight to these findings, highlighting the adverse consequences of unaddressed physical and psychological issues. It is unacceptable that healthcare professionals knowingly or unknowingly discharge patients who are ill-equipped to self-care or to access the supports necessary to develop self-management skills. Survivors should not only benefit from a clinical teaching moment which addresses specific survivorship issues in preparation for discharge, they should also be supported to establish self-management skills throughout the treatment process. Survivors who participated in the interview phase of this study suggested a selection of possible interventions to assist healthcare professionals to overcome shortcomings in discharge preparation, including formal peer support shortly after discharge, a specific discharge consultation to deliver survivorship information and support from an expert patient, a patient advocate or a nurse. The development of self-management strategies may be facilitated through formal nurse-led or peer-led programmes of self-management incorporated into treatment pathways and discharge consultations; these will be discussed further in Sections 8.7.2 and 8.8.4, respectively. A recent feasibility study suggests life coaching may be a suitable means to enhance cancer survivors' self-efficacy and confidence in self-managing cancer-related issues following treatment and may have contributed to improvements in survivors' quality of life (Wagland *et al.* 2015). Such an intervention may be an acceptable means to address the lack of closure experienced by colorectal cancer survivors at the end of treatment, providing a structured programme of phone coaching over a 12-week period. However, further research is necessary to establish the sustainability of these positive results in a larger randomised controlled trial.

8.7 Objective 5: The Personal and Organisational Structures Used to Address Unmet Needs

The fifth objective of this study was to determine the personal and organisational structures used by colorectal cancer survivors to address unmet needs. Survey and interview participants used informal structures of support similar to those described by Foster & Fenlon (2011), including family (36%) and friends (25%). Few survivors engaged with peer support (3%), attended cancer support services (15%) or used online resources (20%). Interviewees suggested that barriers to using these supports were related to fear of stigma, accessibility and fears surrounding the trustworthiness of online resources. These various sources of informal support and information identified in the quantitative and qualitative phases of the study are discussed in relation to the cancer survivorship and chronic illness literature in the current section.

8.7.1 Family and Social Networks

In a positive finding, this sample reported some of the highest scores on the social well-being scale (Table 8.4). Most survey participants described close, supportive family relationships strengthened by the experience of colorectal cancer, echoing previous studies (Phipps *et al.* 2008, Domati *et al.* 2011). Although a number of interviewees described how their family members' fears for the survivor were more significant than the survivor's personal fear, it did not appear to hinder psychological support from the family unit, unlike findings of Hamilton *et al.* (2010) and Swartzman *et al.* (2017). Indeed, interviewees frequently described family members as carrying the burden of cancer, rising to challenges within the household by adopting new roles and responsibilities within the family unit, providing practical support for survivors.

Social support is linked to lower depression and greater quality of life among cancer survivors (Yoo *et al.* 2017). The mixed methods results suggest survivors relied heavily upon their family members, and to a lesser extent, social networks for psychological support. Similar to Taylor *et al.* (2011), a number of interviewees suggested they did not engage support from their social network as frequently, as these groups did not have prior experience or insight into cancer survivorship and could cause survivors unintentional distress with inappropriate or unhelpful advice. Furthermore, the qualitative findings echo those of Ramirez *et al.* (2009, p.9), as stigma experienced by ostomates arose from a "*cultural aversion to faeces*". In the current study, this stigma prevented colorectal cancer survivors from raising awareness of the chronic effects they experience among those in their social circle and hindered their willingness to seek help from support groups which are not specific to colorectal cancer. These findings are supported by the theoretical discussion of Charmaz & Rosenfeld (2006), as survivors endeavour to ensure internal processes are hidden from public view to avoid embarrassment.

The current study extends the understanding of factors which may influence social support; the qualitative results suggest a deterioration in social support and the quality of friendships may be related to inadequate coping mechanisms and lack of understanding of the implications of survival among survivors' friends. Friends who were highly supportive appeared to have had personal experiences of cancer which facilitated their awareness of chronic cancer-related side-effects; there is a dearth of published literature to support or refute these results. Family members and social networks are major constituents of cancer support networks and structures in Ireland. However, a lack of awareness of the chronic physical and psychological implications of colorectal cancer survivorship and stigmas relating to bowel function may impede the quality of such support. The consequence of these issues were isolation and exacerbation of psychosocial distress among some participants. Further research is necessary to determine the factors which motivate social networks to support cancer survivors. An opportunity may exist to enhance public awareness of cancer survivorship issues, cancer survivors' supportive care needs and symptom-related stigmas in colorectal cancer. This may be achieved through the development of information resources for survivors' family members and friends. Such information could be produced in online or booklet format and offered to the survivor upon diagnosis to share with their family and friends. These strategies may be enhanced by public awareness campaigns to increase societal awareness of chronic survivorship issues which may in turn foster informal support of cancer survivors within their community.

8.7.2 Peer Support and Voluntary Cancer Support

This study highlighted the underuse of advocacy-led cancer support services and survivors' difficulties accessing peer support. Opportunistic peer support in the treatment environment was valued by interviewees, offering survivors considerable support in the form of camaraderie and humour. Despite interview narratives implying a strong desire for peer support, more than half of survey participants did not believe they required such support (51%), and less than one-fifth reported barriers to accessing peer or voluntary cancer support, including a lack of awareness (14%), availability (3%) or specific support for colorectal cancer (2%). In keeping with the results of Hamilton *et al.* (2010) and Foster & Fenlon (2011), the physical and functional limitations experienced by colorectal cancer survivors seemed to marginalise colorectal cancer survivors seeking support, as the embarrassing nature and perceived stigma of bowel dysfunction limited the outlets available to survivors seeking support. Despite the potential negative implications of survivors' healthy appearance upon the support of social networks (Section 8.4.3.3), it did not affect survivors' confidence in accessing support programmes or services beyond the hospital. This finding is at odds with a qualitative study of 12 thyroid cancer survivors in Canada, which suggested a healthy appearance contributed to difficulties accessing support from cancer support programmes and healthcare professionals (Easley *et al.* 2013).

As outlined in Section 1.6, the development of psycho-oncology services in Ireland has not been fully realised (DoH Ireland 2006, 2017). Consequently, the provision of psychosocial support has largely fallen to the ICS and affiliated cancer support services. This study suggests the separation of formal tertiary oncology follow-up care services and cancer support services in Ireland may limit the utilisation of cancer support services, constraining the efficacy of their response to survivors' unmet needs. In the UK, the Expert Patients Programme has heralded a growth in initiatives to promote patient-centred care and empower those with chronic illness to self-manage their condition (DoHUK 2001, Squire *et al.* 2006, Squire & Hill 2006, Boylan *et al.* 2011, Job *et al.* 2016). Peer-led self-management programmes have been upheld as exemplary models to deliver these objectives, empowering those with chronic illness to manage their condition through the transfer of knowledge and skills (Lorig *et al.* 1999). However, such programmes have been criticised for potential recruitment bias and inconsistency in self-efficacy outcomes, preventing patients achieving expertise and engagement as an active participant in their care (Wilson 2001, South 2007, Wilson 2008). In Ireland, it may be feasible to develop similar peer-led self-management programmes. However, partnership between the ICS and hospitals providing follow-up care for cancer survivors may be necessary for the successful development and implementation of such programmes. Given the limitations of peer-led self-management programmes which have been identified in the UK, the development, implementation and evaluation of such programmes in Ireland must be driven by rigourous research processes. A participatory research approach which meaningfully involves cancer survivors and stakeholders from healthcare and advocacy backgrounds may help to ensure that these programmes respond to the unmet needs of cancer survivors which are potentially overlooked during follow-up care or cancer support. Finally, there must be rigourous and transparent evaluation of the implementation, acceptability and efficacy of such programmes, which may be achieved via a multi-site randomised controlled trial design.

The scoping study of cancer support services described in Section 1.6 identified only one online support forum for cancer survivors in Ireland. Although online resources were a source of support for one-fifth of survey participants, interview data suggested this support was largely informational, rather than social or emotional. A recent review suggests clinical trials of online cancer support for breast cancer survivors lack power and quality to determine the benefits of participation (McCaughan *et al.* 2017). Nevertheless, the internet may be an important source of support for both male and female cancer survivors (Seale *et al.* 2006, Foster *et al.* 2016a). The anonymity provided by online forums may allow survivors greater freedom to express their emotions and concerns (Seale *et al.* 2006). However, further research is necessary to determine the barriers and facilitators of Irish colorectal cancer survivors' use of online cancer support and to determine the potential benefits of such support for this group.

8.7.3 Sourcing Information Beyond the Healthcare Network

The survey study identified the type and prevalence of colorectal cancer survivors' unmet information needs. In findings aligned with the concept analysis (Section 2.2), interviewees described their resourcefulness, seeking information beyond the confines of the therapeutic relationship to address unmet needs. Despite the large proportion of survivors who reported unmet information needs (68%), fewer than one-quarter used information leaflets (23%), the internet (20%) or cancer helplines (2%), similar to previous studies (McMullen *et al.* 2008, Nikoletti *et al.* 2008, Anderson *et al.* 2013). Although information is increasingly accessible, healthcare professionals remain the most trustworthy source of information (Hesse *et al.* 2005). Interview participants implied they held a healthy scepticism of online resources due to the highly variable quality of cancer-related information on the internet (Sun *et al.* 2014, Nghiem *et al.* 2016). However, the significance and impact of unmet needs within this study demonstrate the need for survivors to be able to access alternative sources of information with confidence. Previous literature confirms the importance of online cancer information services to empower cancer patients and survivors (Sharf 1997, Dickerson *et al.* 2006, Dolce 2011). Accessibility of information and high levels of computer literacy and education are suggested explanations for high levels of self-efficacy in information-seeking among cancer survivors (Foster *et al.* 2015). It has been suggested that self-efficacy is important to cancer survivors' recovery, quality of life and development of self-management skills in the aftermath of treatment (Foster *et al.* 2015, Foster *et al.* 2016b). The findings that healthcare professionals discouraged survivors seeking online information may disempower survivors and potentially undermine their self-efficacy and resourcefulness, fostering dependency upon healthcare professionals and services. Though interviewees were cognisant of potentially untrustworthy online information, they expressed an overwhelming need for information about symptoms, treatment and self-management strategies and suggested that deterrence from online resources by healthcare professionals was a fruitless endeavour.

Access to online information may be an important means of empowering colorectal cancer survivors. Rather than discouraging survivors from accessing such resources, it may be appropriate to assist survivors to interpret the quality and reliability of online information. However, further research is required to explore cancer survivors' engagement with online information and support resources. Healthcare professionals and cancer advocacy organisations are well positioned to assist cancer survivors to interpret information acquired online. To achieve this, healthcare professionals and patient advocacy organisations must firstly engage survivors in open, non-judgemental discussions of the information they acquire beyond the confines of the hospitals. Secondly, tools such as the DISCERN instrument may support cancer patients and survivors to develop the critical evaluation skills necessary to interpret third-party information (Charnock *et al.* 1999, Charnock & Shepperd 2004). DISCERN is a standardised instrument which provides users of health information with guidelines to appraise the quality of health information written for members of the public (Charnock *et al.* 1999). Explanation of such tools at the time of diagnosis or in early treatment consultations may benefit survivors, facilitating independent access and appropriate interpretation of information. Finally, it is possible that cancer survivors and the wider population of individuals with acute and chronic illnesses may be empowered in decision-making were they able to access peer-reviewed evidence. A strategy to ensure accurate translation of peer-reviewed research results to members of the public, and assimilation of evidence into clinical practice, could potentially be achieved via the provision of lay summaries to accompany research publications (Grimshaw *et al.* 2012).

8.8 Objective 6: The Healthcare-Related Factors Influencing Quality of Life

The final objective of this study was to understand the socio-demographic, cancer-related and healthcare-related factors which influence colorectal cancer survivors' quality of life. Quality of life is a complex concept, with physical, psychological, social and spiritual components, affected by an array of personal, cultural, political and health-related factors (Ashing-Giwa 2005). The results of statistical analysis and the subsequent qualitative inquiry in this study endorse the complexity of factors which may influence quality of life in the context of colorectal cancer survivorship. The current section will discuss the key factors influencing quality of life identified within the quantitative and qualitative phases of the study.

8.8.1 Socio-Demographic and Cancer-Related Factors

Many socio-demographic and cancer-related factors were independently associated with colorectal cancer survivors' quality of life. Without exception, unemployment, absence of health insurance, co-morbid conditions and metastatic disease were associated with poorer overall quality of life among colorectal cancer survivors in this study, aligning with the results of previously described research (Table 3.10; Table 3.11). The current study adds to the inconsistent evidence surrounding the relationship between age and quality of life. Older participants experienced greater emotional and social well-being, supporting previous studies (Steginga *et al.* 2009, Jansen *et al.* 2011a, Kilic *et al.* 2012, Li *et al.* 2014). However, lower quality of life and physical well-being were reported by younger survivors, corroborating Krouse *et al.* (2009), Steginga *et al.* (2009), and Dunn *et al.* (2013a). These findings are at odds with a number of larger and smaller scale studies (Phipps *et al.* 2008, Pucciarelli *et al.* 2008, Hoerske *et al.* 2010, Caravati-Jouvenceaux *et al.* 2011, Hornbrook *et al.* 2011, Shun *et al.* 2011, Thong *et al.* 2011a, Thong *et al.* 2011b, Orsini *et al.* 2013, Li *et al.* 2014). Previous literature suggests several factors may explain these discrepancies. Firstly, while the distribution of age within these studies are commensurate with the current study, these previous studies have examined largely long-term colon or rectal cancer survivors who are more than five years post-diagnosis (e.g. Thong *et al.* 2011a, Thong *et al.* 2011b). Secondly, time since diagnosis was significantly associated with quality of life outcomes in these studies, but not within the current study (e.g. Ristvedt & Trinkaus 2009, Kilic *et al.* 2012). Finally, other potential contributory factors include the possibility that older survivors may possess greater coping mechanisms and capacity for post-traumatic growth (Salsman *et al.* 2009), and that survivors may engage in processes of reframing over time (McMullen *et al.* 2008, Serpentini *et al.* 2011, Chambers *et al.* 2012b, McCaughan *et al.* 2012), each of which may impact upon their evaluations of quality of life.

Therefore, the implications of age-related influences upon quality of life must be deliberated with due consideration of these issues.

The qualitative phase of this study facilitates interpretation of the incongruent quantitative findings regarding age and quality of life. Interviewees described the confounding effect of ageing and co-morbidity upon quality of life, similar to previous studies (Schneider *et al.* 2007, Phipps *et al.* 2008, Ramirez *et al.* 2009, McCaughan *et al.* 2012, Anderson *et al.* 2013). However, several younger participants commented upon how care for colorectal cancer survivors was largely tailored to older individuals more typical of the demographic affected by colorectal cancer. Providing a one-size-fits-all service meant younger survivors were disenfranchised socially and emotionally, experiencing unmet support and information needs specific to their age group, including return to work and support for their spouses, children and parents. These unmet needs caused emotional distress, in turn affecting younger survivors' quality of life. Studies of younger individuals with atypical chronic illnesses suggest anomalous patients may be marginalised from the outset, experiencing greater psychological and social disadvantage as their needs are poorly understood, while healthcare and support services are tailored to the needs of those who are demographically typical of the disease (Harris & Keady 2004, Chemali *et al.* 2012, Gibson *et al.* 2014). Further research is necessary to understand the needs of younger colorectal cancer survivors. Given the growing incidence of colorectal cancer in survivors under the age of 50 (Siegel *et al.* 2017), future clinical interventions must be designed to foster individualised care, so that the specific concerns of survivors may be placed at the heart of education and the planning and delivery of follow-up care.

8.8.2 Continuity of Care

The Contextual Model of Health-Related Quality of Life was designed to enhance the exploration of risk factors for poor quality of life outcomes among cancer survivors from minority and under-served populations. Nevertheless, it is a comprehensive framework to inform health-related quality of life research with a particular interest in the influence of healthcare experiences (Ashing-Giwa 2005). The inferential analysis and statistical models presented in Chapter Six and the thematic analysis presented in Chapter Seven support the idea that quality of life is experienced within and affected by the context of healthcare. Within this study, lower quality of life was associated with lower ratings of information, form management, interdisciplinary communication, coordination of care, relationships with healthcare professionals and overall continuity of care. These findings are in keeping with literature in the area of diabetes and chronic illness (Hanninen *et al.* 2001, Chen *et al.* 2017) and recent research which suggests satisfaction with healthcare and the quality of relationships with physicians is associated with greater quality of life among breast cancer survivors (Miller *et al.* 2015).

Investigation of the impact of continuity of care and healthcare experience upon quality of life is limited in the field of colorectal cancer survivorship. However, there is a growing literature of complex interventions to enhance continuity of care following transition from treatment to follow-up care. Interventions under development include models of care, implementation of survivorship care plans, use of pre-clinic symptom assessment tools and development of patient navigation roles (Velikova *et al.* 2010, Brothers *et al.* 2013, Nicolaije *et al.* 2015, Brouwers *et al.* 2016, Nanton *et al.* 2017, Scherz *et al.* 2017). As already discussed, no such interventions are currently used in an Irish context for colorectal cancer survivors (Sections 8.6.1 and 8.6.3). Therefore, further work is required to ensure such interventions are acceptable to cancer survivors and transferable across cultural contexts and the varying models of healthcare delivery which are in use internationally.

8.8.3 Access to and Support from Healthcare Professionals

It is noteworthy that access to a named doctor to discuss cancer-related worries was the only healthcare access or support factor significantly associated with quality of life. The finding that access to a named nurse was not associated with differences in quality of life scores is consistent with the results of a recent randomised control trial which found the addition of a nurse-led supportive care package to usual follow-up care was not associated with improved quality of life, psychological distress or unmet needs, but was related to more positive perceptions of care (Jefford *et al.* 2016). In the current study, access to a named nurse and support from general practice and hospital staff were associated with greater likelihood of reporting satisfaction with overall continuity of care and more positive relationships with healthcare professionals. These findings tentatively suggest access to healthcare professionals and perceptions of support are indirectly related to quality of life outcomes via continuity of care. In addition, the qualitative results suggest that nurses were more available to them than physicians and were able to take greater time to discuss cancer-related concerns. It seemed nurses were more likely to acknowledge the survivor's expertise in managing their condition than doctors and were most often advocates for patients in situations where their expertise was undermined. This is at odds with previous literature from Australia, which suggested cancer survivors consider nurse-led follow-up less credible than oncologist-led follow-up (Baravelli *et al.* 2009). Despite survivors' preference to receive care from a consultant surgeon or medical oncologist in a survey of cancer survivors' follow-up preferences in Scotland, some cohorts, including colorectal cancer survivors, may be willing to accept care from nurses or general practitioners were they to receive greater continuity of care, access to one-to-one counselling and more detailed dietary advice in follow-up consultations (Murchie *et al.* 2016). The findings discussed in this section provide some evidence to suggest that access to a named nurse in follow-up care can address some of these motivating factors. However, further research is required to confirm this finding.

In interpreting the results relating to healthcare access and support, it must be considered that follow-up care in the Irish public health sector is delivered predominantly by clinical nurse specialists, while in the private sector it is physician-led. Having access to a doctor for information and support within the public health sector during colorectal cancer follow-up may influence quality of life outcomes, as it is an additional source of support, whereas the opposite may be true in private healthcare settings. This hypothesis cannot be conclusively determined within the current study due to limitations of the study design, the size of the sample recruited from the private hospital site and the co-delivery of care to patients with and without private health insurance in the Irish public health service. Nevertheless, it would be of interest to examine whether these findings are replicated in larger samples of survivors who receive follow-up care in exclusively private or public healthcare settings, rather than the mixed model of healthcare provision operating in Ireland.

8.8.4 Unmet Needs

Univariate statistical analysis revealed that an increasing number of unmet information needs and social difficulties were associated with lower levels of quality of life, keeping with the results of recent studies (Cheng *et al.* 2016, Faller *et al.* 2016). Bowel dysfunction is a unique consequence of colorectal cancer survivorship, and similar to previous studies, participants expressed dismay at the lack of preparation for the management of chronic bowel dysfunction during follow-up interviews. In addition, the process of trial and error which followed and the unpredictability of bowel function significantly impacted survivors' self-esteem and social activities, causing some survivors to become isolated (DeSnoo & Faithfull 2006, McMullen *et al.* 2008, Ramirez *et al.* 2009, Grant *et al.* 2011, Anderson *et al.* 2013, Palmer *et al.* 2013, Brown *et al.* 2016). Though survivorship care plans may be a means to enhance the communication of information about the potential physical and psychosocial effects of colorectal cancer (Section 8.5.4), these findings suggest a need for more comprehensive and interactive discharge packages, which provide verbal, written and audio-visual information in combination with a discharge consultation. Wells & Kelly (2008) and McCabe *et al.* (2008) caution against the adoption of standardised packages of cancer support, as they are not a one-size-fits-all solution to unmet needs or quality of life concerns. Although discharge consultations are not currently standard practice at the research sites involved in this study, where such consultations were to be introduced, their utility and patient-centredness may be enhanced if written and audio-visual information are provided to cancer survivors in advance of consultations. Development of discharge programmes should consider the integration of information about potential issues of survivorship from the moment of diagnosis to build survivors' awareness of the potential long-term implications of their disease from the outset. This approach could foster survivors' familiarity with survivorship information and empower cancer survivors during discharge consultations, facilitating patient-centred care that is tailored to address each survivor's specific unmet needs and concerns for the future. If appropriately implemented and evaluated, patient-centred approaches to discharge consultations may enhance self-efficacy, satisfaction with care and quality of life in the aftermath of treatment (Brown *et al.* 2016, Jefford *et al.* 2016, Leach *et al.* 2017). However, further research is necessary to optimise the timing and content of information resources and the format of discharge consultations.

8.8.5 Use of Cancer Support Services

Increased access to advocacy-led cancer support has been achieved since the implementation of the ICS affiliation programme (ICS 2010, Gallagher & O'Keeffe 2012). However, this study highlights the continued underutilisation of cancer advocacy and support services and the opportunistic nature of psychosocial support for colorectal cancer survivors more than 20 years since these issue was highlighted in the first Irish Cancer Strategy (DoH Ireland 1996). Without exception, survivors who had attended cancer support groups or services reported poorer overall quality of life in univariate and multivariate statistical analysis. There are a variety of factors which motivate cancer survivors to access cancer support groups, yet the findings of this study suggest support groups may not assist survivors to overcome quality of life issues and unmet needs. Previous studies highlight how cancer support groups may enhance cancer survivors' social support (Rudy *et al.* 2001, Vos *et al.* 2004). However, evidence drawn from two small quantitative studies of prostate cancer (*n*=51; McGovern *et al.* 2002) and head and neck cancer patients (*n*=37; Mowry & Wang 2011) suggest quality of life is no better in survivors who have used support groups, compared to those who have not. Those who attend cancer support groups may be more likely to experience anxiety and cancer-related distress, and in some cases may engage in fatalistic coping strategies (McGovern *et al.* 2002, Grande *et al.* 2006). Such behaviours are characteristic of a Type D personality, which has been associated with poorer quality of life in colorectal cancer survivorship (Mols *et al.* 2012a, Mols *et al.* 2012b).

It is impossible to ascertain from the results of this study whether survivors who accessed cancer support services did so because they experienced poorer quality of life or a greater number of unmet needs at baseline. However, it is of interest that survey participants who had poorer quality of life in the current study were no less likely to feel supported by hospital, primary care and social services than those with higher quality of life scores. This raises questions about whether survivors who are accessing cancer support services are somehow different to cancer survivors who do not access such services and whether existing cancer support services are providing support to address the unmet needs and quality of life issues of this group of cancer survivors. Based on the results of this study, there is a need to gain greater insight into the factors which motivate cancer survivors to access cancer support services in Ireland. Future research may consider investigating the factors which cause distress to cancer survivors who access cancer support services in Ireland, and whether the support services accessed by these survivors contribute to improvements in their quality of life in some capacity. Finally, it would be pertinent to explore the reasons why cancer support services in Ireland may be failing to support survivors to fully overcome the unmet needs and quality of life concerns which may motivate survivors to access these services, so that future interventions may be tailored to address their needs.

8.9 Modelling the Complexity of Healthcare-Related Factors Influencing Colorectal Cancer Survivors' Quality of Life

The results of multivariate regression analysis suggest that colorectal cancer survivors' quality of life is affected by the continuity of their follow-up care and their experience of unmet support or information needs. The regression model fits with Ashing-Giwa's conceptualisation of quality of life, as the model highlights the importance of socio-ecological (*Insurance Status*, *Social Difficulties*), medical (*Tumour Status*) and healthcare (*Continuity of Care*, *Use of Cancer Support*) factors in predicting quality of life in colorectal cancer survivors. The qualitative findings support and extend these results, suggesting that formative healthcare experiences, particularly failures in relational, informational and management aspects of continuity of care during diagnosis and treatment may continue to adversely affect quality of life, even five years later. The results of Easley *et al.* (2016) go some way to support these findings, with descriptions of how shortcomings in communication and support at the time of diagnosis may undermine survivors' trust in healthcare professionals and hinder continuity of care several years after treatment.

Although survivors do not believe they are treated any differently whether or not they have private health insurance, the results of the logistic regression model suggest insurance status influences quality of life outcomes among colorectal cancer survivors. Furthermore, qualitative results highlight survivors' perception that holding private health insurance expedites investigation of disease. These findings are supported by previous literature (Richardson *et al.* 1992, van Doorslaer *et al.* 2006, Macleod *et al.* 2009, Rapiti *et al.* 2009, Steginga *et al.* 2009, Chambers *et al.* 2012b). However, as information on the staging of disease was not collected, it is not possible to conclude whether or not insurance status was related to stage of disease at diagnosis. Within the current study, health insurance status may be a marker of socio-economic status due to the cost implications of private health insurance in Ireland (Section 1.5). The role of insurance status in predicting colorectal cancer survivors' quality of life outcomes may also be linked to the model of follow-up care and the variety of healthcare professionals the survivor has access to in the aftermath of treatment (Section 8.8.3). However, as already discussed, further research is necessary to determine the implications of the model of care delivery in the public and private healthcare sectors in Ireland in determining the quality of life outcomes of colorectal cancer survivors.

The Ashing-Giwa (2005) *Contextual Model of Health-Related Quality of Life* was selected to guide this study as it could support an exploration of the complex factors which may influence quality of life in cancer survivorship, including those derived from the healthcare context of particular interest to this study. In light of the results of this study, Figure 8.2 presents a proposed adaptation of the Ashing-Giwa (2005) Model, representing the various healthcare factors related to colorectal cancer survivors' quality of life, across quantitative and qualitative phases of this study. This joint display illustrates the integration of the quantitative and qualitative findings to address the study aim, in line with approaches to integration recommended by Creswell & Plano Clarke (2011) and Guetterman *et al.* (2015). The adapted model incorporates the five quantitative factors which predicted colorectal cancer survivors' quality of life (*Insurance Status*, *Social Difficulties*, *Continuity of Care*, *Use of Cancer Support* and *Tumour Status*). The qualitative findings extend understanding of the statistical factors influencing quality of life, suggesting the chronic symptoms resulting from colorectal cancer are an integral part of quality of life, a price to pay for survival, even where survivors reported positive quality of life overall. The experience of chronic symptoms may create unmet information and supportive care needs, which mediate survivors' perceptions of access to, support from and continuity of healthcare, in turn affecting survivors' quality of life. The interview data suggest that survivors may seek further support beyond the realms of formal oncology healthcare services to address unmet needs. Survivors attempt to *Bridge the Gap of Unmet Need* through a *Network of Supports Beyond the Healthcare System*, encompassing their family members, their social network, cancer advocacy services and online resources. However, the nature of the *Network of Supports Beyond the Healthcare System* were dependent upon the cultural context in which the individual resided and received healthcare, as beliefs relating to survivors' acculturation, interconnectedness and worldview could hinder survivors from seeking psychosocial support. These potential barriers included social stigmas about the discussion of chronic effects, difficulties discerning the trustworthiness of online resources, a lack of local cancer support services specific to colorectal cancer or a belief that cancer support was not required.

8.10 Limitations and Strengths of the Study

As with any scientific research, the findings of this study should be interpreted in the context of its limitations. Although this is not the first study to evaluate colorectal cancer survivors' quality of life, it is among the earliest studies to evaluate how healthcare experiences, including access to healthcare professionals, support from healthcare services and continuity of follow-up care, may influence the quality of life of colorectal cancer survivors receiving follow-up care in tertiary oncology healthcare settings up to five years following diagnosis. Section 5.6 outlined some of the potential implications of the study procedures for the quality of the study design. In this section,

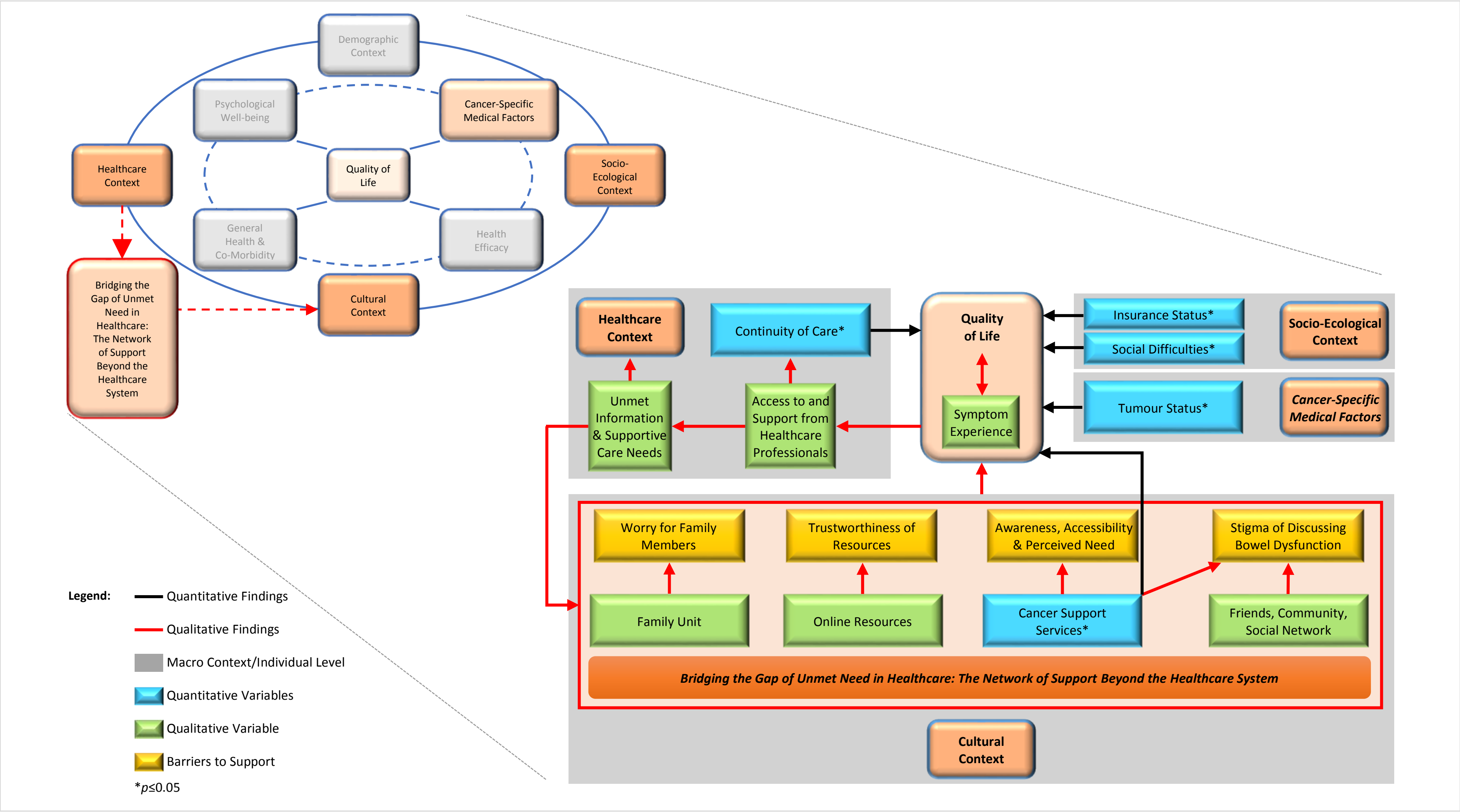

Figure 8.2 Conceptual model demonstrating the multivariate, integrated, mixed methods findings describing the impact of Healthcare, Socio-Ecological and Cultural Factors upon colorectal cancer survivors' quality of life in The Cost of Survival Study, adapted from the Ashing-Giwa (2005) Contextual Model of Health-Related Quality of Life

the limitations of this research and their potential implications for the interpretation of the study results are described.

8.10.1 Recruitment

A strength of the study lies in the recruitment of participants from multiple research sites which serve various socio-economic groups and represent the variety of tertiary public and private healthcare settings in which colorectal cancer follow-up care is routinely delivered in Ireland. However, there was significant variation in the response rates at each research site. This variation may be attributed to delays in launching the study at the private hospital site and differing research processes at this site compared to the public hospital sites. Variations in the research processes at the private hospital site included longer timelines for ethical, administrative and indemnity-related approvals and a different recruitment process at this site (Table 5.11). The researcher was excluded from the recruitment process at the private hospital site due to resource constraints. Therefore, the gatekeepers at this site assumed responsibility for the identification and enrolment of suitable participants. This places a potential limitation on the study findings, including sampling bias, as gatekeepers may have chosen to exclude survivors they perceived to be too vulnerable or frail to participate in the study, who did not experience difficulties with disease-related toxicities, or those who may provide less positive evaluations of their care. In addition, it was not possible to maintain an accurate screening log of eligible survivors attending clinics at the private hospital site. Therefore, the eligible response rate at the private hospital site may have been lower than that estimated, as the response rate is only representative of those who were invited to participate, rather than the proportion of those who may have been eligible. Efforts were made to build relationships with the gatekeepers and clinicians at the private hospital to ensure the success and transparency of recruitment processes. However, the challenges encountered were difficult to overcome. The challenges of conducting research in private healthcare settings are not unique to the current study, nor to Ireland. An Australian study by Nikoletti *et al.* (2008) reported similar challenges with the transparency of recruitment processes, response rates and sample sizes at private oncology clinics. It is not possible to ascertain whether the respondents recruited from the private hospital site are representative of the wider population of colorectal cancer survivors receiving care in private healthcare organisations in Ireland. Therefore, the results of this study must be interpreted with consideration of these limitations.

8.10.2 Response Rate

The low response rate at the private hospital site necessitated the implementation of a contingency plan to recruit colorectal cancer survivors via cancer support centres and viral sampling methods (Section 5.3.3.1). Despite these challenges, the study achieved reasonable response rates and provides useful data to understand the potential impact of healthcare experiences upon the quality of life of colorectal cancer survivors receiving follow-up care in tertiary oncology settings in Ireland. The Phase 1a response rate of 73% is comparable to the PROMs Living with and Beyond Colorectal/Gastro-Intestinal Cancer study (66%) (DoHUK 2012), and baseline recruitment rates of the ColoREctal Wellbeing (CREW) study, a longitudinal multi-site study in the UK (78%) (Fenlon *et al.* 2013). Furthermore, the response rate is more favourable than previous registry-based studies of colorectal cancer survivors in Ireland (39%) (Hanly *et al.* 2013, Thomas *et al.* 2014). The sample size is adequately powered to detect the prevalence of physical and psychosocial issues at a confidence level of 95% with a confidence interval of ±6%. However, in the absence of data on non-respondents, it is not possible to conclusively determine whether the sample recruited are representative of colorectal cancer survivors in Ireland, or whether sampling was affected by recruitment or response bias. Nevertheless, the socio-demographic and cancer-related characteristics of sample were comparable to international studies of colorectal cancer survivors (Section 8.2).

8.10.3 Sample

Although the current sample is comparable to those of previous studies with respect to socio-demographic and cancer-related characteristics and quality of life outcomes (Section 8.2), the results may not be applicable (generalisable and transferable) to more ethnically diverse populations of colorectal cancer survivors as the sample is predominantly of white Irish ethnicity. Despite this, the study provides important statistical and narrative data about the potential relationship between healthcare experiences and quality of life outcomes. A potential limitation of the sample lies in the proportion of participants undergoing treatment at the time of the study who reported metastatic or recurrent disease (59%). Six participants (22%) who reported undergoing treatment at the time of the study described themselves as disease-free, and a further six did not report their disease status. This may point to discrepancies in the recruitment process or potential issues with the validity of survey items assessing current treatment and disease status. These participants may have been receiving adjuvant chemotherapy and were recruited to the study as they were enrolled in the follow-up surveillance programme with surgical and/or medical oncology teams in line with the follow-up care protocols of the hospitals involved in the study. Therefore, their experiences of the process of follow-up care were of relevance to the study (Section 5.3.1). However, it should also be considered that up to 30% of individuals with advanced disease may misunderstand the intent of palliative treatment regimens or underestimate the extent of their disease (Gattellari *et al.* 1999, Craft *et al.* 2005, Lennes *et al.* 2013). Although the effectiveness of physician communication is thought to contribute to such misunderstandings, the individual's denial of disease threat has also been found to be a contributory factor (Gattellari *et al.* 1999). Nevertheless, in the absence of data confirming the disease stage of the survivors who provided these responses, the results must be interpreted with consideration of this potential limitation.

8.10.4 Methodology

The cross-sectional nature of the quantitative study means causality may not be inferred, thus limiting the generalisability of results. Prospective longitudinal studies and randomised controlled trials are necessary to provide a more accurate picture of associations between colorectal cancer survivors' quality of life and socio-demographic, cancer-related and healthcare characteristics. Nevertheless, the cross-sectional data provide evidence suggesting potential relationships between these factors, providing a basis to direct larger-scale longitudinal and epidemiological studies of quality of life and symptom prevalence among colorectal cancer survivors.

8.10.5 Data Collection Methods

The subjective nature of evaluations of quality of life and healthcare experiences in the quantitative and qualitative phases of this study introduces the risk of socially desirable responses. As survivors were recruited from the clinics where they receive follow-up care, there was a possibility of positive response bias. To reduce this risk, all participants were assured 1) the study was conducted by a third party, 2) all data would be anonymised, and 3) the results would be used to improve practice where necessary. Furthermore, participants were encouraged to complete the survey in their own home and were provided with a stamped addressed envelope to return the completed survey to the researcher at the university where she was employed.

A further precursor to response bias may be the researcher's prior experience as an oncology nurse, particularly during Phase 2 interviews. As all interviewees were informed of the researcher's prior oncology nursing experience, this may have precipitated certain biases in their narratives. For example, survivors may have used more medicalised language, or withheld information as they endeavoured to describe their healthcare experiences positively were they to perceive the researcher as a representative of the healthcare system. Although almost all interviewees described unmet needs and negative aspects of oncology-related healthcare during interviews, it is possible that recruitment of participants from a neutral setting and interviews conducted by a researcher without a clinical background may have provided alternative discussions. However, the integration of quantitative and qualitative data may ameliorate the limitations of possible response bias on quality of life and healthcare experience instruments, as interviewees divulged both positive and negative care experiences in the qualitative phase of the study.

8.10.6 Data Collection Instruments

The FACT-C questionnaire limits comparison of quality of life outcomes between colorectal cancer survivors and other disease groups and captures information about a limited range of functional health issues. However, when used appropriately, disease-specific quality of life instruments focus on relevant issues which generic instruments may otherwise overlook (Cella & Nowinski 2002). By its nature, quality of life is abstract, complex and highly individualised. The combination of generic

(EuroQol 5D-5L) and disease-specific (FACT-C) quality of life measures go some way toward addressing the complexity of issues experienced. Participants of the current study rated their self-rated health (EuroQol 5D-5L: $\bar{x}$=81.2) and quality of life (FACT-C: $\bar{x}$=111.9) at similarly ranked levels (EuroQol 5D-5L: 81/100; FACT-C: 82/100). However, the high levels of symptomatology reported and large proportion of survivors who described dissatisfaction with their quality of life suggest a discrepancy in the results, representing potential limitations in the measurement instruments. Previous research has highlighted disparities between quality of life outcomes measured by standardised instruments and single item global assessments of quality of life outcomes (Ashing-Giwa 2000). Ashing-Giwa (2005) suggests that such disparities may be the result of cultural factors which mediate negative health-related outcomes. More recent research suggests that compared to standardised multi-item scales, single item measures provide valid estimates of life satisfaction and are more sensitive to state variance than multi-item scales, but are less likely to capture trait variance than multi-item scales (Gnambs & Buntins 2017). Gnambs & Buntins (2017) suggest that within cross-sectional research, variance arising from situational effects may partly confound measurement issues. For example, the prevalence of body image concerns on the FACT-C are not reflected in the reasonably positive FACT-C scores. Likewise, this issue is reflected by the deviation in the prevalence of bowel control difficulties on the five-point Likert scale (57%) and the dichotomous item (25%) within the FACT-C questionnaire. Finally, while the quality of life instruments selected for the current study represent some of the most valid, reliable and widely used quality of life instruments used in PROMs research, they are orientated toward the assessment of short-term difficulties, and may overlook the difficulties arising in cancer survivorship (Dirven *et al.* 2015). Nevertheless, the combination of quantitative and qualitative research methods in the current study enhances the meaning and understanding of complex quality of life concerns in cancer survivorship, identifying additional quality of life concerns and coping strategies used by survivors to reframe their experiences of illness and expectations of quality of life (Section 8.4.3.3).

Symptom-specific items within this study are not profound assessments of colorectal cancer survivors' symptom experience (e.g. peripheral neuropathy – *Tingling in Hands or Feet*). However, they are drawn from instruments which have established validity and reliability among colorectal cancer survivor populations. Therefore, these items provide a suitable method to assess the point prevalence of specific symptoms within the objectives of this study. Unfortunately, the design of survey instruments means it is not possible to understand the degree of support survivors wish to receive from healthcare professionals for each reported symptom. This is a significant limitation, preventing conclusive evaluation of the prevalence of unmet need surrounding symptom management. Nevertheless, the qualitative data extends the knowledge gained from the symptom items in the survey, giving insight into survivors' experiences of symptoms and their related unmet needs, providing directions for future research.

8.10.7 Statistical Analysis Techniques

The extensive exploratory analysis undertaken in the quantitative phase of this study may have introduced the possibility of a false positive result (Type I error). Multiple comparisons are considered necessary in areas of exploratory research lacking robust theoretical underpinnings to guide statistical model building strategies, as was the case in the current study (Thayer 2002). The use of adjusted *p*-values for multiple comparisons (reported at the level $\alpha \leq 0.05$) and presentation of the nonparametric statistical analysis with the results of corresponding parametric statistical tests may counteract the potential threat of a Type I error, as they are associated with an increased risk of Type II error (Streiner & Norman 2011, Field 2013, Dzikiti & Girdler-Brown 2017). Furthermore, the construction of multivariate models is thought to lessen the probability of producing Type I errors (Field 2013). Nevertheless, the results of univariate statistical analysis conducted in Phase 1 of this study should be interpreted with cognisance of these potential limitations.

8.10.8 Theoretical Limitations

The Ashing-Giwa (2005) *Contextual Model of Health-Related Quality of Life* has primarily been used in research of female cancer survivors from ethnically diverse backgrounds. Therefore, the use of the Ashing-Giwa (2005) Model in this study of mixed-gender, ethnically homogeneous colorectal cancer survivors is a potential limitation of this study. Furthermore, adaptations to the Ashing-Giwa (2005) Model to reflect the findings of the literature review and the culture and model of healthcare provision in operation in Ireland are a potential limitation of this study. As discussed in Section 3.8.3, the exploratory nature of this study and its interest in the potential influence of the *Healthcare Context* upon colorectal cancer survivors' quality of life justify the use of the Ashing-Giwa (2005) Model and adaptations made for this study. However, the omission of *Health Efficacy* and aspects of *Cultural Context* preclude an analysis of their potential influence and contribution to the prediction of quality of life outcomes. Quality of life is a subjective, complex, multi-factorial phenomenon, influenced by a variety of socio-demographic, socio-economic, cultural, psychological and health and cancer-related issues, making it difficult to achieve a comprehensive evaluation of all potential predictive factors. Given this knowledge and the limited empirical literature explaining the relationship between healthcare-related variables and quality of life, a mixed methods sequential explanatory design was considered an appropriate approach to this study. Follow-up with semi-structured interviews permitted survivors to discuss the factors of importance to their quality of life in the aftermath of treatment. Indeed, during interviews, many survivors described engaging in palliative coping strategies which embodied behaviours relating to *Health Efficacy* in the Ashing-Giwa (2005) Model (Section 7.4.3.5). Future studies exploring quality of life outcomes may consider operationalising a full complement of the *Contextual Model of*

Health-Related Quality of Life to assess the relative contribution of healthcare experiences to the prediction of quality of life outcomes with due consideration to other potentially influential factors.

8.11 Chapter Summary

This chapter has presented the integration and discussion of the results of this mixed methods study, responding to its mixed methods objectives (Table 8.1). This study set out to address the limitations of previous colorectal cancer survivorship research, including age, disease stage, clarity of disease status, definition of survivorship timeframes and the use of mono-method data collection techniques (Section 3.8.1). Strengths of this study include the mixed method approach, strong response rate, rigour of inclusion criteria and integration of quantitative and qualitative research methods. The current study has responded to a gap in the colorectal cancer survivorship literature describing the potential impact of healthcare experiences upon the quality of life of colorectal cancer survivors receiving follow-up care in tertiary oncology healthcare settings in Ireland, identifying the potential implications of a public-private healthcare system in determining colorectal cancer survivors' quality of life outcomes. The integration of quantitative and qualitative approaches provides a comprehensive understanding of the potential healthcare-related factors which may influence colorectal cancer survivors' quality of life in Ireland. Collectively, the findings of this mixed methods study highlight the need for interventions in the Irish oncology and primary healthcare systems to address the multifaceted information and supportive care needs of colorectal cancer survivors and assist them during the highly individualised process of recovery. These and other recommendations from the study are discussed further in Chapter Nine, which describes the key meta-inferences derived from this mixed methods study and the implications of these research findings for theory, methodology, policy, healthcare provision, cancer support, oncology practice and future research.

Chapter Nine – Study Implications, Recommendations and Conclusions

9.1 Introduction

This chapter presents a discussion of the implications and recommendations of this research. It opens with a summary of the key meta-inferences derived from the study (Section 9.2). Next, a discussion of the theoretical (Section 9.3.1) and methodological (Section 9.3.2) implications of this research and recommendations for future research. Section 9.3.3 examines the implications of this research for the development of oncology policy and the implementation of the National Cancer Strategy 2017 in Ireland (DoH Ireland 2017). The results of this study are considered in relation to the delivery of follow-up care and psychosocial care for colorectal cancer survivors in Ireland and recommendations are made for oncology healthcare services (Section 9.3.4), clinical oncology practice (Section 9.3.5) and cancer advocacy and support services in Ireland (Section 9.3.6). The chapter concludes with suggested directions for future research in this field (Section 9.4), a reflection upon the researcher's role, influence and learning in this study (Section 9.5) and a summary of the original contributions of this research to the colorectal cancer survivorship literature (Section 9.6).

9.2 Key Meta-Inferences Derived from the Integration of Quantitative and Qualitative Results

A central tenet of mixed methods research is the integration of quantitative and qualitative approaches at one or more points of the planning, design, sampling, data collection, data analysis and interpretation stages of the research process (Creswell & Plano Clarke 2011). In this study, a sequential explanatory design was used to explore colorectal cancer survivors' quality of life outcomes and healthcare experiences in Ireland. Integration was achieved with the use of mixed methods objectives, the sequential staging of quantitative and qualitative phases, the emergent design of the qualitative phase and integration of quantitative and qualitative results responding to the mixed methods objectives in the discussion chapter. The products of integration are the meta-inferences drawn from the quantitative and qualitative findings which provide a more comprehensive understanding of the research problem than would be possible by a mono-method design (Ivankova *et al.* 2006, Creswell & Plano Clarke 2011).

While it appears colorectal cancer survivors in Ireland experience reasonably positive quality of life comparable to normative population scores (Section 8.2.3), as many as three-quarters of survivors experienced one or more complex physical, psychological or social effects impacting quality of life in multiple domains more than half were dissatisfied with their quality of life. Survivors enlisted a variety of coping strategies to adjust to life during and after cancer treatment, including activities facilitating positive reframing of their expectations for quality of life. The mixed methods approach offered valuable information on how healthcare experiences may influence colorectal cancer survivors' quality of life both directly and indirectly following treatment. Although quality of life and healthcare experiences were rated positively overall, the qualitative data highlight the continuum of positive and negative healthcare experiences underpinning these ratings of care. An array of individual, organisational and political factors contributed to inadequate management of survivorship issues. Survivors experienced a range of chronic treatment-related effects and unmet information and supportive care needs, leaving them unprepared for the lasting consequences of colorectal cancer and deprived of appropriate guidance to support the development of self-management strategies. The results suggest there is a need to re-evaluate the delivery of information and care, ensuring a patient-centred approach considering the survivor's age, socio-economic status, disease status, symptom-related concerns and unmet needs.

The mixed methods approach to this inquiry highlighted some divergence between quantitative and qualitative results. Few colorectal cancer survivors accessed cancer support services, and more than half indicated they did not believe they required such support. Follow-up interviews revealed that many survivors held a strong desire for greater support to gain insight into the potential physical, psychological and social issues which may arise after colorectal cancer treatment and associated unmet needs. Survivors believed that peer support could address these needs but should take place within the clinical setting at strategic points of transition, such as diagnosis, commencement of treatment, conclusion of treatment and shortly after discharge. While suboptimal quality of life and unmet needs may motivate some survivors to engage with cancer support services, the use of these services was associated with lower levels of overall quality of life. Barriers to accessing cancer support services were the lack of cancer support specific to colorectal cancer and fears of embarrassment arising from disclosure or incidents of bowel dysfunction. The findings suggest that the separation of formal cancer follow-up care and cancer support services in Ireland may place limitations on the scope and effectiveness of services provided by cancer support organisations. It appears that there is a need to gain greater understanding of whether and how cancer support services are addressing the unmet needs of cancer survivors and explore potential strategies which could enhance collaborative working between oncology healthcare services and cancer support services to maximise the potential impact of each.

9.3 Implications and Recommendations of This Study

The results of this study suggest there is scope for improvement in healthcare and advocacy practices in cancer survivorship in Ireland to address the unmet needs of this group and support survivors to achieve mastery of the physical, psychological and social consequences of colorectal cancer. The findings of this study have implications for the evaluation of quality of life outcomes from theoretical and methodological perspectives and have wider implications for the policies, services and professions tasked with the care of colorectal cancer survivors in the aftermath of cancer treatment in Ireland. These implications are discussed in the following sub-sections.

9.3.1 Theoretical Implications: Evolving Understanding and Utility of the Contextual Model of Health-Related Quality of Life

The findings of this study add to the evidence describing quality of life in cancer survivorship and have implications for *The Contextual Model of Health-Related Quality of Life* which informed this inquiry (Ashing-Giwa 2005). Using the Ashing-Giwa (2005) Model in the context of this pragmatic mixed methods study illustrates the complexity of factors influencing the quality of life outcomes of colorectal cancer survivors at individual (general health and comorbidity; psychological well-being; cancer-related medical factors) and macro levels (demographic context; socio-ecological context; cultural context; healthcare context) (Figure 2.7, Figure 3.6). The Ashing-Giwa (2005) Model has been used primarily to examine quality of life outcomes among ethnically and culturally diverse samples of female cancer survivors. However, this study suggests the Model may be applied to broader populations of cancer survivors in international contexts, particularly where disparities may arise within healthcare delivery models and social and economic policies. However, further research is necessary to ascertain its validity.

Recommendation:

- *Further research is warranted to assess the validity of The Contextual Model of Health-Related Quality of Life with more diverse samples of cancer survivors internationally.*

9.3.2 Methodological Implications: Evaluation of Quality of Life in Cancer Survivorship

Despite the prevalence of physical, psychological and social issues, survivors rated their quality of life and self-rated health positively on the FACT-C and EuroQol VAS. However, more than half expressed dissatisfaction with their quality of life on a single FACT-C item "*I Am Content with the Quality of My Life Right Now*". While these results are comparable to normative data for the instruments (Table 8.2; Table 8.3), they point to discrepancies in the measurement instruments which may affect their validity. As discussed in Section 8.10.6, such disparities may arise from discrepancies between single and multiple item assessment instruments, affected by their sensitivity to situational, state and trait variance and the orientation of FACT-C items to acute treatment-related effects, rather than survivorship concerns (Ashing-Giwa 2000, Dirven *et al.* 2015, Gnambs & Buntins 2017). It may be that survivors who reported greater dissatisfaction with their quality of life experienced greater exacerbation of symptoms or survivorship concerns that were not assessed by the FACT-C. Indeed, the variation in the prevalence of symptoms, including body image and sexual dysfunction, on the EuroQol 5D-5L (today), FACT-C (in the past week) and SDI (in the past month) provide evidence to support this hypothesis (Table 8.6). While further research is necessary to evaluate these results, there may be scope to develop survivorship-specific subscales to support FACIT instruments, similar to the EORTC module currently under development (van de Poll-Franse *et al.* 2018).

Collectively, these findings have implications for the measurement of cancer survivors' quality of life. The combination of generic and disease-specific quality of life instruments enhances understanding of the broad health experiences of colorectal cancer survivors and specific concerns relating to colorectal cancer (Section 2.3.2). In addition, qualitative inquiry allowed survivors to describe the scope and meaning of quality of life outcomes and the impact of physical, psychological and social issues and the healthcare context upon their well-being. Future research to ascertain whether the findings of Gnambs & Buntins (2017) regarding the use of single-item and multiple-item scales for the measurement of life satisfaction have similar implications for the measurement of quality of life and symptom evaluation. In addition, it would be of interest to ascertain whether concurrent mixed methods approaches could provide greater insight into colorectal cancer survivors' experiences of quality of life outcomes, using interview approaches to provide deeper understanding of state-trait variances in quality of life evaluation. Concurrent mixed methods approaches may consider administering standardised generic and/or disease-specific quality of life survey instruments within a semi-structured interview to explore survivors' responses to specific survey items in greater detail. A concurrent approach ensures the qualitative aspect may provide greater insight into survivors' quality of life at the time of the survey, which could not be achieved by a sequential approach due to the lapse in time between phases.

Recommendations:

- *Future research should evaluate the validity of current cancer-specific quality of life instruments for the assessment of quality of life issues in cancer survivorship.*
- *The development of additional subscales to evaluate specific cancer survivorship quality of life issues may compliment the FACT-C instrument, ensuring survivorship concerns are not overlooked in quality of life studies.*

9.3.3 Implications and Recommendations for Oncology Policy in Ireland

In terms of policy, this study was conducted against the backdrop of the National Cancer Strategy (2006). This Strategy placed focus upon reducing the rates of cancer illness and death and enhancing the effectiveness of care via cancer screening services, cancer centres of excellence, research and the education of oncology professionals (DoH Ireland 2006). Unfortunately, the 2006 Strategy failed to make provisions or recommendations to advance national policy surrounding the care and support of cancer survivors (DoH Ireland 2006, Warde *et al.* 2014). However, the most recent strategy published in July 2017 has recognised the need to allocate greater attention and resources to address the needs of the growing population of cancer survivors in Ireland (DoH Ireland 2017). A major objective of the 2017 Strategy is to achieve optimal care for cancer patients and survivors; that is, care that is timely, delivered by an expert clinical team in an appropriate location which is responsive to the individuals’ needs. The results of this study suggest that a substantial proportion of colorectal cancer survivors experience unmet information and supportive care needs which appear to contribute to shortcomings in quality of life outcomes. Furthermore, these results raise the possibility that care is not always patient-centred, as not all healthcare professionals are willing or able to recognise cancer survivors’ personal circumstances, experiences and expertise in their condition.

It is important that stakeholders in the provision of cancer follow-up care in Ireland, including DoH Ireland, the HSE and the National Cancer Control Programme, consider how the recommendations of the National Cancer Strategy (2017) relating to person-centred care may be achieved. A cornerstone of the Strategy is to maximise the quality of life of individuals diagnosed with cancer at all points of the cancer care continuum. For cancer survivors, treatment summaries and survivorship care plans are central recommendations of the Strategy to advance supportive care provision and support the enablement of cancer survivors to implement self-management strategies. The Strategy recommends the development of person-centred cancer survivorship programmes to address the physical, psychological and social consequences of cancer which affect cancer survivors’ health and well-being (DoH Ireland 2017). Although survivorship care plans and treatment summaries were not a standard of practice in Ireland at the time of this study, more than one-quarter of survey respondents reported receiving one or both documents, yet they did not appear to be related to quality of life outcomes. Survivorship care plans, treatment summaries and cancer survivorship programmes have long been accepted as worthwhile interventions due to their backing by IoM (2006), and recommendations for their implementation by the National Cancer Strategy (2017) presents an opportunity for innovations in Irish oncology practice. However, there is limited evidence to support their efficacy for the improvement of quality of life outcomes and self-management strategies in the manner proposed by the National Cancer Strategy. It is therefore essential that their development and implementation is underpinned by rigourous research. Furthermore, clinical and advocacy stakeholders must continue to explore alternative interventions which may contribute to improved quality of life outcomes and greater capacity for self-management among cancer survivors.

Recommendation:

- *Stakeholders in cancer survivorship care must consider how to achieve recommendations relating to person-centred care arising from the National Cancer Strategy (2017). Current evidence surrounding the benefits of cancer survivorship care plans and treatment summaries are mixed, and their development, implementation and evaluation must be underpinned by rigourous research.*

9.3.4 Implications and Recommendations for Oncology Healthcare Services in Ireland

While the recommendations for the introduction of cancer survivorship care plans, treatment summaries and cancer survivorship programmes are admirable goals, the National Cancer Strategy 2017 acknowledges that the implementation of its recommendations are challenged by capacity and resourcing issues in the oncology services (DoH Ireland 2017). The use of and levels of support from hospital, primary care and advocacy services for colorectal cancer survivors in this study suggest that tertiary models of oncology follow-up care may have fostered an over-reliance on specialist oncology services to address all aspects of survivors' information and supportive care needs. Although primary care practitioners and advocacy services were valuable sources of psychosocial support for some colorectal cancer survivors, current models of follow-up care seem to have contributed to oncology professionals operating within silos, independent of these potential resources. As already discussed, further research is necessary to ascertain the efficacy of cancer support services and primary care services to address the psychosocial needs and quality of life concerns of cancer survivors (Section 8.8.5). However, strategies to enhance collaboration and cohesiveness in the delivery of care across primary care, cancer advocacy and support services and tertiary oncology services may augment the development of integrated interventions which support cancer survivors in the person-centred and timely manner envisioned by the National Cancer Strategy (2017).

Recommendation:

- *Further research and innovations in care are required to support the development of timely, person-centred interventions to support cancer survivors following treatment and may be supported by collaborative approaches between healthcare and advocacy services.*

9.3.5 Implications and Recommendations for Healthcare Professionals' Oncology Practice in Ireland

This study has illustrated substantial physical, psychological and social effects among Irish colorectal cancer survivors and shortcomings in 1) the preparation of survivors for chronic effects, 2) clinical assessment of these effects, and 3) oncology professionals' awareness of and preparation to manage complex survivorship symptoms. These findings have implications for the education of cancer patients and survivors, communication between professionals and patients and the education and training of oncology professionals.

A lack of preparation for potential cancer survivorship issues have significant implications for ethical treatment-related decision-making and development of self-management skills. It is imperative that healthcare professionals and their organisations devise strategies to integrate information about the long-term effects of colorectal cancer treatment to ensure survivors are prepared to make informed decisions about their care and are supported to identify and implement symptom-related self-management strategies from the point of diagnosis. Survivors may be empowered to engage in decision-making and self-management strategies if they are supported to obtain and evaluate information about their disease and its implications independent of the healthcare system. The results of this study relating to symptom experience could be used to inform the design of information and education programmes which assist colorectal cancer survivors to understand the expected trajectories of recovery in a patient-centred manner, with due consideration of their personal circumstances.

For some survivors, the surveillance-orientated nature of follow-up care precluded assessment of chronic symptoms. Survivors suggested they were complicit in this approach due to their preoccupation with the results of investigations arising from their fear of recurrence. While the policies directing oncology-related healthcare in Ireland over the past two decades have placed priority on prevention, early detection and treatment of cancer (DoH Ireland 1996, 2006), awareness of the need for greater attention to the long-term needs of cancer survivors is emerging (DoH Ireland 2017). As we move forward with the implementation of the National Cancer Strategy 2017, professional and continuing education of oncology professionals must integrate information about cancer survivorship issues, equipping them with the knowledge and skills necessary to provide appropriate, person-centred information and care, considering the implications of cancer survivorship. In addition, it is imperative that strategies to open dialogues between cancer survivors and healthcare professionals about the chronic effects of treatment are identified, so that appropriate supportive care and symptom management interventions may be implemented.

Recommendations:

- *Interventions must be devised to support the delivery of information about the potential chronic effects of colorectal cancer during treatment. This could be supported by tools which help survivors to independently seek and interpret information.*
- *Healthcare professionals must be prepared to appropriately assess and manage the chronic issues associated with cancer survivorship, through continuing education and innovations in healthcare technology and practice.*

9.3.6 Implications and Recommendations for Cancer Support and Advocacy Services in Ireland

This study highlights the insufficiency of formal psychological support in the aftermath of treatment, 20 years after it was first prioritised in the first National Cancer Strategy (DoH Ireland 1996). This study has highlighted high levels of unmet information and supportive care needs and a desire for greater support for physical, psychological and social survivorship issues, yet few survivors sought support from cancer support organisations. Given the inadequate development of psycho-oncology services, the ICS and its affiliates continue to be primary players in the delivery of psychosocial care (DoH Ireland 2017). However, poor uptake of these services and their association with poorer quality of life outcomes in the current study have important implications for these services and their future development. Future research must investigate the factors that motivate cancer survivors to access cancer support services and ascertain what the impact of these services are upon survivors' quality of life outcomes, as it is not possible to deduce this from the results of the current study. As work begins on the development and implementation of cancer survivorship programmes recommended by the National Cancer Strategy (2017), exploratory research must consider the potential contribution of cancer advocacy and support services to proposed cancer survivorship programmes and potential points of integration with oncology healthcare services to maximise their impact upon cancer survivors' quality of life outcomes. In the meantime, the results of this study suggest that greater efforts are necessary to raise awareness of the types of support and services advocacy organisations provide and their availability to colorectal cancer survivors both during and after treatment.

Recommendations:

- *Further larger-scale research is required to understand the capacity of current cancer support services to address colorectal cancer survivors' unmet needs.*
- *Greater efforts are required to raise awareness of the availability of cancer support services for colorectal cancer survivors after treatment.*

9.4 Directions for Future Research

The current study has provided important information about the impact of healthcare experiences upon the quality of life outcomes of colorectal cancer survivors receiving follow-up care in tertiary oncology settings up to five years after diagnosis in Ireland. The mixed methods approach offers a contextual understanding of survivors' healthcare experiences and their potential influence upon quality of life. However, this study has identified potentially modifiable unmet information and supportive care needs within this sample. It is recommended that further research is undertaken to identify and ascertain the feasibility of education and supportive care interventions to address these unmet needs within the Irish healthcare system.

It is necessary to ascertain whether the findings of this study are transferable to other international contexts and models of healthcare provision, including universal and private healthcare systems. This study suggested that healthcare experiences during diagnosis and treatment may have continued to impact survivors' quality of life outcomes following treatment. Future studies may consider longitudinal evaluation of the relationship between healthcare experience and quality of life among cancer survivors from the time of diagnosis. It would also be of use ascertain whether other constructs of healthcare experience may affect survivors' quality of life, including quality of care and symptom-specific supportive care needs.

Adaptations to *The Contextual Model of Health-Related Quality of Life* for this study were proposed to reflect the potential influence of the healthcare context upon quality of life outcomes of colorectal cancer survivors during follow-up care in Irish tertiary oncology settings. Future research could explore whether the proposed model (Figure 8.2) explains the potential influence of the *Healthcare Context* upon the quality of life of other groups of cancer survivors in Ireland.

Furthermore, given the exclusion of *Health Efficacy* and aspects of *Cultural Context* in the adapted *Contextual Model of Health-Related Quality of Life* used to inform this study, future research may consider incorporating these aspects of the model to gain a more comprehensive understanding of cancer survivors' quality of life outcomes in Ireland.

Recommendations:	- *Further research is necessary to identify and ascertain the feasibility of interventions to address colorectal cancer survivors' unmet needs in the Irish healthcare system.* - *Longitudinal research is required to ascertain the potential long-term influence of acute healthcare experiences during diagnosis and treatment upon cancer survivors' quality of life.* - *To obtain a more comprehensive understanding of how the Irish healthcare context may influence cancer survivors' quality of life, it is recommended that this study is replicated with other groups of cancer survivors, considering the full complement of the Ashing-Giwa (2005) Model.*

9.5 Reflection Upon the Research Process

This section describes my critical reflection throughout the research process within this study, which has been informed principally by Taylor (2006) and heavily influenced by Lipp (2007). Engaging in cancer survivorship research as an oncology nurse raises important considerations about myself and my role within this research. This study was inspired and shaped by my professional experience, my awareness of the complex challenges experienced by colorectal cancer survivors and my concern for the inadequate preparation for, and management of these issues in clinical practice. My experience, attitudes and values about health, illness and patient care have undoubtedly impacted the way I designed and conducted the study. However, Etherington (2004) and others suggest that no research endeavour is truly value-free, and recommend that a reflexive approach where the researcher remains cognisant of their identity, experience and personal connection to the research topic can enrich research inquiry. I believe that the adoption of a pragmatic, reflexive approach placed priority on uncovering colorectal cancer survivors' objective and subjective truths, fostering a greater depth of understanding of the healthcare experiences which may influence colorectal cancer survivors' quality of life.

I entered this PhD programme with a quantitative background, accepting the post-positivist philosophy which placed importance upon objectivity and neutrality in research. However, as my understanding of the concept and literature evolved, I began to see that objective, quantitative measurement was not the only way of knowing. It became clear that a pragmatic, mixed methods design was a legitimate approach to gather information about the relationship between healthcare experiences and quality of life outcomes in tertiary oncology follow-up care settings. Conducting a mixed methods research study has been a rewarding and enriching experience for me. It has been an intensive process which required me to maintain a balance between doing the research, being the researcher and avoiding shifting into the role of nurse (Section 5.5.4). Upon reflection, as I strove to ‘be’ a researcher (rather than a nurse), I underestimated the potential value of the experience, knowledge and interpersonal skills I cultivated during my clinical career. Although my professional background may be considered a potential source of bias, I believe it has prepared me to be a well-rounded researcher, empathetic to the experiences of colorectal cancer survivors, yet aware of the need to critically reflect upon the impact of my knowledge and experience on the research study, the potential power imbalance in the researcher-participant relationship, and finding balance between the researcher-participant relationship and the nurse-patient relationship in the course of conducting research.

As an outside researcher in the hospitals where data were collected, I believe my nursing background and familiarity with the organisation and governance structures of hospitals in the public health sector assisted me in designing the recruitment processes and gaining access and ethical approval for the study. However, I was unprepared for the different organisation and governance structures relating to research in the private healthcare sector, encountering significant challenges and delays in obtaining ethical and organisational approval to conduct the study and my exclusion from the recruitment process. Although the arm of the study conducted within the private health sector was not as successful as hoped, its limited success is testament to the importance of the early identification of insiders within the organisation who support the project and are willing to champion and gatekeep research endeavours. I believe I am better prepared to address the barriers that may arise as an outside researcher in private organisations and will endeavour to implement strategies to enhance buy-in from clinical stakeholders in future research by including them in the research planning process from the outset and where possible, empowering them to become clinical co-investigators.

9.6 Original Contribution to Knowledge in the Field of Colorectal Cancer Survivorship

This research makes several original contributions to the literature relating to colorectal cancer survivorship and the impact of health experiences on survivors’ quality of life. First, a concept analysis has proposed a definition of the key attributes and consequences of colorectal cancer survivorship and provided a conceptual basis for the conduct of this research. Second, the study has provided evidence to support the use of the Ashing-Giwa (2005) *Contextual Model of Health-Related Quality of Life* as a theoretical framework to underpin research examining quality of life outcomes in a gender-diverse and ethnically homogeneous sample. Finally, this study has provided new evidence about the impact of healthcare experiences upon the quality of life of colorectal cancer survivors receiving follow-up care in tertiary oncology settings, particularly in an Irish context. For the first time in Ireland, the healthcare experiences and quality of life outcomes of colorectal cancer survivors receiving care in mixed economy healthcare systems were explored. The results have informed an adaptation of the Ashing-Giwa (2005) *Contextual Model of Health-Related Quality of Life*, to explain the pathways by which various healthcare-related factors may influence quality of life outcomes (Figure 8.2).

9.7 Conclusion

This study has explored the quality of life outcomes of colorectal cancer survivors and sought to understand how survivors' experiences of follow-up care may influence their quality of life outcomes in the course of follow-up care within tertiary oncology settings up to five years after diagnosis. This study used a mixed methods sequential explanatory design, underpinned by a pragmatic approach. In the first, quantitative phase a survey was administered to a purposive sample of 304 colorectal cancer survivors which explored survivors' quality of life, symptom experience, healthcare experience and unmet needs in the aftermath of treatment. In the second, qualitative phase, an in-depth exploration of the individual experiences and complexities of quality of life outcomes and survivors' perceptions of the potential impact of healthcare experiences upon their quality of life was conducted via semi-structured interviews with a subsample of 22 survey participants identified via a maximum variation sampling strategy.

The findings of this study suggest that the healthcare experiences of colorectal cancer survivors impact their quality of life outcomes in the course of follow-up care in tertiary oncology settings in Ireland. It was apparent that a variety of individual, organisational and political activities and failures in the healthcare system influenced colorectal cancer survivors' quality of life and contributed to unmet needs within this group. In response to these unmet needs, survivors developed a network of support beyond the healthcare system encompassing family members, social networks, local advocacy services and virtual communities. However, engagement with these networks was dependent upon the cultural context in which the individual resided and received healthcare and barriers to accessing support such as availability.

Considered collectively, the findings of this study provide a strong evidence base supporting the notion that cancer survivorship care should not be concerned with surveillance activities alone. Healthcare professionals must take an active role in the implementation of strategies to maximise cancer survivors' quality of life through partnership with the network of formal and informal supports which survivors build. It is hoped the results of this research and the subsequent recommendations will improve understanding of the information and supportive care needs of colorectal cancer survivors among healthcare professionals, advocates and the general public. Such awareness must be used to motivate implementation of the study recommendations to advance strategies to optimise the care and quality of life outcomes of colorectal cancer survivors and address the cultures which appear to hinder survivors' physical and psychosocial recovery.

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Appendices

Appendix 2.1 Concept Analysis Search Strategy Results

Database	Search No.	Search Terms	Search Options	Results	Search Date
PUBMED	5	((((("Colorectal Neoplasms"[Mesh] OR "Colonic Neoplasms"[Mesh] OR "Rectal Neoplasms"[Mesh]))) OR ((((neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors[Title/Abstract]))) AND ((colonic OR colon OR rectal OR rectum OR colorectal OR anal OR anus[Title/Abstract]))))) AND (("Survivors"[Mesh]) AND ((Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer[Title/Abstract])))	Filter: Humans Adult: 19+ years	364	18/11/2013
CINAHL	3	(TI (colonic OR colon OR rectal OR rectum OR colorectal OR anal or anus) OR AB (colonic OR colon OR rectal OR rectum OR colorectal OR anal or anus)) AND (TI (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors) OR AB (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors)) AND (TI (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer) OR AB (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))	Search modes – Boolean / Phrase	72	18/11/2013
PsycINFO	3	(TI (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors) OR AB (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors)) AND (TI (colonic OR colon OR rectal OR rectum OR colorectal OR anal OR anus) OR AB (colonic OR colon OR rectal OR rectum OR colorectal OR anal OR anus)) AND (TI (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer) OR AB (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))	Search modes – Boolean / Phrase	167	18/11/2013
The Cochrane Library	5	(((colonic OR colon OR rectal OR rectum OR colorectal OR anal or anus: ti,ab) AND (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors: ti,ab)) AND (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))		54	18/11/2013

Table A2.1 Initial colorectal cancer survivorship database search strategies (November 2013)

Database	Search Terms	Search Options	Results	Search Date
PUBMED	((((("Colorectal Neoplasms"[Mesh] OR "Colonic Neoplasms"[Mesh] OR "Rectal Neoplasms"[Mesh]))) OR ((((neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors[Title/Abstract]))) AND ((colonic OR colon OR rectal OR rectum OR colorectal OR anal OR anus[Title/Abstract]))))) AND (("Survivors"[Mesh]) AND ((Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer[Title/Abstract])))	Filter: Humans Adult: 19+ years	576	24/11/2016
CINAHL	(TI (colonic OR colon OR rectal OR rectum OR colorectal OR anal or anus) OR AB (colonic OR colon OR rectal OR rectum OR colorectal OR anal or anus)) AND (TI (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors) OR AB (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors)) AND (TI (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer) OR AB (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))	Search modes: Boolean/Phrase	309	24/11/2016
PsycINFO	(TI (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors) OR AB (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors)) AND (TI (colonic OR colon OR rectal OR rectum OR colorectal OR anal OR anus) OR AB (colonic OR colon OR rectal OR rectum OR colorectal OR anal OR anus)) AND (TI (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer) OR AB (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))	Search modes: Boolean/Phrase	288	24/11/2016
The Cochrane Library	(((colonic OR colon OR rectal OR rectum OR colorectal OR anal or anus: ti,ab) AND (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors: ti,ab)) AND (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))		98	24/11/2016

Table A2.2 Updated colorectal cancer survivorship database search strategies (November 2016)

Appendix 3.1: Literature Review Search Strategy Results

Database	Search No.	Search Terms	Search Options	Results	Search Date
PUBMED	25	(((((((((“colon neoplasm” OR “colon neoplasms” OR “colon tumor” OR “colon tumors” OR “colon tumour” OR “colon tumours” OR “colon carcinoma” OR “colon carcinomas” OR “colon cancer” OR “colon cancers” OR “cancer of the colon” OR “cancer of colon”))) OR ((“colonic neoplasm” OR “colonic neoplasms” OR “colonic tumor” OR “colonic tumors” OR “colonic tumour” OR “colonic tumours” OR “colonic carcinoma” OR “colonic carcinomas” OR “colonic cancer” OR “colonic cancers”))) OR ((“rectum neoplasm” OR “rectum neoplasms” OR “rectum tumor” OR “rectum tumors” OR “rectum tumour” OR “rectum tumours” OR “rectum carcinoma” OR “rectum carcinomas” OR “rectum cancer” OR “rectum cancers” OR “cancer of the rectum” OR “cancer of rectum”))) OR ((“rectal neoplasm” OR “rectal neoplasms” OR “rectal tumor” OR “rectal tumors” OR “rectal tumour” OR “rectal tumours” OR “rectal carcinoma” OR “rectal carcinomas” OR “rectal cancer” OR “rectal cancers”))) OR ((“colorectal neoplasm” OR “colorectal neoplasms” OR “colorectal tumor” OR “colorectal tumors” OR “colorectal tumour” OR “colorectal tumours” OR “colorectal carcinoma” OR “colorectal carcinomas” OR “colorectal cancer” OR “colorectal cancers”))) OR ((“colo rectal neoplasm” OR “colo rectal neoplasms” OR “colo rectal tumor” OR “colo rectal tumors” OR “colo rectal tumours” OR “colo rectal carcinoma” OR “colo rectal carcinomas” OR “colo rectal cancer” OR “colo rectal cancers”))) OR ((“colo-rectal neoplasm” OR “colo-rectal neoplasms” OR “colo-rectal tumor” OR “colo-rectal tumors” OR “colo-rectal tumours” OR “colo-rectal carcinoma” OR “colo-rectal carcinomas” OR “colo-rectal cancer” OR “colo-rectal cancers”)))) AND ((("Survivors"[Mesh]) OR (((“survivor”[Title/Abstract]) OR “survivors”[Title/Abstract]) OR “survivorship”[Title/Abstract])) OR (((“cancer survivor”[Title/Abstract]) OR “cancer survivors”[Title/Abstract]) OR “cancer survivorship”[Title/Abstract]))	None	1162	10/10/14
EMBASE	24	((('colorectal neoplasms'/exp OR 'colorectal neoplasms') OR ('colonic neoplasms'/exp OR 'colonic neoplasms') OR ('rectal neoplasms'/exp)) OR ((‘colon neoplasm’ OR ‘colon neoplasms’ OR ‘colon tumor’ OR ‘colon tumors’ OR ‘colon tumour’ OR ‘colon tumours’ OR ‘colon carcinoma’ OR ‘colon carcinomas’ OR ‘colon cancer’ OR ‘colon cancers’ OR ‘cancer of the colon’ OR ‘cancer of colon’) OR (‘colonic neoplasm’ OR ‘colonic neoplasms’ OR ‘colonic tumor’ OR ‘colonic tumors’ OR ‘colonic tumour’ OR ‘colonic tumours’ OR ‘colonic carcinoma’ OR ‘colonic carcinomas’ OR ‘colonic cancer’ OR ‘colonic cancers’) OR (‘rectum neoplasm’ OR ‘rectum neoplasms’ OR ‘rectum tumor’ OR ‘rectum tumors’ OR ‘rectum tumour’ OR ‘rectum tumours’ OR ‘rectum carcinoma’ OR ‘rectum carcinomas’ OR ‘rectum cancer’ OR ‘rectum cancers’ OR ‘cancer of the rectum’ OR ‘cancer of rectum’) OR (‘rectal neoplasm’ OR ‘rectal neoplasms’ OR ‘rectal tumor’ OR ‘rectal tumors’ OR ‘rectal tumour’ OR ‘rectal tumours’ OR ‘rectal carcinoma’ OR ‘rectal carcinomas’ OR ‘rectal cancer’ OR ‘rectal cancers’) OR (‘colorectal neoplasm’ OR ‘colorectal neoplasms’ OR ‘colorectal tumor’ OR ‘colorectal tumors’ OR ‘colorectal tumour’ OR ‘colorectal tumours’ OR ‘colorectal carcinoma’ OR ‘colorectal carcinomas’ OR ‘colorectal cancer’ OR ‘colorectal cancers’) OR (‘colorectum neoplasm’ OR ‘colorectum neoplasms’ OR ‘colorectum tumor’ OR ‘colorectum tumors’ OR ‘colorectum tumour’ OR ‘colorectum tumours’ OR ‘colorectum carcinoma’ OR ‘colorectum carcinomas’ OR ‘colorectum cancer’ OR ‘colorectum cancers’ OR ‘cancer of the colorectum’ OR ‘cancer of colorectum’) OR (‘colo rectal neoplasm’ OR ‘colo rectal neoplasms’ OR ‘colo rectal tumor’ OR ‘colo rectal tumors’ OR ‘colo rectal tumour’ OR ‘colo rectal tumours’ OR ‘colo rectal carcinoma’ OR ‘colo rectal carcinomas’ OR ‘colo rectal cancer’ OR ‘colo rectal cancers’) OR (‘colo rectum neoplasm’ OR ‘colo rectum neoplasms’ OR ‘colo rectum tumor’ OR ‘colo rectum tumors’ OR ‘colo rectum tumour’ OR ‘colo rectum tumours’ OR ‘colo rectum carcinoma’ OR ‘colo rectum carcinomas’ OR ‘colo rectum cancer’ OR ‘colo rectum cancers’ OR ‘cancer of the colo rectum’ OR ‘cancer of colo rectum’) OR (‘colo-rectal neoplasm’ OR ‘colo-rectal neoplasms’ OR ‘colo-rectal tumor’ OR ‘colo-rectal tumors’ OR ‘colo-rectal tumour’ OR ‘colo-rectal tumours’ OR ‘colo-rectal carcinoma’ OR ‘colo-rectal carcinomas’ OR ‘colo-rectal cancer’ OR ‘colo-rectal cancers’) OR (‘colo-rectum neoplasm’ OR ‘colo-rectum neoplasms’ OR ‘colo-rectum tumor’ OR ‘colo-rectum tumors’ OR ‘colo-rectum tumour’ OR ‘colo-rectum tumours’ OR ‘colo-rectum carcinoma’ OR ‘colo-rectum carcinomas’ OR ‘colo-rectum cancer’ OR ‘colo-rectum cancers’ OR ‘cancer of the colo-rectum’ OR ‘cancer of colo-rectum’))) AND ((('survivor'/exp) OR ('survivors'/exp)) OR ((‘survivor’:ti,ab OR ‘survivors’:ti,ab OR ‘survivorship’:ti,ab) OR ('cancer survivor':ab,ti OR 'cancer survivors':ab,ti OR 'cancer survivorship':ab,ti)))	None	1870	10/10/14
SCOPUS	27	(((TITLE-ABS("colon neoplasm") OR TITLE-ABS("colon neoplasms") OR TITLE-ABS("colon tumor") OR TITLE-ABS("colon tumors") OR TITLE-ABS("colon tumour") OR TITLE-ABS("colon tumours") OR TITLE-ABS("colon carcinoma") OR TITLE-ABS("colon carcinomas") OR TITLE-ABS("colon cancer") OR TITLE-ABS("colon cancers") OR TITLE-ABS("cancer of the colon") OR TITLE-ABS("cancer of colon")) OR (TITLE-ABS("colonic neoplasm") OR TITLE-ABS("colonic neoplasms") OR TITLE-ABS("colonic tumor") OR TITLE-ABS("colonic tumors") OR TITLE-ABS("colonic tumour") OR TITLE-ABS("colonic tumours") OR TITLE-ABS("colonic carcinoma") OR TITLE-ABS("colonic carcinomas") OR TITLE-ABS("colonic cancer") OR TITLE-ABS("colonic cancers")) OR (TITLE-ABS("rectum neoplasm") OR TITLE-ABS("rectum neoplasms") OR TITLE-ABS("rectum tumor") OR TITLE-ABS("rectum tumors") OR TITLE-ABS("rectum tumour") OR TITLE-ABS("rectum tumours") OR TITLE-ABS("rectum carcinoma") OR TITLE-ABS("rectum carcinomas") OR TITLE-ABS("rectum cancer") OR TITLE-ABS("rectum cancers") OR TITLE-ABS("cancer of the rectum") OR TITLE-ABS("cancer of rectum")) OR (TITLE-ABS("rectal neoplasm") OR TITLE-ABS("rectal neoplasms") OR TITLE-ABS("rectal tumor") OR TITLE-ABS("rectal tumors") OR TITLE-ABS("rectal tumour") OR TITLE-ABS("rectal tumours") OR TITLE-ABS("rectal carcinoma") OR TITLE-ABS("rectal carcinomas") OR TITLE-ABS("rectal cancer") OR TITLE-ABS("rectal cancers")) OR (TITLE-ABS("colorectal neoplasm") OR TITLE-ABS("colorectal neoplasms") OR TITLE-ABS("colorectal tumor") OR TITLE-ABS("colorectal tumors") OR TITLE-ABS("colorectal tumour") OR TITLE-ABS("colorectal tumours") OR TITLE-ABS("colorectal carcinoma") OR TITLE-ABS("colorectal carcinomas") OR TITLE-ABS("colorectal cancer") OR TITLE-ABS("colorectal cancers"))) OR ((TITLE-ABS("colorectum neoplasm") OR TITLE-ABS("colorectum neoplasms") OR TITLE-ABS("colorectum tumor") OR TITLE-ABS("colorectum tumors") OR TITLE-ABS("colorectum tumour") OR TITLE-ABS("colorectum tumours") OR TITLE-ABS("colorectum carcinoma") OR TITLE-ABS("colorectum carcinomas") OR TITLE-ABS("colorectum cancer") OR TITLE-ABS("colorectum cancers") OR TITLE-ABS("cancer of the colorectum") OR TITLE-ABS("cancer of colorectum")) OR (TITLE-ABS("colo rectal neoplasm") OR TITLE-ABS("colo rectal neoplasms") OR TITLE-ABS("colo rectal tumor") OR TITLE-ABS("colo rectal tumors") OR TITLE-ABS("colo rectal tumour") OR TITLE-ABS("colo rectal tumours") OR TITLE-ABS("colo rectal carcinoma") OR TITLE-ABS("colo rectal carcinomas") OR TITLE-ABS("colo rectal cancer") OR TITLE-ABS("colo rectal cancers")) OR (TITLE-ABS("colo rectum neoplasm") OR TITLE-ABS("colo rectum neoplasms") OR TITLE-ABS("colo rectum tumor") OR TITLE-ABS("colo rectum tumors") OR TITLE-ABS("colo rectum tumour") OR TITLE-ABS("colo rectum tumours") OR TITLE-ABS("colo rectum carcinoma") OR TITLE-ABS("colo rectum carcinomas") OR TITLE-ABS("colo rectum cancer") OR TITLE-ABS("colo rectum cancers") OR TITLE-ABS("cancer of the colo rectum") OR TITLE-ABS("cancer of colo	None	968	10/10/14

Database	Search No.	Search Terms	Search Options	Results	Search Date
		rectum")) OR (TITLE-ABS("colo-rectal neoplasm") OR TITLE-ABS("colo-rectal neoplasms") OR TITLE-ABS("colo-rectal tumor") OR TITLE-ABS("colo-rectal tumors") OR TITLE-ABS("colo-rectal tumour") OR TITLE-ABS("colo-rectal tumours") OR TITLE-ABS("colo-rectal carcinoma") OR TITLE-ABS("colo-rectal carcinomas") OR TITLE-ABS("colo-rectal cancer") OR TITLE-ABS("colo-rectal cancers")) OR (TITLE-ABS("colo-rectum neoplasm") OR TITLE-ABS("colo-rectum neoplasms") OR TITLE-ABS("colo-rectum tumor") OR TITLE-ABS("colo-rectum tumors") OR TITLE-ABS("colo-rectum tumour") OR TITLE-ABS("colo-rectum tumours") OR TITLE-ABS("colo-rectum carcinoma") OR TITLE-ABS("colo-rectum carcinomas") OR TITLE-ABS("colo-rectum cancer") OR TITLE-ABS("colo-rectum cancers") OR TITLE-ABS("cancer of the colo-rectum") OR TITLE-ABS("cancer of colo-rectum")))) AND ((((TITLE-ABS("colon neoplasm") OR TITLE-ABS("colon neoplasms") OR TITLE-ABS("colon tumor") OR TITLE-ABS("colon tumors") OR TITLE-ABS("colon tumour") OR TITLE-ABS("colon tumours") OR TITLE-ABS("colon carcinoma") OR TITLE-ABS("colon carcinomas") OR TITLE-ABS("colon cancer") OR TITLE-ABS("colon cancers") OR TITLE-ABS("cancer of the colon") OR TITLE-ABS("cancer of colon")) OR (TITLE-ABS("colonic neoplasm") OR TITLE-ABS("colonic neoplasms") OR TITLE-ABS("colonic tumor") OR TITLE-ABS("colonic tumors") OR TITLE-ABS("colonic tumour") OR TITLE-ABS("colonic tumours") OR TITLE-ABS("colonic carcinoma") OR TITLE-ABS("colonic carcinomas") OR TITLE-ABS("colonic cancer") OR TITLE-ABS("colonic cancers")) OR (TITLE-ABS("rectum neoplasm") OR TITLE-ABS("rectum neoplasms") OR TITLE-ABS("rectum tumor") OR TITLE-ABS("rectum tumors") OR TITLE-ABS("rectum tumour") OR TITLE-ABS("rectum tumours") OR TITLE-ABS("rectum carcinoma") OR TITLE-ABS("rectum carcinomas") OR TITLE-ABS("rectum cancer") OR TITLE-ABS("rectum cancers") OR TITLE-ABS("cancer of the rectum") OR TITLE-ABS("cancer of rectum")) OR (TITLE-ABS("rectal neoplasm") OR TITLE-ABS("rectal neoplasms") OR TITLE-ABS("rectal tumor") OR TITLE-ABS("rectal tumors") OR TITLE-ABS("rectal tumour") OR TITLE-ABS("rectal tumours") OR TITLE-ABS("rectal carcinoma") OR TITLE-ABS("rectal carcinomas") OR TITLE-ABS("rectal cancer") OR TITLE-ABS("rectal cancers")) OR (TITLE-ABS("colorectal neoplasm") OR TITLE-ABS("colorectal neoplasms") OR TITLE-ABS("colorectal tumor") OR TITLE-ABS("colorectal tumors") OR TITLE-ABS("colorectal tumour") OR TITLE-ABS("colorectal tumours") OR TITLE-ABS("colorectal carcinoma") OR TITLE-ABS("colorectal carcinomas") OR TITLE-ABS("colorectal cancer") OR TITLE-ABS("colorectal cancers"))) OR ((TITLE-ABS("colorectum neoplasm") OR TITLE-ABS("colorectum neoplasms") OR TITLE-ABS("colorectum tumor") OR TITLE-ABS("colorectum tumors") OR TITLE-ABS("colorectum tumour") OR TITLE-ABS("colorectum tumours") OR TITLE-ABS("colorectum carcinoma") OR TITLE-ABS("colorectum carcinomas") OR TITLE-ABS("colorectum cancer") OR TITLE-ABS("colorectum cancers") OR TITLE-ABS("cancer of the colorectum") OR TITLE-ABS("cancer of colorectum")) OR (TITLE-ABS("colo rectal neoplasm") OR TITLE-ABS("colo rectal neoplasms") OR TITLE-ABS("colo rectal tumor") OR TITLE-ABS("colo rectal tumors") OR TITLE-ABS("colo rectal tumour") OR TITLE-ABS("colo rectal tumours") OR TITLE-ABS("colo rectal carcinoma") OR TITLE-ABS("colo rectal carcinomas") OR TITLE-ABS("colo rectal cancer") OR TITLE-ABS("colo rectal cancers")) OR (TITLE-ABS("colo rectum neoplasm") OR TITLE-ABS("colo rectum neoplasms") OR TITLE-ABS("colo rectum tumor") OR TITLE-ABS("colo rectum tumors") OR TITLE-ABS("colo rectum tumour") OR TITLE-ABS("colo rectum tumours") OR TITLE-ABS("colo rectum carcinoma") OR TITLE-ABS("colo rectum carcinomas") OR TITLE-ABS("colo rectum cancer") OR TITLE-ABS("colo rectum cancers") OR TITLE-ABS("cancer of the colo rectum") OR TITLE-ABS("cancer of colo rectum")) OR (TITLE-ABS("colo-rectal neoplasm") OR TITLE-ABS("colo-rectal neoplasms") OR TITLE-ABS("colo-rectal tumor") OR TITLE-ABS("colo-rectal tumors") OR TITLE-ABS("colo-rectal tumour") OR TITLE-ABS("colo-rectal tumours") OR TITLE-ABS("colo-rectal carcinoma") OR TITLE-ABS("colo-rectal carcinomas") OR TITLE-ABS("colo-rectal cancer") OR TITLE-ABS("colo-rectal cancers")) OR (TITLE-ABS("colo-rectum neoplasm") OR TITLE-ABS("colo-rectum neoplasms") OR TITLE-ABS("colo-rectum tumor") OR TITLE-ABS("colo-rectum tumors") OR TITLE-ABS("colo-rectum tumour") OR TITLE-ABS("colo-rectum tumours") OR TITLE-ABS("colo-rectum carcinoma") OR TITLE-ABS("colo-rectum carcinomas") OR TITLE-ABS("colo-rectum cancer") OR TITLE-ABS("colo-rectum cancers") OR TITLE-ABS("cancer of the colo-rectum") OR TITLE-ABS("cancer of colo-rectum")))) AND (TITLE-ABS("survivor") OR TITLE-ABS("survivors") OR TITLE-ABS("survivorship")) OR (TITLE-ABS("cancer survivor") OR TITLE-ABS("cancer survivors") OR TITLE-ABS("cancer survivorship")))			
CINAHL	31	((MH "Colorectal Neoplasms") OR (MH "Colorectal Neoplasms, Hereditary Nonpolyposis") OR (MH "Colonic Neoplasms") OR (MH "Rectal Neoplasms")) OR ((TX “colon neoplasm” OR TX “colon neoplasms” OR TX “colon tumor” OR TX “colon tumors” OR TX “colon tumour” OR TX “colon tumours” OR TX “colon carcinoma” OR TX “colon carcinomas” OR TX “colon cancer” OR TX “colon cancers” OR TX “cancer of the colon” OR TX “cancer of colon”) OR (TX “colonic neoplasm” OR TX “colonic neoplasms” OR TX “colonic tumor” OR TX “colonic tumors” OR TX “colonic tumour” OR TX “colonic tumours” OR TX “colonic carcinoma” OR TX “colonic carcinomas” OR TX “colonic cancer” OR TX “colonic cancers”) OR (TX “rectum neoplasm” OR TX “rectum neoplasms” OR TX “rectum tumor” OR TX “rectum tumors” OR TX “rectum tumour” OR TX “rectum tumours” OR TX “rectum carcinoma” OR TX “rectum carcinomas” OR TX “rectum cancer” OR TX “rectum cancers” OR TX “cancer of the rectum” OR TX “cancer of rectum”) OR (TX “rectal neoplasm” OR TX “rectal neoplasms” OR TX “rectal tumor” OR TX “rectal tumors” OR TX “rectal tumour” OR TX “rectal tumours” OR TX “rectal carcinoma” OR TX “rectal carcinomas” OR TX “rectal cancer” OR TX “rectal cancers”) OR (TX “colorectal neoplasm” OR TX “colorectal neoplasms” OR TX “colorectal tumor” OR TX “colorectal tumors” OR TX “colorectal tumour” OR TX “colorectal tumours” OR TX “colorectal carcinoma” OR TX “colorectal carcinomas” OR TX “colorectal cancer” OR TX “colorectal cancers”) OR (TX “colorectum neoplasm” OR TX “colorectum neoplasms” OR TX “colorectum tumor” OR TX “colorectum tumors” OR TX “colorectum tumour” OR TX “colorectum tumours” OR TX “colorectum carcinoma” OR TX “colorectum carcinomas” OR TX “colorectum cancer” OR TX “colorectum cancers” OR TX “cancer of the colorectum” OR TX “cancer of colorectum”) OR (TX “colo rectal neoplasm” OR TX “colo rectal neoplasms” OR TX “colo rectal tumor” OR TX “colo rectal tumors” OR TX “colo rectal tumour” OR TX “colo rectal tumours” OR TX “colo rectal carcinoma” OR TX “colo rectal carcinomas” OR TX “colo rectal cancer” OR TX “colo rectal cancers”) OR (TX “colo rectum neoplasm” OR TX “colo rectum neoplasms” OR TX “colo rectum tumor” OR TX “colo rectum tumors” OR TX “colo rectum tumour” OR TX “colo rectum tumours” OR TX “colo rectum carcinoma” OR TX “colo rectum carcinomas” OR TX “colo rectum cancer” OR TX “colo rectum cancers” OR TX “cancer of the colo rectum” OR TX “cancer of colo rectum”) OR (TX “colo-rectal neoplasm” OR TX “colo-rectal neoplasms” OR TX “colo-rectal tumor” OR TX “colo-rectal tumors” OR TX “colo-rectal tumour” OR TX “colo-rectal tumours” OR TX “colo-rectal carcinoma” OR TX “colo-rectal carcinomas” OR TX “colo-rectal cancer” OR TX “colo-rectal cancers”) OR (TX “colo-rectum neoplasm” OR TX “colo-rectum neoplasms” OR TX “colo-rectum tumor” OR TX “colo-rectum tumors” OR TX “colo-rectum tumour” OR TX “colo-rectum tumours” OR TX “colo-rectum carcinoma” OR TX “colo-rectum carcinomas” OR TX “colo-rectum cancer” OR TX “colo-rectum cancers” OR TX “cancer of the colo-rectum” OR TX “cancer of colo-rectum”)) AND ((((MH "Survivors") OR (MH "Cancer Survivors") OR (MH "Survival")) OR ((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”))) OR (TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”))	Search modes Boolean / Phrase	1033	10/10/2014

Database	Search No.	Search Terms	Search Options	Results	Search Date
CINAHL COMPLETE	63	((((MH "Colorectal Neoplasms") OR (MH "Colorectal Neoplasms, Hereditary Nonpolyposis") OR (MH "Colonic Neoplasms") OR (MH "Rectal Neoplasms")) OR (((TI “colon neoplasm” OR TI “colon neoplasms” OR TI “colon tumor” OR TI “colon tumors” OR TI “colon tumour” OR TI “colon tumours” OR TI “colon carcinoma” OR TI “colon carcinomas” OR TI “colon cancer” OR TI “colon cancers” OR TI “cancer of the colon” OR TI “cancer of colon”) OR (TI “colonic neoplasm” OR TI “colonic neoplasms” OR TI “colonic tumor” OR TI “colonic tumors” OR TI “colonic tumour” OR TI “colonic tumours” OR TI “colonic carcinoma” OR TI “colonic carcinomas” OR TI “colonic cancer” OR TI “colonic cancers”) OR (TI “rectum neoplasm” OR TI “rectum neoplasms” OR TI “rectum tumor” OR TI “rectum tumors” OR TI “rectum tumour” OR TI “rectum tumours” OR TI “rectum carcinoma” OR TI “rectum carcinomas” OR TI “rectum cancer” OR TI “rectum cancers” OR TI “cancer of the rectum” OR TI “cancer of rectum”) OR (TI “rectal neoplasm” OR TI “rectal neoplasms” OR TI “rectal tumor” OR TI “rectal tumors” OR TI “rectal tumour” OR TI “rectal tumours” OR TI “rectal carcinoma” OR TI “rectal carcinomas” OR TI “rectal cancer” OR TI “rectal cancers”) OR (TI “colorectal neoplasm” OR TI “colorectal neoplasms” OR TI “colorectal tumor” OR TI “colorectal tumors” OR TI “colorectal tumour” OR TI “colorectal tumours” OR TI “colorectal carcinoma” OR TI “colorectal carcinomas” OR TI “colorectal cancer” OR TI “colorectal cancers”) OR (TI “colorectum neoplasm” OR TI “colorectum neoplasms” OR TI “colorectum tumor” OR TI “colorectum tumors” OR TI “colorectum tumour” OR TI “colorectum tumours” OR TI “colorectum carcinoma” OR TI “colorectum carcinomas” OR TI “colorectum cancer” OR TI “colorectum cancers” OR TI “cancer of the colorectum” OR TI “cancer of colorectum”) OR (TI “colo rectal neoplasm” OR TI “colo rectal neoplasms” OR TI “colo rectal tumor” OR TI “colo rectal tumors” OR TI “colo rectal tumour” OR TI “colo rectal tumours” OR TI “colo rectal carcinoma” OR TI “colo rectal carcinomas” OR TI “colo rectal cancer” OR TI “colo rectal cancers”) OR (TI “colo rectum neoplasm” OR TI “colo rectum neoplasms” OR TI “colo rectum tumor” OR TI “colo rectum tumors” OR TI “colo rectum tumour” OR TI “colo rectum tumours” OR TI “colo rectum carcinoma” OR TI “colo rectum carcinomas” OR TI “colo rectum cancer” OR TI “colo rectum cancers” OR TI “cancer of the colo rectum” OR TI “cancer of colo rectum”) OR (TI “colo-rectal neoplasm” OR TI “colo-rectal neoplasms” OR TI “colo-rectal tumor” OR TI “colo-rectal tumors” OR TI “colo-rectal tumour” OR TI “colo-rectal tumours” OR TI “colo-rectal carcinoma” OR TI “colo-rectal carcinomas” OR TI “colo-rectal cancer” OR TI “colo-rectal cancers”) OR (TI “colo-rectum neoplasm” OR TI “colo-rectum neoplasms” OR TI “colo-rectum tumor” OR TI “colo-rectum tumors” OR TI “colo-rectum tumour” OR TI “colo-rectum tumours” OR TI “colo-rectum carcinoma” OR TI “colo-rectum carcinomas” OR TI “colo-rectum cancer” OR TI “colo-rectum cancers” OR TI “cancer of the colo-rectum” OR TI “cancer of colo-rectum”))) OR ((AB “colon neoplasm” OR AB “colon neoplasms” OR AB “colon tumor” OR AB “colon tumors” OR AB “colon tumour” OR AB “colon tumours” OR AB “colon carcinoma” OR AB “colon carcinomas” OR AB “colon cancer” OR AB “colon cancers” OR AB “cancer of the colon” OR AB “cancer of colon”) OR (AB “colonic neoplasm” OR AB “colonic neoplasms” OR AB “colonic tumor” OR AB “colonic tumors” OR AB “colonic tumour” OR AB “colonic tumours” OR AB “colonic carcinoma” OR AB “colonic carcinomas” OR AB “colonic cancer” OR AB “colonic cancers”) OR (AB “rectum neoplasm” OR AB “rectum neoplasms” OR AB “rectum tumor” OR AB “rectum tumors” OR AB “rectum tumour” OR AB “rectum tumours” OR AB “rectum carcinoma” OR AB “rectum carcinomas” OR AB “rectum cancer” OR AB “rectum cancers” OR AB “cancer of the rectum” OR AB “cancer of rectum”) OR (AB “rectal neoplasm” OR AB “rectal neoplasms” OR AB “rectal tumor” OR AB “rectal tumors” OR AB “rectal tumour” OR AB “rectal tumours” OR AB “rectal carcinoma” OR AB “rectal carcinomas” OR AB “rectal cancer” OR AB “rectal cancers”) OR (AB “colorectal neoplasm” OR AB “colorectal neoplasms” OR AB “colorectal tumor” OR AB “colorectal tumors” OR AB “colorectal tumour” OR AB “colorectal tumours” OR AB “colorectal carcinoma” OR AB “colorectal carcinomas” OR AB “colorectal cancer” OR AB “colorectal cancers”) OR (AB “colorectum neoplasm” OR AB “colorectum neoplasms” OR AB “colorectum tumor” OR AB “colorectum tumors” OR AB “colorectum tumour” OR AB “colorectum tumours” OR AB “colorectum carcinoma” OR AB “colorectum carcinomas” OR AB “colorectum cancer” OR AB “colorectum cancers” OR AB “cancer of the colorectum” OR AB “cancer of colorectum”) OR (AB “colo rectal neoplasm” OR AB “colo rectal neoplasms” OR AB “colo rectal tumor” OR AB “colo rectal tumors” OR AB “colo rectal tumour” OR AB “colo rectal tumours” OR AB “colo rectal carcinoma” OR AB “colo rectal carcinomas” OR AB “colo rectal cancer” OR AB “colo rectal cancers”) OR (AB “colo rectum neoplasm” OR AB “colo rectum neoplasms” OR AB “colo rectum tumor” OR AB “colo rectum tumors” OR AB “colo rectum tumour” OR AB “colo rectum tumours” OR AB “colo rectum carcinoma” OR AB “colo rectum carcinomas” OR AB “colo rectum cancer” OR AB “colo rectum cancers” OR AB “cancer of the colo rectum” OR AB “cancer of colo rectum”) OR (AB “colo-rectal neoplasm” OR AB “colo-rectal neoplasms” OR AB “colo-rectal tumor” OR AB “colo-rectal tumors” OR AB “colo-rectal tumour” OR AB “colo-rectal tumours” OR AB “colo-rectal carcinoma” OR AB “colo-rectal carcinomas” OR AB “colo-rectal cancer” OR AB “colo-rectal cancers”) OR (AB “colo-rectum neoplasm” OR AB “colo-rectum neoplasms” OR AB “colo-rectum tumor” OR AB “colo-rectum tumors” OR AB “colo-rectum tumour” OR AB “colo-rectum tumours” OR AB “colo-rectum carcinoma” OR AB “colo-rectum carcinomas” OR AB “colo-rectum cancer” OR AB “colo-rectum cancers” OR AB “cancer of the colo-rectum” OR AB “cancer of colo-rectum”)))) AND (((MH "Survivors") OR (MH "Cancer Survivors") OR (MH "Survival")) OR ((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”)) OR ((TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”))))	Search modes Boolean / Phrase	1594	10/10/2014
PsycINFO	59	(DE "Neoplasms") OR ((((TI “colon neoplasm” OR TI “colon neoplasms” OR TI “colon tumor” OR TI “colon tumors” OR TI “colon tumour” OR TI “colon tumours” OR TI “colon carcinoma” OR TI “colon carcinomas” OR TI “colon cancer” OR TI “colon cancers” OR TI “cancer of the colon” OR TI “cancer of colon”) OR (TI “colonic neoplasm” OR TI “colonic neoplasms” OR TI “colonic tumor” OR TI “colonic tumors” OR TI “colonic tumour” OR TI “colonic tumours” OR TI “colonic carcinoma” OR TI “colonic carcinomas” OR TI “colonic cancer” OR TI “colonic cancers”) OR (TI “rectum neoplasm” OR TI “rectum neoplasms” OR TI “rectum tumor” OR TI “rectum tumors” OR TI “rectum tumour” OR TI “rectum tumours” OR TI “rectum carcinoma” OR TI “rectum carcinomas” OR TI “rectum cancer” OR TI “rectum cancers” OR TI “cancer of the rectum” OR TI “cancer of rectum”) OR (TI “rectal neoplasm” OR TI “rectal neoplasms” OR TI “rectal tumor” OR TI “rectal tumors” OR TI “rectal tumour” OR TI “rectal tumours” OR TI “rectal carcinoma” OR TI “rectal carcinomas” OR TI “rectal cancer” OR TI “rectal cancers”) OR (TI “colorectal neoplasm” OR TI “colorectal neoplasms” OR TI “colorectal tumor” OR TI “colorectal tumors” OR TI “colorectal tumour” OR TI “colorectal tumours” OR TI “colorectal carcinoma” OR TI “colorectal carcinomas” OR TI “colorectal cancer” OR TI “colorectal cancers”) OR TI “colorectum neoplasm” OR TI “colorectum neoplasms” OR TI “colorectum tumor” OR TI “colorectum tumors” OR TI “colorectum tumour” OR TI “colorectum tumours” OR TI “colorectum carcinoma” OR TI “colorectum carcinomas” OR TI “colorectum cancer” OR TI “colorectum cancers” OR TI “cancer of the colorectum” OR TI “cancer of colorectum”) OR (TI “colo rectal neoplasm” OR TI “colo rectal neoplasms” OR TI “colo rectal tumor” OR TI “colo rectal tumors” OR TI “colo rectal tumour” OR TI “colo rectal tumours” OR TI “colo rectal carcinoma” OR TI “colo rectal carcinomas” OR TI “colo rectal cancer” OR TI “colo rectal cancers”) OR (TI “colo rectum neoplasm” OR TI “colo rectum neoplasms” OR TI “colo rectum tumor” OR TI “colo rectum tumors” OR TI “colo rectum tumour” OR TI “colo rectum tumours” OR TI “colo rectum carcinoma” OR TI “colo rectum carcinomas” OR TI “colo rectum cancer” OR TI “colo rectum cancers” OR TI “cancer of the colo	Search modes Boolean / Phrase	169	10/10/2014

Database	Search No.	Search Terms	Search Options	Results	Search Date
		rectum” OR TI “cancer of colo rectum”) OR (TI “colo-rectal neoplasm” OR TI “colo-rectal neoplasms” OR TI “colo-rectal tumor” OR TI “colo-rectal tumors” OR TI “colo-rectal tumour” OR TI “colo-rectal tumours” OR TI “colo-rectal carcinoma” OR TI “colo-rectal carcinomas” OR TI “colo-rectal cancer” OR TI “colo-rectal cancers”) OR (TI “colo-rectum neoplasm” OR TI “colo-rectum neoplasms” OR TI “colo-rectum tumor” OR TI “colo-rectum tumors” OR TI “colo-rectum tumour” OR TI “colo-rectum tumours” OR TI “colo-rectum carcinoma” OR TI “colo-rectum carcinomas” OR TI “colo-rectum cancer” OR TI “colo-rectum cancers” OR TI “cancer of the colo-rectum” OR TI “cancer of colo-rectum”)) OR (((AB “colon neoplasm” OR AB “colon neoplasms” OR AB “colon tumor” OR AB “colon tumors” OR AB “colon tumour” OR AB “colon tumours” OR AB “colon carcinoma” OR AB “colon carcinomas” OR AB “colon cancer” OR AB “colon cancers” OR AB “cancer of the colon” OR AB “cancer of colon”) OR (AB “colonic neoplasm” OR AB “colonic neoplasms” OR AB “colonic tumor” OR AB “colonic tumors” OR AB “colonic tumour” OR AB “colonic tumours” OR AB “colonic carcinoma” OR AB “colonic carcinomas” OR AB “colonic cancer” OR AB “colonic cancers”) OR (AB “rectum neoplasm” OR AB “rectum neoplasms” OR AB “rectum tumor” OR AB “rectum tumors” OR AB “rectum tumour” OR AB “rectum tumours” OR AB “rectum carcinoma” OR AB “rectum carcinomas” OR AB “rectum cancer” OR AB “rectum cancers” OR AB “cancer of the rectum” OR AB “cancer of rectum”) OR (AB “rectal neoplasm” OR AB “rectal neoplasms” OR AB “rectal tumor” OR AB “rectal tumors” OR AB “rectal tumour” OR AB “rectal tumours” OR AB “rectal carcinoma” OR AB “rectal carcinomas” OR AB “rectal cancer” OR AB “rectal cancers”) OR (AB “colorectal neoplasm” OR AB “colorectal neoplasms” OR AB “colorectal tumor” OR AB “colorectal tumors” OR AB “colorectal tumour” OR AB “colorectal tumours” OR AB “colorectal carcinoma” OR AB “colorectal carcinomas” OR AB “colorectal cancer” OR AB “colorectal cancers”) OR AB “colorectum neoplasm” OR AB “colorectum neoplasms” OR AB “colorectum tumor” OR AB “colorectum tumors” OR AB “colorectum tumour” OR AB “colorectum tumours” OR AB “colorectum carcinoma” OR AB “colorectum carcinomas” OR AB “colorectum cancer” OR AB “colorectum cancers” OR AB “cancer of the colorectum” OR AB “cancer of colorectum”) OR (AB “colo rectal neoplasm” OR AB “colo rectal neoplasms” OR AB “colo rectal tumor” OR AB “colo rectal tumors” OR AB “colo rectal tumour” OR AB “colo rectal tumours” OR AB “colo rectal carcinoma” OR AB “colo rectal carcinomas” OR AB “colo rectal cancer” OR AB “colo rectal cancers”) OR (AB “colo rectum neoplasm” OR AB “colo rectum neoplasms” OR AB “colo rectum tumor” OR AB “colo rectum tumors” OR AB “colo rectum tumour” OR AB “colo rectum tumours” OR AB “colo rectum carcinoma” OR AB “colo rectum carcinomas” OR AB “colo rectum cancer” OR AB “colo rectum cancers” OR AB “cancer of the colo rectum” OR AB “cancer of colo rectum”) OR (AB “colo-rectal neoplasm” OR AB “colo-rectal neoplasms” OR AB “colo-rectal tumor” OR AB “colo-rectal tumors” OR AB “colo-rectal tumour” OR AB “colo-rectal tumours” OR AB “colo-rectal carcinoma” OR AB “colo-rectal carcinomas” OR AB “colo-rectal cancer” OR AB “colo-rectal cancers”) OR (AB “colo-rectum neoplasm” OR AB “colo-rectum neoplasms” OR AB “colo-rectum tumor” OR AB “colo-rectum tumors” OR AB “colo-rectum tumour” OR AB “colo-rectum tumours” OR AB “colo-rectum carcinoma” OR AB “colo-rectum carcinomas” OR AB “colo-rectum cancer” OR AB “colo-rectum cancers” OR AB “cancer of the colo-rectum” OR AB “cancer of colo-rectum”))) AND ((DE "Survivors") OR ((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”)) OR (TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”)) AND ((DE "Survivors") OR ((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”)) OR (TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”))			
PsycARTICLES	26	((TX “colon neoplasm” OR TX “colon neoplasms” OR TX “colon tumor” OR TX “colon tumors” OR TX “colon tumour” OR TX “colon tumours” OR TX “colon carcinoma” OR TX “colon carcinomas” OR TX “colon cancer” OR TX “colon cancers” OR TX “cancer of the colon” OR TX “cancer of colon”) OR (TX “rectal neoplasm” OR TX “rectal neoplasms” OR TX “rectal tumor” OR TX “rectal tumors” OR TX “rectal tumour” OR TX “rectal tumours” OR TX “rectal carcinoma” OR TX “rectal carcinomas” OR TX “rectal cancer” OR TX “rectal cancers”) OR (TX “colorectal neoplasm” OR TX “colorectal neoplasms” OR TX “colorectal tumor” OR TX “colorectal tumors” OR TX “colorectal tumour” OR TX “colorectal tumours” OR TX “colorectal carcinoma” OR TX “colorectal carcinomas” OR TX “colorectal cancer” OR TX “colorectal cancers”) OR (TX “colo rectal neoplasm” OR TX “colo rectal neoplasms” OR TX “colo rectal tumor” OR TX “colo rectal tumors” OR TX “colo rectal tumour” OR TX “colo rectal tumours” OR TX “colo rectal carcinoma” OR TX “colo rectal carcinomas” OR TX “colo rectal cancer” OR TX “colo rectal cancers”) OR (TX “colo-rectal neoplasm” OR TX “colo-rectal neoplasms” OR TX “colo-rectal tumor” OR TX “colo-rectal tumors” OR TX “colo-rectal tumour” OR TX “colo-rectal tumours” OR TX “colo-rectal carcinoma” OR TX “colo-rectal carcinomas” OR TX “colo-rectal cancer” OR TX “colo-rectal cancers”)) AND (((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”)) OR ((TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”)))	Search modes Boolean / Phrase	22	10/10/2014
The Cochrane Library	21	((MeSH descriptor: [Colorectal Neoplasms] this term only) OR (MeSH descriptor: [Colonic Neoplasms] this term only) OR (MeSH descriptor: [Rectal Neoplasms] this term only)) OR ((“colon neoplasm” OR “colon neoplasms” OR “colon tumor” OR “colon tumors” OR “colon tumour” OR “colon tumours” OR “colon carcinoma” OR “colon carcinomas” OR “colon cancer” OR “colon cancers” OR “cancer of the colon” OR “cancer of colon”) OR (“colonic neoplasm” OR “colonic neoplasms” OR “colonic tumor” OR “colonic tumors” OR “colonic tumour” OR “colonic tumours” OR “colonic carcinoma” OR “colonic carcinomas” OR “colonic cancer” OR “colonic cancers”) OR (“rectum neoplasm” OR “rectum neoplasms” OR “rectum tumor” OR “rectum tumors” OR “rectum tumour” OR “rectum tumours” OR “rectum carcinoma” OR “rectum carcinomas” OR “rectum cancer” OR “rectum cancers” OR “cancer of the rectum” OR “cancer of rectum”) OR (“rectal neoplasm” OR “rectal neoplasms” OR “rectal tumor” OR “rectal tumors” OR “rectal tumour” OR “rectal tumours” OR “rectal carcinoma” OR “rectal carcinomas” OR “rectal cancer” OR “rectal cancers”) OR ("colorectal neoplasm" or "colorectal neoplasms" or "colorectal tumor" or "colorectal tumors" or "colorectal tumour" or "colorectal tumours" or "colorectal carcinoma" or "colorectal carcinomas" or "colorectal cancer" or "colorectal cancers") OR ("colorectum neoplasm" or "colorectum neoplasms" or "colorectum tumor" or "colorectum tumors" or "colorectum tumour" or "colorectum tumours" or "colorectum carcinoma" or "colorectum carcinomas" or "colorectum cancer" or "colorectum cancers" or "cancer of the colorectum" or "cancer of colorectum") OR (“colo rectal neoplasm” OR “colo rectal neoplasms” OR “colo rectal tumor” OR “colo rectal tumors” OR “colo rectal tumour” OR “colo rectal tumours” OR “colo rectal carcinoma” OR “colo rectal carcinomas” OR “colo rectal cancer” OR “colo rectal cancers”) OR “colo-rectal neoplasm” OR “colo-rectal neoplasms” OR “colo-rectal tumor” OR “colo-rectal tumors” OR “colo-rectal tumour” OR “colo-rectal tumours” OR “colo-rectal carcinoma” OR “colo-rectal carcinomas” OR “colo-rectal cancer” OR “colo-rectal cancers”))) AND ((MeSH descriptor: [Survivors] this term only) OR ((“survivor” or “survivors” or “survivorship”) OR (“cancer survivor” or “cancer survivors” or “cancer survivorship”)))		104	17/10/2014

Database	Search No.	Search Terms	Search Options	Results	Search Date
MEDLINE	28	(((MH "Colonic Neoplasms") OR (MH "Rectal Neoplasms") OR (MH "Colorectal Neoplasms") OR (MH "Colorectal Neoplasms, Hereditary Nonpolyposis")) OR ((TX “colon neoplasm” OR TX “colon neoplasms” OR TX “colon tumor” OR TX “colon tumors” OR TX “colon tumour” OR TX “colon tumours” OR TX “colon carcinoma” OR TX “colon carcinomas” OR TX “colon cancer” OR TX “colon cancers” OR TX “cancer of the colon” OR TX “cancer of colon”) OR (TX “colonic neoplasm” OR TX “colonic neoplasms” OR TX “colonic tumor” OR TX “colonic tumors” OR TX “colonic tumour” OR TX “colonic tumours” OR TX “colonic carcinoma” OR TX “colonic carcinomas” OR TX “colonic cancer” OR TX “colonic cancers”) OR (TX “rectum neoplasm” OR TX “rectum neoplasms” OR TX “rectum tumor” OR TX “rectum tumors” OR TX “rectum tumour” OR TX “rectum tumours” OR TX “rectum carcinoma” OR TX “rectum carcinomas” OR TX “rectum cancer” OR TX “rectum cancers” OR TX “cancer of the rectum” OR TX “cancer of rectum”) OR (TX “rectal neoplasm” OR TX “rectal neoplasms” OR TX “rectal tumor” OR TX “rectal tumors” OR TX “rectal tumour” OR TX “rectal tumours” OR TX “rectal carcinoma” OR TX “rectal carcinomas” OR TX “rectal cancer” OR TX “rectal cancers”) OR (TX “colorectal neoplasm” OR TX “colorectal neoplasms” OR TX “colorectal tumor” OR TX “colorectal tumors” OR TX “colorectal tumour” OR TX “colorectal tumours” OR TX “colorectal carcinoma” OR TX “colorectal carcinomas” OR TX “colorectal cancer” OR TX “colorectal cancers”) OR (TX “colorectum neoplasm” OR TX “colorectum neoplasms” OR TX “colorectum tumor” OR TX “colorectum tumors” OR TX “colorectum tumour” OR TX “colorectum tumours” OR TX “colorectum carcinoma” OR TX “colorectum carcinomas” OR TX “colorectum cancer” OR TX “colorectum cancers” OR TX “cancer of the colorectum” OR TX “cancer of colorectum”) OR (TX “colo rectal neoplasm” OR TX “colo rectal neoplasms” OR TX “colo rectal tumor” OR TX “colo rectal tumors” OR TX “colo rectal tumour” OR TX “colo rectal tumours” OR TX “colo rectal carcinoma” OR TX “colo rectal carcinomas” OR TX “colo rectal cancer” OR TX “colo rectal cancers”) OR (TX “colo rectum neoplasm” OR TX “colo rectum neoplasms” OR TX “colo rectum tumor” OR TX “colo rectum tumors” OR TX “colo rectum tumour” OR TX “colo rectum tumours” OR TX “colo rectum carcinoma” OR TX “colo rectum carcinomas” OR TX “colo rectum cancer” OR TX “colo rectum cancers” OR TX “cancer of the colo rectum” OR TX “cancer of colo rectum”) OR (TX “colo-rectal neoplasm” OR TX “colo-rectal neoplasms” OR TX “colo-rectal tumor” OR TX “colo-rectal tumors” OR TX “colo-rectal tumour” OR TX “colo-rectal tumours” OR TX “colo-rectal carcinoma” OR TX “colo-rectal carcinomas” OR TX “colo-rectal cancer” OR TX “colo-rectal cancers”) OR (TX “colo-rectum neoplasm” OR TX “colo-rectum neoplasms” OR TX “colo-rectum tumor” OR TX “colo-rectum tumors” OR TX “colo-rectum tumour” OR TX “colo-rectum tumours” OR TX “colo-rectum carcinoma” OR TX “colo-rectum carcinomas” OR TX “colo-rectum cancer” OR TX “colo-rectum cancers” OR TX “cancer of the colo-rectum” OR TX “cancer of colo-rectum”)) AND (((MH "Survivors") OR (MH "Survival")) OR ((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”)) OR ((TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”)))	Search modes Boolean / Phrase	1252	18/10/2014
ProQuest Nursing and Allied Health Source	29	((MESH.EXACT("Colonic Neoplasms") OR MESH.EXACT("Rectal Neoplasms") OR MESH.EXACT("Colorectal Neoplasms") OR MESH.EXACT("Colorectal Neoplasms, Hereditary Nonpolyposis")) OR SU.EXACT("Colorectal cancer") OR ((("colon neoplasm") OR ("colon neoplasms") OR ("colon tumor") OR ("colon tumors") OR ("colon tumour") OR ("colon tumours") OR ("colon carcinoma") OR ("colon carcinomas") OR ("colon cancer") OR ("colon cancers") OR ("cancer of the colon") OR ("cancer of colon")) OR (("colonic neoplasm") OR ("colonic neoplasms") OR ("colonic tumor") OR ("colonic tumors") OR ("colonic tumour") OR ("colonic tumours") OR ("colonic carcinoma") OR ("colonic carcinomas") OR ("colonic cancer") OR ("colonic cancers")) OR (("rectum neoplasm") OR ("rectum neoplasms") OR ("rectum tumor") OR ("rectum tumors") OR ("rectum tumour") OR ("rectum tumours") OR ("rectum carcinoma") OR ("rectum carcinomas") OR ("rectum cancer") OR ("rectum cancers") OR ("cancer of the rectum") OR ("cancer of rectum")) OR (("rectal neoplasm") OR ("rectal neoplasms") OR ("rectal tumor") OR ("rectal tumors") OR ("rectal tumour") OR ("rectal tumours") OR ("rectal carcinoma") OR ("rectal carcinomas") OR ("rectal cancer") OR ("rectal cancers")) OR (("colorectal neoplasm") OR ("colorectal neoplasms") OR ("colorectal tumor") OR ("colorectal tumors") OR ("colorectal tumour") OR ("colorectal tumours") OR ("colorectal carcinoma") OR ("colorectal carcinomas") OR ("colorectal cancer") OR ("colorectal cancers")) OR (("colorectum neoplasm") OR ("colorectum neoplasms") OR ("colorectum tumor") OR ("colorectum tumors") OR ("colorectum tumour") OR ("colorectum tumours") OR ("colorectum carcinoma") OR ("colorectum carcinomas") OR ("colorectum cancer") OR ("colorectum cancers") OR ("cancer of the colorectum") OR ("cancer of colorectum")) OR (("colo rectal neoplasm") OR ("colo rectal neoplasms") OR ("colo rectal tumor") OR ("colo rectal tumors") OR ("colo rectal tumour") OR ("colo rectal tumours") OR ("colo rectal carcinoma") OR ("colo rectal carcinomas") OR ("colo rectal cancer") OR ("colo rectal cancers")) OR (("colo rectum neoplasm") OR ("colo rectum neoplasms") OR ("colo rectum tumor") OR ("colo rectum tumors") OR ("colo rectum tumour") OR ("colo rectum tumours") OR ("colo rectum carcinoma") OR ("colo rectum carcinomas") OR ("colo rectum cancer") OR ("colo rectum cancers") OR ("cancer of the colo rectum") OR ("cancer of colo rectum")) OR (("colo-rectal neoplasm") OR ("colo-rectal neoplasms") OR ("colo-rectal tumor") OR ("colo-rectal tumors") OR ("colo-rectal tumour") OR ("colo-rectal tumours") OR ("colo-rectal carcinoma") OR ("colo-rectal carcinomas") OR ("colo-rectal cancer") OR ("colo-rectal cancers")) OR (("colo-rectum neoplasm") OR ("colo-rectum neoplasms") OR ("colo-rectum tumor") OR ("colo-rectum tumors") OR ("colo-rectum tumour") OR ("colo-rectum tumours") OR ("colo-rectum carcinoma") OR ("colo-rectum carcinomas") OR ("colo-rectum cancer") OR ("colo-rectum cancers") OR ("cancer of the colo-rectum") OR ("cancer of colo-rectum")))) AND ((MESH.EXACT("Survivors") OR MESH.EXACT("Survival")) OR ((TI("survivor") OR TI("survivors") OR TI("survivorship")) OR (AB("survivor") OR AB("survivors") OR AB("survivorship"))) OR ((TI("cancer survivor") OR TI("cancer survivors") OR TI("cancer survivorship")) OR (AB(“cancer survivor”) or AB(“cancer survivors”) or AB(“cancer survivorship”))))		1135	18/10/2014
Social Sciences Full Text	23	((DE "Cancer") OR ((TX “colon neoplasm” OR TX “colon neoplasms” OR TX “colon tumor” OR TX “colon tumors” OR TX “colon tumour” OR TX “colon tumours” OR TX “colon carcinoma” OR TX “colon carcinomas” OR TX “colon cancer” OR TX “colon cancers” OR TX “cancer of the colon” OR TX “cancer of colon”) OR (TX “colonic neoplasm” OR TX “colonic neoplasms” OR TX “colonic tumor” OR TX “colonic tumors” OR TX “colonic tumour” OR TX “colonic tumours” OR TX “colonic carcinoma” OR TX “colonic carcinomas” OR TX “colonic cancer” OR TX “colonic cancers”) OR (TX “rectum neoplasm” OR TX “rectum neoplasms” OR TX “rectum tumor” OR TX “rectum tumors” OR TX “rectum tumour” OR TX “rectum tumours” OR TX “rectum carcinoma” OR TX “rectum carcinomas” OR TX “rectum cancer” OR TX “rectum cancers” OR TX “cancer of the rectum” OR TX “cancer of rectum”) OR (TX “rectal neoplasm” OR TX “rectal neoplasms” OR TX “rectal tumor” OR TX “rectal tumors” OR TX “rectal tumour” OR TX “rectal tumours” OR TX “rectal carcinoma” OR TX “rectal carcinomas” OR TX “rectal cancer” OR TX “rectal cancers”) OR (TX “colorectal neoplasm” OR TX “colorectal neoplasms” OR TX “colorectal tumor” OR TX “colorectal tumors” OR TX “colorectal tumour” OR TX “colorectal tumours” OR TX “colorectal carcinoma” OR TX “colorectal carcinomas” OR TX “colorectal cancer” OR TX “colorectal cancers”) OR (TX “colorectum neoplasm” OR TX “colorectum neoplasms” OR TX “colorectum tumor”	Search modes Boolean / Phrase	22	21/10/2014

Database	Search No.	Search Terms	Search Options	Results	Search Date
		OR TX “colorectum tumors” OR TX “colorectum tumour” OR TX “colorectum tumours” OR TX “colorectum carcinoma” OR TX “colorectum carcinomas” OR TX “colorectum cancer” OR TX “colorectum cancers” OR TX “cancer of the colorectum” OR TX “cancer of colorectum”) OR (TX “colo rectal neoplasm” OR TX “colo rectal neoplasms” OR TX “colo rectal tumor” OR TX “colo rectal tumors” OR TX “colo rectal tumour” OR TX “colo rectal tumours” OR TX “colo rectal carcinoma” OR TX “colo rectal carcinomas” OR TX “colo rectal cancer” OR TX “colo rectal cancers”) OR (TX “colo rectum neoplasm” OR TX “colo rectum neoplasms” OR TX “colo rectum tumor” OR TX “colo rectum tumors” OR TX “colo rectum tumour” OR TX “colo rectum tumours” OR TX “colo rectum carcinoma” OR TX “colo rectum carcinomas” OR TX “colo rectum cancer” OR TX “colo rectum cancers” OR TX “cancer of the colo rectum” OR TX “cancer of colo rectum”) OR (TX “colo-rectal neoplasm” OR TX “colo-rectal neoplasms” OR TX “colo-rectal tumor” OR TX “colo-rectal tumors” OR TX “colo-rectal tumour” OR TX “colo-rectal tumours” OR TX “colo-rectal carcinoma” OR TX “colo-rectal carcinomas” OR TX “colo-rectal cancer” OR TX “colo-rectal cancers”) OR (TX “colo-rectum neoplasm” OR TX “colo-rectum neoplasms” OR TX “colo-rectum tumor” OR TX “colo-rectum tumors” OR TX “colo-rectum tumour” OR TX “colo-rectum tumours” OR TX “colo-rectum carcinoma” OR TX “colo-rectum carcinomas” OR TX “colo-rectum cancer” OR TX “colo-rectum cancers” OR TX “cancer of the colo-rectum” OR TX “cancer of colo-rectum”))) AND (((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”)) OR ((TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”)))			
AMED	29	(((DE "COLORECTAL NEOPLASMS") OR (DE "RECTAL NEOPLASMS") OR (DE "COLONIC NEOPLASMS")) OR ((TX “colon neoplasm” OR TX “colon neoplasms” OR TX “colon tumor” OR TX “colon tumors” OR TX “colon tumour” OR TX “colon tumours” OR TX “colon carcinoma” OR TX “colon carcinomas” OR TX “colon cancer” OR TX “colon cancers” OR TX “cancer of the colon” OR TX “cancer of colon”) OR (TX “colonic neoplasm” OR TX “colonic neoplasms” OR TX “colonic tumor” OR TX “colonic tumors” OR TX “colonic tumour” OR TX “colonic tumours” OR TX “colonic carcinoma” OR TX “colonic carcinomas” OR TX “colonic cancer” OR TX “colonic cancers”) OR (TX “rectum neoplasm” OR TX “rectum neoplasms” OR TX “rectum tumor” OR TX “rectum tumors” OR TX “rectum tumour” OR TX “rectum tumours” OR TX “rectum carcinoma” OR TX “rectum carcinomas” OR TX “rectum cancer” OR TX “rectum cancers” OR TX “cancer of the rectum” OR TX “cancer of rectum”) OR (TX “rectal neoplasm” OR TX “rectal neoplasms” OR TX “rectal tumor” OR TX “rectal tumors” OR TX “rectal tumour” OR TX “rectal tumours” OR TX “rectal carcinoma” OR TX “rectal carcinomas” OR TX “rectal cancer” OR TX “rectal cancers”) OR (TX “colorectal neoplasm” OR TX “colorectal neoplasms” OR TX “colorectal tumor” OR TX “colorectal tumors” OR TX “colorectal tumour” OR TX “colorectal tumours” OR TX “colorectal carcinoma” OR TX “colorectal carcinomas” OR TX “colorectal cancer” OR TX “colorectal cancers”) OR (TX “colorectum neoplasm” OR TX “colorectum neoplasms” OR TX “colorectum tumor” OR TX “colorectum tumors” OR TX “colorectum tumour” OR TX “colorectum tumours” OR TX “colorectum carcinoma” OR TX “colorectum carcinomas” OR TX “colorectum cancer” OR TX “colorectum cancers” OR TX “cancer of the colorectum” OR TX “cancer of colorectum”) OR (TX “colorectum neoplasm” OR TX “colorectum neoplasms” OR TX “colorectum tumor” OR TX “colorectum tumors” OR TX “colorectum tumour” OR TX “colorectum tumours” OR TX “colorectum carcinoma” OR TX “colorectum carcinomas” OR TX “colorectum cancer” OR TX “colorectum cancers” OR TX “cancer of the colorectum” OR TX “cancer of colorectum”) OR (TX “colo rectal neoplasm” OR TX “colo rectal neoplasms” OR TX “colo rectal tumor” OR TX “colo rectal tumors” OR TX “colo rectal tumour” OR TX “colo rectal tumours” OR TX “colo rectal carcinoma” OR TX “colo rectal carcinomas” OR TX “colo rectal cancer” OR TX “colo rectal cancers”) OR (TX “colo rectum neoplasm” OR TX “colo rectum neoplasms” OR TX “colo rectum tumor” OR TX “colo rectum tumors” OR TX “colo rectum tumour” OR TX “colo rectum tumours” OR TX “colo rectum carcinoma” OR TX “colo rectum carcinomas” OR TX “colo rectum cancer” OR TX “colo rectum cancers” OR TX “cancer of the colo rectum” OR TX “cancer of colo rectum”) OR (TX “colo-rectal neoplasm” OR TX “colo-rectal neoplasms” OR TX “colo-rectal tumor” OR TX “colo-rectal tumors” OR TX “colo-rectal tumour” OR TX “colo-rectal tumours” OR TX “colo-rectal carcinoma” OR TX “colo-rectal carcinomas” OR TX “colo-rectal cancer” OR TX “colo-rectal cancers”) OR (TX “colo-rectum neoplasm” OR TX “colo-rectum neoplasms” OR TX “colo-rectum tumor” OR TX “colo-rectum tumors” OR TX “colo-rectum tumour” OR TX “colo-rectum tumours” OR TX “colo-rectum carcinoma” OR TX “colo-rectum carcinomas” OR TX “colo-rectum cancer” OR TX “colo-rectum cancers” OR TX “cancer of the colo-rectum” OR TX “cancer of colo-rectum”))) AND ((DE "SURVIVORS") OR (((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”)) OR ((TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”)))	Search modes Boolean / Phrase	19	21/10/2014
Academic Search Complete	66	((DE "COLON cancer") OR (DE "RECTAL cancer") OR (DE "HEREDITARY nonpolyposis colorectal cancer")) OR (((TI “colon neoplasm” OR TI “colon neoplasms” OR TI “colon tumor” OR TI “colon tumors” OR TI “colon tumour” OR TI “colon tumours” OR TI “colon carcinoma” OR TI “colon carcinomas” OR TI “colon cancer” OR TI “colon cancers” OR TI “cancer of the colon” OR TI “cancer of colon”) OR (AB “colon neoplasm” OR AB “colon neoplasms” OR AB “colon tumor” OR AB “colon tumors” OR AB “colon tumour” OR AB “colon tumours” OR AB “colon carcinoma” OR AB “colon carcinomas” OR AB “colon cancer” OR AB “colon cancers” OR AB “cancer of the colon” OR AB “cancer of colon”)) OR ((TI “colonic neoplasm” OR TI “colonic neoplasms” OR TI “colonic tumor” OR TI “colonic tumors” OR TI “colonic tumour” OR TI “colonic tumours” OR TI “colonic carcinoma” OR TI “colonic carcinomas” OR TI “colonic cancer” OR TI “colonic cancers”) OR (AB “colonic neoplasm” OR AB “colonic neoplasms” OR AB “colonic tumor” OR AB “colonic tumors” OR AB “colonic tumour” OR AB “colonic tumours” OR AB “colonic carcinoma” OR AB “colonic carcinomas” OR AB “colonic cancer” OR AB “colonic cancers”)) OR ((TI “rectum neoplasm” OR TI “rectum neoplasms” OR TI “rectum tumor” OR TI “rectum tumors” OR TI “rectum tumour” OR TI “rectum tumours” OR TI “rectum carcinoma” OR TI “rectum carcinomas” OR TI “rectum cancer” OR TI “rectum cancers” OR TI “cancer of the rectum” OR TI “cancer of rectum”) OR (AB “rectum neoplasm” OR AB “rectum neoplasms” OR AB “rectum tumor” OR AB “rectum tumors” OR AB “rectum tumour” OR AB “rectum tumours” OR AB “rectum carcinoma” OR AB “rectum carcinomas” OR AB “rectum cancer” OR AB “rectum cancers” OR AB “cancer of the rectum” OR AB “cancer of rectum”)) OR ((TI “rectal neoplasm” OR TI “rectal neoplasms” OR TI “rectal tumor” OR TI “rectal tumors” OR TI “rectal tumour” OR TI “rectal tumours” OR TI “rectal carcinoma” OR TI “rectal carcinomas” OR TI “rectal cancer” OR TI “rectal cancers”) OR (AB “rectal neoplasm” OR AB “rectal neoplasms” OR AB “rectal tumor” OR AB “rectal tumors” OR AB “rectal tumour” OR AB “rectal tumours” OR AB “rectal carcinoma” OR AB “rectal carcinomas” OR AB “rectal cancer” OR AB “rectal cancers”)) OR ((TI “colorectal neoplasm” OR TI “colorectal neoplasms” OR TI “colorectal tumor” OR TI “colorectal tumors” OR TI “colorectal tumour” OR TI “colorectal tumours” OR TI “colorectal carcinoma” OR TI “colorectal carcinomas” OR TI “colorectal cancer” OR TI “colorectal cancers”) OR (AB “colorectal neoplasm” OR AB “colorectal neoplasms” OR AB “colorectal tumor” OR AB “colorectal tumors” OR AB “colorectal tumour” OR AB “colorectal tumours” OR AB “colorectal carcinoma” OR AB “colorectal carcinomas” OR AB “colorectal cancer” OR AB “colorectal cancers”)) OR ((TI “colo rectal neoplasm” OR TI “colo rectal neoplasms” OR TI “colo rectal tumor” OR TI “colo rectal tumors” OR	Search modes Boolean / Phrase	346	21/10/2014

Database	Search No.	Search Terms	Search Options	Results	Search Date
		TI “colo rectal tumour” OR TI “colo rectal tumours” OR TI “colo rectal carcinoma” OR TI “colo rectal carcinomas” OR TI “colo rectal cancer” OR TI “colo rectal cancers”) OR (AB “colo rectal neoplasm” OR AB “colo rectal neoplasms” OR AB “colo rectal tumor” OR AB “colo rectal tumors” OR AB “colo rectal tumour” OR AB “colo rectal tumours” OR AB “colo rectal carcinoma” OR AB “colo rectal carcinomas” OR AB “colo rectal cancer” OR AB “colo rectal cancers”)) OR ((TI “colo-rectal neoplasm” OR TI “colo-rectal neoplasms” OR TI “colo-rectal tumor” OR TI “colo-rectal tumors” OR TI “colo-rectal tumour” OR TI “colo-rectal tumours” OR TI “colo-rectal carcinoma” OR TI “colo-rectal carcinomas” OR TI “colo-rectal cancer” OR TI “colo-rectal cancers”) OR (AB “colo-rectal neoplasm” OR AB “colo-rectal neoplasms” OR AB “colo-rectal tumor” OR AB “colo-rectal tumors” OR AB “colo-rectal tumour” OR AB “colo-rectal tumours” OR AB “colo-rectal carcinoma” OR AB “colo-rectal carcinomas” OR AB “colo-rectal cancer” OR AB “colo-rectal cancers”))) AND (((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”)) OR ((TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”)))			
ASSIA	24	((SU.EXACT("Colon cancer") OR SU.EXACT("Colorectal cancer")) OR ((("colon neoplasm") OR ("colon neoplasms") OR ("colon tumor") OR ("colon tumors") OR ("colon tumour") OR ("colon tumours") OR ("colon carcinoma") OR ("colon carcinomas") OR ("colon cancer") OR ("colon cancers") OR ("cancer of the colon") OR ("cancer of colon")) OR (("colonic neoplasm") OR ("colonic neoplasms") OR ("colonic tumor") OR ("colonic tumors") OR ("colonic tumour") OR ("colonic tumours") OR ("colonic carcinoma") OR ("colonic carcinomas") OR ("colonic cancer") OR ("colonic cancers")) OR (("rectum neoplasm") OR ("rectum neoplasms") OR ("rectum tumor") OR ("rectum tumors") OR ("rectum tumour") OR ("rectum tumours") OR ("rectum carcinoma") OR ("rectum carcinomas") OR ("rectum cancer") OR ("rectum cancers") OR ("cancer of the rectum") OR ("cancer of rectum")) OR (("rectal neoplasm") OR ("rectal neoplasms") OR ("rectal tumor") OR ("rectal tumors") OR ("rectal tumour") OR ("rectal tumours") OR ("rectal carcinoma") OR ("rectal carcinomas") OR ("rectal cancer") OR ("rectal cancers")) OR (("colorectal neoplasm") OR ("colorectal neoplasms") OR ("colorectal tumor") OR ("colorectal tumors") OR ("colorectal tumour") OR ("colorectal tumours") OR ("colorectal carcinoma") OR ("colorectal carcinomas") OR ("colorectal cancer") OR ("colorectal cancers")) OR (("colorectum neoplasm") OR ("colorectum neoplasms") OR ("colorectum tumor") OR ("colorectum tumors") OR ("colorectum tumour") OR ("colorectum tumours") OR ("colorectum carcinoma") OR ("colorectum carcinomas") OR ("colorectum cancer") OR ("colorectum cancers") OR ("cancer of the colorectum") OR ("cancer of colorectum")) OR (("colo rectal neoplasm") OR ("colo rectal neoplasms") OR ("colo rectal tumor") OR ("colo rectal tumors") OR ("colo rectal tumour") OR ("colo rectal tumours") OR ("colo rectal carcinoma") OR ("colo rectal carcinomas") OR ("colo rectal cancer") OR ("colo rectal cancers")) OR (("colo rectum neoplasm") OR ("colo rectum neoplasms") OR ("colo rectum tumor") OR ("colo rectum tumors") OR ("colo rectum tumour") OR ("colo rectum tumours") OR ("colo rectum carcinoma") OR ("colo rectum carcinomas") OR ("colo rectum cancer") OR ("colo rectum cancers") OR ("cancer of the colo rectum") OR ("cancer of colo rectum")) OR (("colo-rectal neoplasm") OR ("colo-rectal neoplasms") OR ("colo-rectal tumor") OR ("colo-rectal tumors") OR ("colo-rectal tumour") OR ("colo-rectal tumours") OR ("colo-rectal carcinoma") OR ("colo-rectal carcinomas") OR ("colo-rectal cancer") OR ("colo-rectal cancers")) OR (("colo-rectum neoplasm") OR ("colo-rectum neoplasms") OR ("colo-rectum tumor") OR ("colo-rectum tumors") OR ("colo-rectum tumour") OR ("colo-rectum tumours") OR ("colo-rectum carcinoma") OR ("colo-rectum carcinomas") OR ("colo-rectum cancer") OR ("colo-rectum cancers") OR ("cancer of the colo-rectum") OR ("cancer of colo-rectum")))) AND (SU.EXACT("Survivors") OR ((TI("survivor") OR TI("survivors") OR TI("survivorship")) OR (AB("survivor") OR AB("survivors") OR AB("survivorship"))) OR ((TI("cancer survivor") OR TI("cancer survivors") OR TI("cancer survivorship")) OR (AB("cancer survivor") OR AB("cancer survivors") OR AB("cancer survivorship"))))		42	21/10/2014
Social Services Abstracts	22	(SU.EXACT("Cancer") OR ((("colon neoplasm") OR ("colon neoplasms") OR ("colon tumor") OR ("colon tumors") OR ("colon tumour") OR ("colon tumours") OR ("colon carcinoma") OR ("colon carcinomas") OR ("colon cancer") OR ("colon cancers") OR ("cancer of the colon") OR ("cancer of colon")) OR (("colonic neoplasm") OR ("colonic neoplasms") OR ("colonic tumor") OR ("colonic tumors") OR ("colonic tumour") OR ("colonic tumours") OR ("colonic carcinoma") OR ("colonic carcinomas") OR ("colonic cancer") OR ("colonic cancers")) OR (("rectum neoplasm") OR ("rectum neoplasms") OR ("rectum tumor") OR ("rectum tumors") OR ("rectum tumour") OR ("rectum tumours") OR ("rectum carcinoma") OR ("rectum carcinomas") OR ("rectum cancer") OR ("rectum cancers") OR ("cancer of the rectum") OR ("cancer of rectum")) OR (("rectal neoplasm") OR ("rectal neoplasms") OR ("rectal tumor") OR ("rectal tumors") OR ("rectal tumour") OR ("rectal tumours") OR ("rectal carcinoma") OR ("rectal carcinomas") OR ("rectal cancer") OR ("rectal cancers")) OR (("colorectal neoplasm") OR ("colorectal neoplasms") OR ("colorectal tumor") OR ("colorectal tumors") OR ("colorectal tumour") OR ("colorectal tumours") OR ("colorectal carcinoma") OR ("colorectal carcinomas") OR ("colorectal cancer") OR ("colorectal cancers")) OR (("colorectum neoplasm") OR ("colorectum neoplasms") OR ("colorectum tumor") OR ("colorectum tumors") OR ("colorectum tumour") OR ("colorectum tumours") OR ("colorectum carcinoma") OR ("colorectum carcinomas") OR ("colorectum cancer") OR ("colorectum cancers") OR ("cancer of the colorectum") OR ("cancer of colorectum")) OR (("colo rectal neoplasm") OR ("colo rectal neoplasms") OR ("colo rectal tumor") OR ("colo rectal tumors") OR ("colo rectal tumour") OR ("colo rectal tumours") OR ("colo rectal carcinoma") OR ("colo rectal carcinomas") OR ("colo rectal cancer") OR ("colo rectal cancers")) OR (("colo rectum neoplasm") OR ("colo rectum neoplasms") OR ("colo rectum tumor") OR ("colo rectum tumors") OR ("colo rectum tumour") OR ("colo rectum tumours") OR ("colo rectum carcinoma") OR ("colo rectum carcinomas") OR ("colo rectum cancer") OR ("colo rectum cancers") OR ("cancer of the colo rectum") OR ("cancer of colo rectum")) OR (("colo-rectal neoplasm") OR ("colo-rectal neoplasms") OR ("colo-rectal tumor") OR ("colo-rectal tumors") OR ("colo-rectal tumour") OR ("colo-rectal tumours") OR ("colo-rectal carcinoma") OR ("colo-rectal carcinomas") OR ("colo-rectal cancer") OR ("colo-rectal cancers")) OR (("colo-rectum neoplasm") OR ("colo-rectum neoplasms") OR ("colo-rectum tumor") OR ("colo-rectum tumors") OR ("colo-rectum tumour") OR ("colo-rectum tumours") OR ("colo-rectum carcinoma") OR ("colo-rectum carcinomas") OR ("colo-rectum cancer") OR ("colo-rectum cancers") OR ("cancer of the colo-rectum") OR ("cancer of colo-rectum")))) AND (SU.EXACT("Victims") OR ((TI("survivor") OR TI("survivors") OR TI("survivorship")) OR (AB("survivor") OR AB("survivors") OR AB("survivorship"))) OR ((TI("cancer survivor") OR TI("cancer survivors") OR TI("cancer survivorship")) OR (AB("cancer survivor") OR AB("cancer survivors") OR AB("cancer survivorship"))))		177	21/10/2014
Sociological Abstracts	22	(SU.EXACT("Cancer") OR ((("colon neoplasm") OR ("colon neoplasms") OR ("colon tumor") OR ("colon tumors") OR ("colon tumour") OR ("colon tumours") OR ("colon carcinoma") OR ("colon carcinomas") OR ("colon cancer") OR ("colon cancers") OR ("cancer of the colon") OR ("cancer of colon")) OR (("colonic neoplasm") OR ("colonic neoplasms") OR ("colonic tumor") OR ("colonic tumors") OR ("colonic tumour") OR ("colonic tumours") OR ("colonic carcinoma") OR ("colonic carcinomas") OR ("colonic cancer") OR ("colonic cancers")) OR (("rectum neoplasm") OR ("rectum neoplasms") OR ("rectum tumor") OR ("rectum tumors") OR ("rectum tumour") OR ("rectum tumours") OR ("rectum carcinoma") OR ("rectum carcinomas") OR ("rectum cancer") OR ("rectum cancers") OR ("cancer of the rectum") OR ("cancer of rectum")) OR		123	21/10/2014

Database	Search No.	Search Terms	Search Options	Results	Search Date
		(("rectal neoplasm") OR ("rectal neoplasms") OR ("rectal tumor") OR ("rectal tumors") OR ("rectal tumour") OR ("rectal tumours") OR ("rectal carcinoma") OR ("rectal carcinomas") OR ("rectal cancer") OR ("rectal cancers")) OR (("colorectal neoplasm") OR ("colorectal neoplasms") OR ("colorectal tumor") OR ("colorectal tumors") OR ("colorectal tumour") OR ("colorectal tumours") OR ("colorectal carcinoma") OR ("colorectal carcinomas") OR ("colorectal cancer") OR ("colorectal cancers")) OR (("colorectum neoplasm") OR ("colorectum neoplasms") OR ("colorectum tumor") OR ("colorectum tumors") OR ("colorectum tumour") OR ("colorectum tumours") OR ("colorectum carcinoma") OR ("colorectum carcinomas") OR ("colorectum cancer") OR ("colorectum cancers") OR ("cancer of the colorectum") OR ("cancer of colorectum")) OR (("colo rectal neoplasm") OR ("colo rectal neoplasms") OR ("colo rectal tumor") OR ("colo rectal tumors") OR ("colo rectal tumour") OR ("colo rectal tumours") OR ("colo rectal carcinoma") OR ("colo rectal carcinomas") OR ("colo rectal cancer") OR ("colo rectal cancers")) OR (("colo rectum neoplasm") OR ("colo rectum neoplasms") OR ("colo rectum tumor") OR ("colo rectum tumors") OR ("colo rectum tumour") OR ("colo rectum tumours") OR ("colo rectum carcinoma") OR ("colo rectum carcinomas") OR ("colo rectum cancer") OR ("colo rectum cancers") OR ("cancer of the colo rectum") OR ("cancer of colo rectum")) OR (("colo-rectal neoplasm") OR ("colo-rectal neoplasms") OR ("colo-rectal tumor") OR ("colo-rectal tumors") OR ("colo-rectal tumour") OR ("colo-rectal tumours") OR ("colo-rectal carcinoma") OR ("colo-rectal carcinomas") OR ("colo-rectal cancer") OR ("colo-rectal cancers")) OR (("colo-rectum neoplasm") OR ("colo-rectum neoplasms") OR ("colo-rectum tumor") OR ("colo-rectum tumors") OR ("colo-rectum tumour") OR ("colo-rectum tumours") OR ("colo-rectum carcinoma") OR ("colo-rectum carcinomas") OR ("colo-rectum cancer") OR ("colo-rectum cancers") OR ("cancer of the colo-rectum") OR ("cancer of colo-rectum")))) AND (SU.EXACT("Victims") OR ((TI("survivor") OR TI("survivors") OR TI("survivorship")) OR (AB("survivor") OR AB("survivors") OR AB("survivorship"))) OR ((TI("cancer survivor") OR TI("cancer survivors") OR TI("cancer survivorship")) OR (AB("cancer survivor") OR AB("cancer survivors") OR AB("cancer survivorship"))))			
Web of Science	15	((TOPIC: (“colon neoplasm”) OR TOPIC: (“colon neoplasms”) OR TOPIC: (“colon tumor”) OR TOPIC: (“colon tumors”) OR TOPIC: (“colon tumour”) OR TOPIC: (“colon tumours”) OR TOPIC: (“colon carcinoma”) OR TOPIC: (“colon carcinomas”) OR TOPIC: (“colon cancer”) OR TOPIC: (“colon cancers”) OR TOPIC: (“cancer of the colon”) OR TOPIC: (“cancer of colon”)) OR (TOPIC: (“colonic neoplasm”) OR TOPIC: (“colonic neoplasms”) OR TOPIC: (“colonic tumor”) OR TOPIC: (“colonic tumors”) OR TOPIC: (“colonic tumour”) OR TOPIC: (“colonic tumours”) OR TOPIC: (“colonic carcinoma”) OR TOPIC: (“colonic carcinomas”) OR TOPIC: (“colonic cancer”) OR TOPIC: (“colonic cancers”) OR (TOPIC: (“rectum neoplasm”) OR TOPIC: (“rectum neoplasms”) OR TOPIC: (“rectum tumor”) OR TOPIC: (“rectum tumors”) OR TOPIC: (“rectum tumour”) OR TOPIC: (“rectum tumours”) OR TOPIC: (“rectum carcinoma”) OR TOPIC: (“rectum carcinomas”) OR TOPIC: (“rectum cancer”) OR TOPIC: (“rectum cancers”) OR TOPIC: (“cancer of the rectum”) OR TOPIC: (“cancer of rectum”)) OR (TOPIC: (“rectal neoplasm”) OR TOPIC: (“rectal neoplasms”) OR TOPIC: (“rectal tumor”) OR TOPIC: (“rectal tumors”) OR TOPIC: (“rectal tumour”) OR TOPIC: (“rectal tumours”) OR TOPIC: (“rectal carcinoma”) OR TOPIC: (“rectal carcinomas”) OR TOPIC: (“rectal cancer”) OR TOPIC: (“rectal cancers”) OR (TOPIC: (“colorectal neoplasm”) OR TOPIC: (“colorectal neoplasms”) OR TOPIC: (“colorectal tumor”) OR TOPIC: (“colorectal tumors”) OR TOPIC: (“colorectal tumour”) OR TOPIC: (“colorectal tumours”) OR TOPIC: (“colorectal carcinoma”) OR TOPIC: (“colorectal carcinomas”) OR TOPIC: (“colorectal cancer”) OR TOPIC: (“colorectal cancers”)) OR ((TOPIC: (“colorectum neoplasm”) OR TOPIC: (“colorectum neoplasms”) OR TOPIC: (“colorectum tumor”) OR TOPIC: (“colorectum tumors”) OR TOPIC: (“colorectum tumour”) OR TOPIC: (“colorectum tumours”) OR TOPIC: (“colorectum carcinoma”) OR TOPIC: (“colorectum carcinomas”) OR TOPIC: (“colorectum cancer”) OR TOPIC: (“colorectum cancers”) OR TOPIC: (“cancer of the colorectum”) OR TOPIC: (“cancer of colorectum”)) OR (TOPIC: (“colo rectal neoplasm”) OR TOPIC: (“colo rectal neoplasms”) OR TOPIC: (“colo rectal tumor”) OR TOPIC: (“colo rectal tumors”) OR TOPIC: (“colo rectal tumour”) OR TOPIC: (“colo rectal tumours”) OR TOPIC: (“colo rectal carcinoma”) OR TOPIC: (“colo rectal carcinomas”) OR TOPIC: (“colo rectal cancer”) OR TOPIC: (“colo rectal cancers”)) OR ((TOPIC: (“colo rectum neoplasm”) OR TOPIC: (“colo rectum neoplasms”) OR TOPIC: (“colo rectum tumor”) OR TOPIC: (“colo rectum tumors”) OR TOPIC: (“colo rectum tumour”) OR TOPIC: (“colo rectum tumours”) OR TOPIC: (“colo rectum carcinoma”) OR TOPIC: (“colo rectum carcinomas”) OR TOPIC: (“colo rectum cancer”) OR TOPIC: (“colo rectum cancers”) OR TOPIC: (“cancer of the colo rectum”) OR TOPIC: (“cancer of colo rectum”)) OR ((TOPIC: (“colo-rectal neoplasm”) OR TOPIC: (“colo-rectal neoplasms”) OR TOPIC: (“colo-rectal tumor”) OR TOPIC: (“colo-rectal tumors”) OR TOPIC: (“colo-rectal tumour”) OR TOPIC: (“colo-rectal tumours”) OR TOPIC: (“colo-rectal carcinoma”) OR TOPIC: (“colo-rectal carcinomas”) OR TOPIC: (“colo-rectal cancer”) OR TOPIC: (“colo-rectal cancers”)) OR ((TOPIC: (“colo-rectum neoplasm”) OR TOPIC: (“colo-rectum neoplasms”) OR TOPIC: (“colo-rectum tumor”) OR TOPIC: (“colo-rectum tumors”) OR TOPIC: (“colo-rectum tumour”) OR TOPIC: (“colo-rectum tumours”) OR TOPIC: (“colo-rectum carcinoma”) OR TOPIC: (“colo-rectum carcinomas”) OR TOPIC: (“colo-rectum cancer”) OR TOPIC: (“colo-rectum cancers”) OR TOPIC: (“cancer of the colo-rectum”) OR TOPIC: (“cancer of colo-rectum”)) AND (TITLE: (“survivor”) OR TITLE: (“survivors”) OR TITLE: (“survivorship”)) OR (TITLE: (“cancer survivor”) OR TITLE: (“cancer survivors”) OR TITLE: (“cancer survivorship”))	None	685	21/10/2014
British Nursing Index	21	(SU.EXACT("Colorectal Cancer") OR ((("colon neoplasm") OR ("colon neoplasms") OR ("colon tumor") OR ("colon tumors") OR ("colon tumour") OR ("colon tumours") OR ("colon carcinoma") OR ("colon carcinomas") OR ("colon cancer") OR ("colon cancers") OR ("cancer of the colon") OR ("cancer of colon")) OR (("colonic neoplasm") OR ("colonic neoplasms") OR ("colonic tumor") OR ("colonic tumors") OR ("colonic tumour") OR ("colonic tumours") OR ("colonic carcinoma") OR ("colonic carcinomas") OR ("colonic cancer") OR ("colonic cancers")) OR (("rectum neoplasm") OR ("rectum neoplasms") OR ("rectum tumor") OR ("rectum tumors") OR ("rectum tumour") OR ("rectum tumours") OR ("rectum carcinoma") OR ("rectum carcinomas") OR ("rectum cancer") OR ("rectum cancers") OR ("cancer of the rectum") OR ("cancer of rectum")) OR (("rectal neoplasm") OR ("rectal neoplasms") OR ("rectal tumor") OR ("rectal tumors") OR ("rectal tumour") OR ("rectal tumours") OR ("rectal carcinoma") OR ("rectal carcinomas") OR ("rectal cancer") OR ("rectal cancers")) OR (("colorectal neoplasm") OR ("colorectal neoplasms") OR ("colorectal tumor") OR ("colorectal tumors") OR ("colorectal tumour") OR ("colorectal tumours") OR ("colorectal carcinoma") OR ("colorectal carcinomas") OR ("colorectal cancer") OR ("colorectal cancers")) OR (("colorectum neoplasm") OR ("colorectum neoplasms") OR ("colorectum tumor") OR ("colorectum tumors") OR ("colorectum tumour") OR ("colorectum tumours") OR ("colorectum carcinoma") OR ("colorectum carcinomas") OR ("colorectum cancer") OR ("colorectum cancers") OR ("cancer of the colorectum") OR ("cancer of colorectum")) OR (("colo rectal neoplasm") OR ("colo rectal neoplasms") OR ("colo rectal tumor") OR ("colo rectal tumors") OR ("colo rectal tumour") OR ("colo rectal tumours") OR ("colo rectal carcinoma") OR ("colo rectal carcinomas") OR ("colo rectal cancer") OR ("colo rectal cancers")) OR (("colo rectum neoplasm") OR ("colo rectum neoplasms") OR ("colo rectum tumor") OR ("colo rectum tumors") OR ("colo rectum tumour") OR ("colo rectum tumours") OR ("colo rectum carcinoma") OR ("colo rectum carcinomas") OR ("colo rectum cancer") OR ("colo rectum cancers") OR ("cancer of the colo rectum") OR ("cancer of colo rectum")) OR (("colo-rectal neoplasm") OR ("colo-rectal neoplasms") OR ("colo-rectal tumor") OR ("colo-rectal tumors") OR ("colo-rectal tumour") OR ("colo-rectal tumours") OR ("colo-rectal carcinoma") OR		48	22/10/2014

Database	Search No.	Search Terms	Search Options	Results	Search Date
		("colo-rectal carcinomas") OR ("colo-rectal cancer") OR ("colo-rectal cancers")) OR (("colo-rectum neoplasm") OR ("colo-rectum neoplasms") OR ("colo-rectum tumor") OR ("colo-rectum tumors") OR ("colo-rectum tumour") OR ("colo-rectum tumours") OR ("colo-rectum carcinoma") OR ("colo-rectum carcinomas") OR ("colo-rectum cancer") OR ("colo-rectum cancers") OR ("cancer of the colo-rectum") OR ("cancer of colo-rectum")))) AND (((TI("survivor") OR TI("survivors") OR TI("survivorship")) OR (AB("survivor") OR AB("survivors") OR AB("survivorship"))) OR ((TI("cancer survivor") OR TI("cancer survivors") OR TI("cancer survivorship")) OR (AB("cancer survivor") OR AB("cancer survivors") OR AB("cancer survivorship"))))			
OmniFile Full-Text Mega	26	((DE "Colon cancer") OR (DE "Rectal cancer") OR (DE "Hereditary nonpolyposis colorectal cancer")) OR ((TX “colon neoplasm” OR TX “colon neoplasms” OR TX “colon tumor” OR TX “colon tumors” OR TX “colon tumour” OR TX “colon tumours” OR TX “colon carcinoma” OR TX “colon carcinomas” OR TX “colon cancer” OR TX “colon cancers” OR TX “cancer of the colon” OR TX “cancer of colon”) OR (TX “colonic neoplasm” OR TX “colonic neoplasms” OR TX “colonic tumor” OR TX “colonic tumors” OR TX “colonic tumour” OR TX “colonic tumours” OR TX “colonic carcinoma” OR TX “colonic carcinomas” OR TX “colonic cancer” OR TX “colonic cancers”) OR (TX “colonic neoplasm” OR TX “colonic neoplasms” OR TX “colonic tumor” OR TX “colonic tumors” OR TX “colonic tumour” OR TX “colonic tumours” OR TX “colonic carcinoma” OR TX “colonic carcinomas” OR TX “colonic cancer” OR TX “colonic cancers”) OR (TX “rectum neoplasm” OR TX “rectum neoplasms” OR TX “rectum tumor” OR TX “rectum tumors” OR TX “rectum tumour” OR TX “rectum tumours” OR TX “rectum carcinoma” OR TX “rectum carcinomas” OR TX “rectum cancer” OR TX “rectum cancers” OR TX “cancer of the rectum” OR TX “cancer of rectum”) OR (TX “rectal neoplasm” OR TX “rectal neoplasms” OR TX “rectal tumor” OR TX “rectal tumors” OR TX “rectal tumour” OR TX “rectal tumours” OR TX “rectal carcinoma” OR TX “rectal carcinomas” OR TX “rectal cancer” OR TX “rectal cancers”) OR (TX “colorectal neoplasm” OR TX “colorectal neoplasms” OR TX “colorectal tumor” OR TX “colorectal tumors” OR TX “colorectal tumour” OR TX “colorectal tumours” OR TX “colorectal carcinoma” OR TX “colorectal carcinomas” OR TX “colorectal cancer” OR TX “colorectal cancers”) OR (TX “colorectum neoplasm” OR TX “colorectum neoplasms” OR TX “colorectum tumor” OR TX “colorectum tumors” OR TX “colorectum tumour” OR TX “colorectum tumours” OR TX “colorectum carcinoma” OR TX “colorectum carcinomas” OR TX “colorectum cancer” OR TX “colorectum cancers” OR TX “cancer of the colorectum” OR TX “cancer of colorectum”) OR (TX “colo rectal neoplasm” OR TX “colo rectal neoplasms” OR TX “colo rectal tumor” OR TX “colo rectal tumors” OR TX “colo rectal tumour” OR TX “colo rectal tumours” OR TX “colo rectal carcinoma” OR TX “colo rectal carcinomas” OR TX “colo rectal cancer” OR TX “colo rectal cancers”) OR (TX “colo-rectal neoplasm” OR TX “colo-rectal neoplasms” OR TX “colo-rectal tumor” OR TX “colo-rectal tumors” OR TX “colo-rectal tumour” OR TX “colo-rectal tumours” OR TX “colo-rectal carcinoma” OR TX “colo-rectal carcinomas” OR TX “colo-rectal cancer” OR TX “colo-rectal cancers”))) AND (DE "Cancer patients") OR ((TI “survivor” OR TI “survivors” OR TI “survivorship”) OR (AB “survivor” OR AB “survivors” OR AB “survivorship”)) OR ((TI “cancer survivor” OR TI “cancer survivors” OR TI “cancer survivorship”) OR (AB “cancer survivor” OR AB “cancer survivors” OR AB “cancer survivorship”))	Search modes Boolean / Phrase	113	22/10/2014

Appendix 3.2: Characteristics of Publications included in the Literature Review

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
Abu-Helalah et al. (2014)	Jordan	To establish quality of life and psychological well-being among colorectal cancer survivors in Jordan	Cross-sectional Survey	EORTC QLQ-CR29	241	NR	12-36 mths	52%/ 48%	60%/ 40%	NR	11%/ 38%/ 38%/ 13%	25%/ 88%/ 97%
Altschuler et al. (2009)	USA	To examine the influence of male partners' support on women's psychosocial adjustment to having an ostomy	Mixed Methods	City of Hope QOL – Ostomy Interview	284 22	52% 41%	> 5 yrs	0%/ 100%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR
Anderson et al. (2013)	United Kingdom	To explore colorectal cancer survivors' perceived needs for diet and physical activity advice, and beliefs about the role of lifestyle for reducing disease recurrence	Qualitative Focus Group	Focus Group	40	NA	1-48 mths	50%/ 50%	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR
Andrykowski et al. (2013)	The Netherlands	To examine the relationship between socioeconomic status and mental health outcomes among colorectal cancer survivors	Cross-sectional Survey	SF-36 HADS	1300	82%	1-10 yrs	57%/ 43%	66%/ 34%	NR	28%/ 39%/ 29%/ 5%	26%/ 27%/ 99%
Appleton et al. (2013)	United Kingdom	To explore the experience of living beyond colorectal cancer, and the physical, psychological and social aspects associated with adjusting to everyday life	Qualitative Phenomenological	Interviews	13	NA	1-8 yrs	62%/ 39%	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR
Au et al. (2012a)	Taiwan	To investigate the relationship between demographic and cancer-related factors and sexual function in rectal cancer survivors	Cross-sectional Survey	IIEF FSFI	120	76%	3-180 mths	73%/ 27%	0%/ 100%	25%	33%/ 27%/ 41%/ X	11%/ 48%/ 100%
Au et al. (2012b)	Taiwan	To examine relationships between health-seeking behaviours and sexuality among rectal cancer survivors	Cross-sectional Survey	IIEF FSFI	120	76%	<5 yrs	73%/ 27%	0%/ 100%	NR	NR/ 60%/ 40%/ X	NR/ NR/ 52%
Austin et al. (2010)	Australia	To measure the quality of life of longer-term disease-free rectal cancer survivors after pelvic exenteration	Cross-sectional Survey	FACT-C SF-36	37 15	84% 80%	8.5 - 123 mths 3 mths	43%/ 57% NA	0%/ 100% NA/ NA	27% NA	NR/ NR/ NR/ NR NR/ NR/ NR/ NR	NR/ NR/ NR NR/ NR/ NR
Bailey et al. (2014)	USA	To investigate functional outcomes and symptoms of long-term colorectal cancer survivors	Cross-sectional Survey	EORTC QLQ-CR29	830	68%	> 5 yrs	56%/ 44%	46%/ 52%	15%	X/ 30%/ 31%/ 10%	54%/ 81%/ 95%
Baldwin et al. (2009)	USA	To examine differences in sleep disruption, fatigue and their association with health-related quality of life in males and females with ostomies	Mixed Methods	City of Hope QOL – Ostomy SF-36 Focus Groups	284	52%	>5 yrs	59%/ 41%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR

NR – Not Reported; NA – Not Applicable; X – Excluded; RR – Response Rate; RT – Radiotherapy; CT – Chemotherapy; SX - Surgery

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
Ball et al. (2013)	USA	To understand men's experience with sexual dysfunction following treatment for rectal cancer	Qualitative Interview	Interviews Focus Groups	13	41%	6.4 yrs	100%/ 0%	0%/ 100%	0%	NR/ NR/ NR/ X	39%/ 54%/ 100%
Baravelli et al. (2009)	Australia	To examine follow-up and survivorship care planning for colorectal cancer survivors	Mixed Methods	Evaluation Questionnaire Structured Interview	20 12	80%	NR NR	65%/ 35% 58%/ 42%	15%/ 85% 8%/ 92%	NR NR	10%/ 40%/ 45%/ 5% 0%/ 58%/ 34%/ 8%	NR/ NR/ NR NR/ NR/ NR
Beech et al. (2012)	United Kingdom	To explain the experience of recovery following surgery for colorectal cancer	Qualitative Grounded Theory	Interviews	12	NA	2 wks - 12 mths	42%/ 58%	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR
Bennett et al. (2012)	Australia	To explore and compare differences in self-assessed and healthcare professional-assessed neuropathic symptoms among Oxaliplatin-treated colorectal cancer survivors	Mixed Methods	NCI-CTC PNQ	20	NR	1 yr	35%/ 65%	80%/ 20%	NR	X/ X/ 45%/ 55%	NR/ 100%/ NR
Bouvier et al. (2008)	France	To assess the impact of adjuvant treatments on the quality of life of elderly colorectal cancer survivors	Longitudinal Survey	EORTC QLQ-C30	125	60%	< 12 mths	51%/ 56%	55%/ 52%	NA	57%/ 35%/ 30%/ 10%	14%/ 9%/ 90%
Brawarsky et al. (2013)	USA	To describe the rates of and ethnic disparities in post-operative surveillance for colorectal cancer survivors	Retrospective Cohort Study	Registry Data Insurance Data	38889	NA	< 12 yrs	44%/ 56%	78%/ 23%	NR	30%/ 40%/ 30%/ X	NR/ NR/ 100%
Buffart et al. (2012)	The Netherlands	To describe the relationship between levels of physical activity and quality of life	Cross-sectional Survey	SF-36 (Dutch)	1371	82%	2-11 yrs	56%/ 44%	66%/ 34%	NR	28%/ 39%/ 28%/ 5%	27%/ 27%/ 99%
Bulkley et al. (2013)	USA	To describe the spiritual well-being of colorectal cancer survivors with ostomies	Mixed Methods	City of Hope QOL – Ostomy Open-ended Survey Question	283	53%	>5 yrs	59%/ 41%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR
Caravati-Jouvenceaux et al. (2011)	France	To compare the quality of life of disease-free colorectal cancer survivors at 5, 10 and 15 years post-diagnosis with healthy controls	Longitudinal Survey	SF-36 EORTC QLQ-C30	542	37%	5, 10 and 15 yrs	51%/ 49%	63%/ 37%	11%	41%/ 26%/ 19%/ 2%	21%/ 36%/ 100%
Cardella et al. (2008)	Canada	To assess adherence and barriers to follow-up for colorectal cancer	Retrospective Cohort Study Cross-sectional Survey	Medical record data Original Survey	96 46	49%	< 5 yrs	60%/ 40%	57%/ 43%	NR	21%/ 43%/ 37%/ X	NR/ NR/ NR
Carlsen et al. (2013)	Denmark	To evaluate the impact of socioeconomic and clinical factors on the transitions between work, sickness absence and retirement among colorectal cancer survivors	Retrospective Cohort Study	Registry Data	4343	NA	1-10 yrs	56%/ 44%	57%/ 43%	NR	35%/ 3%/ 32%/ 18%	NR/ NR/ 100%
Cercek et al. (2013)	USA	To evaluate the incidence of FOLFOX-induced amenorrhea in women aged 50 or younger treated with adjuvant therapy for colorectal cancer	Retrospective Cohort Study	Amenorrhea Questionnaire	49	61%	6 mths-1 yrs	0%/ 100%	NR	NR	X/ NR/ NR/ X	NR/ NR/ NR

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
Chambers et al. (2009)	Australia	To investigate the relationship between psychological distress and physical activity among colorectal cancer survivors	Longitudinal Survey	Constructed meaning scale	978	29%	5, 12, 24, 36 mths	56%/ 44%	69%/ 31%	NR	29%/ 31%/ 26%/ 1%	NR/ NR/ NR
Chambers et al. (2012)	Australia	To compare quality of life and psychological distress in colorectal cancer survivors following diagnosis and in the long-term (>5 years)	Longitudinal Survey	FACT-C	763	56%	5 mths and 5 yrs	54%/ 46%	64%/ 36%	15%	33%/ 33%/ 22%/ 0%	NR/ NR/ 98%
Chao et al. (2010)	Taiwan	To examine acceptance of disability and its relationship to other disease-related factors among colorectal cancer survivors	Cross-sectional Survey	Acceptance of Disability Scale	110	100%	<1 - 194 mths	59%/ 41%	NR	32%	NR/ 57%/ 43%/ NR	NR/ NR/ NR
Cooper & Payes (2006)	USA	To describe changes in the use of post-treatment surveillance procedures among colorectal cancer survivors	Retrospective Cohort Study	Registry Data Insurance Data	62882	NA	12, 18 and 36 mths	45%/ 55%	75%/ 25%	NR	7%/ 50%/ 43%/ X	NR/ NR/ NR
Cooper et al. (2008)	USA	To assess adherence to recommended CEA, colonoscopy and follow-up visits following colorectal cancer	Retrospective Cohort Study	Registry Data Insurance Data	9426	NA	<36-42 mths	46%/ 55%	76%/ 24%	NR	NR/ 60%/ 40%/ NR	NR/ NR/ NR
Costrini (2011)	USA	To assess quality of life of rural colorectal cancer survivors	Cross-sectional Survey	SF-36 FACT-C	39	NR	> 12 mths	54%/ 46%	76%/ 24%	NR	13%/ 41%/ 33%/ 8%	13%/ 44%/ 44%
Den Oudsten et al. (2012)	The Netherlands	To compare erectile dysfunction, ejaculation problems, dyspareunia, vaginal dryness, sexual functioning and sexual enjoyment among colorectal cancer survivors with that of normative populations	Cross-sectional Survey	EORTC QLQ-CR38	1359	82%	2-11 yrs	56%/ 44%	68%/ 34%	15%	29%/ 39%/ 28%/ 4%	25%/ 26%/ 100%
Desnoo & Faithfull (2006)	United Kingdom	To explore colorectal cancer survivors' recovery following anterior resection	Qualitative Grounded Theory	Interviews	7	100%	7-20 mths	29%/ 71%	0%/ 100%	0%	NR/ NR/ NR/ NR	14%/ 71%/ 100%
Di Fabio et al. (2008)	Italy	To explore colorectal cancer survivors' quality of life during long-term follow-up, and surgeons' awareness of patient needs	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CR38	62	90%	14-74 mths	58%/ 42%	66%/ 34%	NR	23%/ 39%/ 39%/ 0%	NR/ NR/ NR
Domati et al. (2011)	Italy	To examine the quality of life of colorectal cancer survivors five years after diagnosis	Cross-sectional Survey	SF-36	220	39%	> 5 yrs following diagnosis	57%/ 43%	80%/ 20%	10%	27%/ 49%/ 26%/ X	4%/ 8%/ X
Dunn et al. (2013a)	Australia	To describe the five-year trajectories of health-related quality of life and life satisfaction of long-term colorectal cancer survivors	Longitudinal Survey	FACT-C	1884	59%	5, 12, 24, 36, 48 and 60 mths	NR	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR
Dunn et al. (2013b)	Australia	To describe long-term psychological outcomes and trajectories of adjustment among colorectal cancer survivors	Longitudinal Survey	Brief Symptom Inventory - 18	1884	59%	5, 12, 24, 36, 48 and 60 mths	NR	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
Ellis et al. (2010)	United Kingdom	To establish the prevalence of erectile dysfunction in post-surgery colorectal cancer survivors	Cross-sectional Survey	IIEF	229	46%	1-8 yrs	100%/ 0%	68%/ 32%	38%	NR/ NR/ NR/ NR	26%/ 41%/ 100%
Esplen et al. (2007)	Canada	To examine motivational factors, expectations and psychosocial functioning among colorectal cancer survivors undergoing genetic testing for hereditary non-polyposis colorectal cancer	Cross-sectional Survey	Impact of Events Scale CES Depression Scale The State-Trait Anxiety Inventory	314	35%	< 5 yrs	47%/ 53%	NR	NR	5%/ 29%/ 9%/ 2%	NR/ NR/ NR
Foley et al. (2012)	USA	To determine the proportion of Medicaid-insured colorectal cancer survivors who have had a colonoscopy 3-18 months post-surgery	Retrospective Cohort Study	Registry Data Medicaid Data	1044	NA	3-18 mths	32%/ 68%	83%/ 17%	NR	NR/ 44%/ 56%/ NR	10%/ 34%/ 100%
Fucini et al. (2008)	Italy	To compare the quality of life of long-term rectal cancer survivors treated with low anterior resection to those treated with a standard abdominoperineal excision and stoma	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CR38	30 32	67% 69%	5 yrs	33%/ 67% 44%/ 56%	0%/ 100% 0%/ 100%	100% 0%	NR/ 33%/ 66%/ NR NR/ 44%/ 56%/ NR	33%/ 13%/ 100% 56%/ 9%/ 100%
Goldzweig et al. (2009)	Israel	To assess the impact of marital status and gender on levels of psychological distress, coping and social support in colorectal cancer survivors	Cross-sectional Survey	Brief Symptom Inventory	339	93%	> 24 mths	55%/ 45%	NR	NR	18%/ 62%/ 20%/ 0%	NR/ NR/ NR
Gordon et al. (2008)	Australia	To identify the extent to which people leave work after a diagnosis of colorectal cancer	Longitudinal Survey	Work Participation Survey Items FACT-C	975	57%	< 5 yrs after diagnosis	64%/ 36%	64%/ 32%	NR	23%/ 27%/ 29%/ 2%	14%/ 50%/ 97%
Gosselink et al. (2006)	The Netherlands	To provide a comprehensive insight into functional outcomes, urinary problems, sexual dysfunction and quality of life in rectal cancer patients	Cross-sectional Survey	EQ-5D EORTC QLQ-C30 EORTC QLQ-CR38	204	82%	9-72 mths	62%/ 38%	0%/ 100%	NA	7%/ 49%/ 37%/ 6%	21%/ X/ 100%
Grant et al. (2011)	USA	To describe how gender shapes the concerns and adaptions of long-term colorectal cancer survivors with ostomies	Qualitative Focus Group	Focus Groups	33	NA	> 5 yrs	52%/ 49%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR
Grimmett et al. (2011)	United Kingdom	To examine the prevalence of health-related behaviours and their relationship with quality of life	Cross-sectional Survey	EORTC QLQ-C30	495	49%	< 5 yrs	59%/ 41%	NR	NR	NR/ NR/ NR/ NR	NR/NR/ NR
Haggstrom et al. (2009)	USA	To evaluate the association of physician speciality with the content and quality of follow-up cancer care	Cross-Sectional Survey	Original Survey	303	49%	2-5 yrs	49%/ 51%	NR	NR	29%/ 37%/ 32%/ 2%	NR/ NR/ NR
Hanly et al. (2013)	Ireland	To investigate the patterns and costs of lost productivity due to colorectal cancer in Ireland, and examine how rising pension ages affect these costs	Cross-sectional Survey	Original Survey	159	39%	6-30 mths	62%/ 38%	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
Hauglann et al. (2014)	Norway	To investigate long-term development of sickness absence and disability pension among colorectal cancer survivors compared to cancer free controls	Retrospective Cohort Study	Registry Data: Labour Market Status	648	NA	0-9 yrs	52%/ 49%	60%/ 40%	NR	NR/ 29%/ 41%/ 29%	NR/ NR/ NR
Hoerske et al. (2010)	Germany	To investigate the long-term oncological outcome, late adverse effects and quality of life of rectal cancer survivors	Longitudinal Survey	EORTC QLQ-C30 EORTC QLQ-CR38	268 97	100% 85%	0-14 yrs	62%/ 44% 60%/ 40%	0%/ 100% 0%/ 100%	26% NA	13%/ 15%/ 48%/ 4% X/ X/ X/ X	19%/ 19%/ 96% NR/ NR/ NR
Hornbrook et al. (2011)	USA	To compare the effects of living with a permanent intestinal stoma versus a major bowel resection	Cross-sectional Survey	SF-6D SF-36 City of Hope QOL – Ostomy	640	52%	5-30 yrs	59%/ 41%	27%/ 73%	42%	NR/ NR/ NR/ NR	26%/ 36%/ 100%
Hu et al. (2011)	USA	To determine patient compliance with guideline recommended post-treatment surveillance	Retrospective Cohort Study	Registry Data	7348	NA	43-75 mths	40%/ 60%	100%/ 0%	NR	30%/ 45%/ 25%/ X	NR/ 34%/ NR
Husson et al. (2014)	The Netherlands	To examine the relationship between health literacy and health behaviour and their association with quality of life	Cross-sectional Survey	EORTC QLQ-C30 HADS	1643	83%	2-11 yrs	57%/ 43%	NR	NR	29%/ 35%/ 29%/ 3%	32%/ 30%/ 98%
Jansen et al. (2011a)	Germany	To compare long-term quality of life of colorectal cancer survivors with the general population and investigate changes in quality of life during the 10 years following diagnosis	Longitudinal Survey	EORTC QLQ-C30	117	27%	1-10 yrs after diagnosis	46%/ 54%	63%/ 37%	NR	X/ 74%/ 25%/ 1%	NR/ NR/ NR
Jansen et al. (2011b)	Germany	To investigate benefit finding and post-traumatic growth among long-term colorectal cancer survivors, and their relationship with quality of life	Cross-sectional Survey	EORTC QLQ-C30	483	83%	4.8-6.4 yrs	62%/ 38%	59%/ 41%	NA	33%/ 35%/ 30%/ 3%	18%/ 39%/ 98%
Jansen et al. (2011c)	Germany	To investigate the age-specific pattern of administration of chemotherapy and its association with long-term survival and quality of life in stage II and III colorectal cancer patients	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CR38	312	90%	> 5 yrs	54%/ 46%	66%/ 44%	NA	X/ 52%/ 48%/ X	23%/ 50%/ 100%
Johansson et al. (2014)	Sweden	To explore illness perceptions in relation to contemporary cancer care settings among colorectal cancer survivors and their partners	Qualitative Grounded Theory	Interview	9	NA	3-10 mths	33%/ 67%	33%/ 67%	56%	NR/ NR/ NR/ NR	11%/ 0%/ 100%
Johnson et al. (2009)	USA	To evaluate the association between physical activity and function in older, long-term colorectal cancer survivors	Cross-sectional Survey	SF-36	843	64%	6-12 yrs	48%/ 52%	NR	NR	NR/ NR/ NR/ NR	18%/ 35%/ 97%
Kidwell et al. (2012)	USA	To investigate the presence of excess neurotoxicity among	Cross-section survey Longitudinal survey	NTX-12 (FACIT)	353	34%	4.2-8.6 yrs 4 mths - 8.1 yrs	61%/ 39%	100%/ 0%	NR	NR/ NR/ NR/ NR	NR/ NR/ NR

Author / Year	Country	Aim	Method	Instrument	# Participants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ostomy	Stage I/ II/ III/ IV	RT/ CT/ SX
		colorectal cancer survivors in the long-term			92	23%		65%/ 35%	100%/ 0%	NR	NR/ NR/ NR/ NR	NR/ NR/ NR
Kilic et al. (2012)	Turkey	To examine the long-term effects of adjuvant chemo-radiation on long-term colorectal cancer survivors' quality of life and experience of late side-effects	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CR38	230	NR	>1 yrs (1.1-14.6 yrs)	55%/ 45%	0%/ 100%	NA	NR/ NR/ NR/ NR	100%/ 100%/ N/R
Kim et al. (2014)	USA	To determine the role of ethnicity in the appraisal of cancer's impact upon physical and social well-being	Longitudinal Survey	SF-12	60	71%	2 and 12 mths	70%/ 30%	65%/ 35%	NR	X/ 47%/ 43%/ 10%	NR/ NR/ NR
Knowles et al. (2013)	United Kingdom	To define quality of life and the long-term prevalence of pelvic dysfunction following curative rectal cancer surgery within the context of quality of life	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CR38	381	57%	2-7 yrs	59%/ 41%	64%/ 36%	NA	15%/ 54%/ 32%/ X	13%/ X/ 100%
Krouse et al. (2009)	USA	To identify common challenges of intestinal stomas and their impact on health-related quality of life	Cross-sectional Survey	City of Hope QOL – Ostomy SF-36	491	54%	> 5 yrs	60%/ 40%	0%/ 100%	100%	X/ 50%/ 40%/ 1%	46%/ 44%/ NR
Kunitake et al. (2010)	USA	To examine routine preventative care and cancer surveillance in long-term colorectal cancer survivors	Cross-sectional Survey	Original Survey	708	95%	> 5 yrs	57%/ 43%	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR
Le et al. (2014)	USA	To explore the role of social support in post-colorectal cancer treatment surveillance in African-American cancer survivors	Qualitative Interview	Interviews	60	47%	4-6 yrs	43%/ 57%	NR	NR	30%/ 32%/ 38%/ X	NR/ NR/ NR
Lewis et al. (2014)	USA	To examine the association between change in physical activity and quality of life over a 2-year period beginning at diagnosis	Longitudinal Survey	FACT-C SF-12	453	64%	0-2 yrs	40%/ 60%	100%/ X	NR	NR/ NR/ NR/ NR	NR/ NR/ NR
Li et al. (2014)	China	To examine the impact of socio-demographic and clinical characteristics on health-related quality of life	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CR38	285	65%	6 mths - 9 yrs	64%/ 36%	X/ 100%	17%	30%/ 38%/ 32%/ X	X/ X/ 100%
Liu et al. (2010)	USA	To compare the incidence of complications and quality of life among long-term colorectal cancer survivors with permanent ostomy or anastomosis	Cross-sectional Survey	City of Hope QOL – Ostomy	284 395	50% 50%	> 5 yrs (5-33 yrs)	59%/ 41% 59%/ 41%	12%/ 88% 38%/ 63%	100% X	X/ 49%/ 39%/ 2% X/ 48%/ 50%/ 2%	36%/ 35%/ 100% 19%/ 37%/ 100%
Lowery et al. (2013)	USA	To examine the prevalence and characteristics of pain in a sample of colorectal cancer survivors up to 10 years post-diagnosis	Cross-sectional Survey	Neuropathic Pain - Short form Quality of Life Cancer Survivor Summary	99	50%	16-120 mths	55%/ 45%	NR	NR	X/ 47%/ 39%/ 12%	38%/ 69%/ 100%
Lundy et al. (2009)	USA	To determine the contribution of household income to the variance explained in psychological well-being among colorectal cancer survivors	Cross-sectional Survey	Modified City of Hope QOL – Ostomy SF-36	679	52%	> 5 yrs	NR	NR	42%	NR/ NR/ NR/ NR	NR/ NR/ NR

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
Lynch et al. (2007)	Australia	To examine associations between physical activity and quality of Life, and associations of medical and demographic attributes with quality of life	Longitudinal Survey	FACT-C	1996	57%	< 6 mths	60%/ 40%	70%/ 30%	NA	29%/ 34%/ 38%/ 5%	NR/ NR/ NR
Lynch et al. (2008a)	Australia	To examine the relationships between physical activity and quality of life over two years after diagnosis	Longitudinal Survey	FACT-C	1488	47%	6-24 mths	59%/ 41%	70%/ 30%	8%	27%/ 39%/ 30%/ 4%	X/ X/ X
Lynch et al. (2008b)	Australia	To assess the difficulties experienced by colorectal cancer patients with a temporary or permanent ostomy over two years following diagnosis and satisfaction with information from healthcare providers	Longitudinal Survey	Ostomy-related Items	332	57%	5-24 mths	70%/ 30%	31%/ 69%	100%	16%/ 38%/ 35%/ 10%	NR/ NR/ 100%
Lynch et al. (2008c)	Australia	To assess psychological distress and identify socio-demographic, medical, psychological and lifestyle predictors of distress	Longitudinal Survey	Brief Symptom Inventory	1822	53%	6 and 12 mths	60%/ 40%	70%/ 30%	NR	29%/ 35%/ 33%/ 3%	NR/ NR/ NR
Lynch et al. (2011)	Australia	To examine prospective associations of television viewing time with quality of life	Longitudinal Survey	FACT-C	1266	40%	5, 12, 24 and 36 mths	57%/ 43%	69%/ 31%	16%	36%/ 3%/ 30%/ 1%	NR/ NR/ 93%
McCaughan et al. (2012)	United Kingdom	To explore and compare the experience and coping behaviour of men and women after treatment for colorectal cancer	Qualitative Interview	Interview	38	68%	6-12 mths post-chemotherapy	63%/ 37%	NR	37%	NR/ NR/ NR/ NR	16%/ 71%/ 84%
McMullen et al. (2008)	USA	To describe the greatest challenges reported by long-term colorectal cancer survivors with ostomies	Cross-sectional Survey	Open-ended Question City of Hope QOL – Ostomy	178	56%	> 5 yrs	57%/ 43%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR
McMullen et al. (2011)	USA	To explore why peristomal skin complications are common and undertreated among colorectal cancer survivors	Qualitative Ethnography	Interview	31	30%	> 5 yrs	45%/ 55%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR
McMullen et al. (2014)	USA	To describe the ways informal caregivers participate in healthcare-related activities for colorectal cancer survivors with Ostomies	Qualitative Ethnography	Semi-structured Interviews	31	30%	> 5 yrs	45%/ 55%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR
Milbury et al. (2013)	USA	To identify the contribution of demographic, medical and psychosocial factors to sexual dysfunction	Cross-sectional Survey	IIEF FSFI EORTC QLQ-CR38	261	33%	> 6 mths	55%/ 45%	43%/ 57%	16%	14%/ 40%/ 42%/ 0%	56%/ 80%/ X
Mols et al. (2012a)	The Netherlands	To examine the association between type D personality and illness perceptions among colorectal cancer survivors	Cross-sectional Survey	B-IPQ HADS	3977	80%	1-10 yrs	56%/ 44%	63%/ 37%	NR	29%/ 37%/ 28%/ 5%	29%/ 28%/ 99%
Mols et al. (2013)	The Netherlands	To estimate the prevalence and severity of chemotherapy-induced	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CIPN-20	1643	83%	2-11 yrs	57%/ 43%	59%/ 40%	NR	30%/ 35%/ 30%/ 3%	33%/ 31%/ 100%

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
		peripheral neuropathy and its influence on health-related quality of life										
Mols et al. (2014)	The Netherlands	To examine the physical and mental consequences of an ostomy	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CR38	1019	76%	1-10 yrs	59%/ 41%	0%/ 100%	43%	41%/ 27%/ 25%/ 4%	81%/ 24%/ 99%
Mrak et al. (2011)	Austria	To compare quality of life of long-term rectal cancer survivors following ultra-low anterior resection, total mesorectal excision and J-pouch anastomosis with those following abdominoperineal excision and end colostomy	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CR29	59	90%	37-119 mths	69%/ 31%	0%/ 100%	63%	15%/ 59%/ 24%/ X	70%/ 75%/ 100%
Nikoletti et al. (2008)	Australia	To describe the bowel problems, self-care practices and information needs of patients who have recovered from the acute effects of sphincter-saving surgery	Cross-sectional Survey	Structured Interview: Bowel Problems Self-Care Practice Information Needs	101	71%	6-24 mths	70%/ 30%	NR	NR	NR/ NR/ NR/ NR	18%/ 43%/ 100%
Orsini et al. (2013)	The Netherlands	To investigate the impact of a stoma on health-related quality of life, with a special focus on age	Cross-sectional Survey	SF-36 EORTC QLQ-CR38	143	42%	1-11 yrs	62%/ 38%	0%/ 100%	NA	48%/ 25%/ 28%/ 8%	90%/ 17%/ 100%
Palmer et al. (2013)	USA	To describe the post-treatment goals of colorectal cancer survivors	Qualitative Interview	Semi-structured Interview	41	NA	0-24 mths	78%/ 22%	56%/ 15%	NR	22%/ 34%/ 44%/ X	39%/ 71%/ 100%
Parsons et al. (2012)	USA	To examine the association between lymph node evaluation and comprehensive post-surgical care	Retrospective Cohort Study	Registry Data	17906	NA	6 mths - 3 yrs	41%/ 59%	100%/ NA	NR	X/ X/ 100%/ X	NR/ NR/ 100%
Peddle et al. (2008)	Canada	To examine quality of life and fatigue in colorectal cancer survivors, and their relationship to exercise	Cross-sectional Survey	FACT-C	413	61%	1-16 yrs	55%/ 46%	77%/ 23%	NA	9%/ 13%/ 20%/ 6%	24%/ 53%/ 96%
Phipps et al. (2008)	USA	To investigate the health, functional status and quality of life of long-term colon cancer survivors	Cross-sectional Survey	SF-36 Quality of Life - Cancer Survivor Scale	30	64%	5-14 yrs	50%/ 50%	100%/ 0%	0%	50%/ 27%/ 17%/ 6%	13%/ 73%/ 100%
Pisu et al. (2014)	USA	To explore African-American colorectal cancer survivors' understanding of surveillance instructions and purpose	Qualitative Interview	Interviews	60	60%	4-6 yrs	43%/ 57%	NR	NR	30%/ 32%/ 38%/ X	NR/ NR/ NR
Pucciarelli et al. (2008)	Italy	To investigate health-related quality of life in relation to symptoms and functional outcomes	Cross-sectional Survey	EORTC QLQ-C30 EORTC QLQ-CR38	117	81%	25-176 mths	63%/ 37%	0%/ 100%	9%	45%/ 19%/ 17%/ 3%	68%/ 68%/ 100%
Pullar et al. (2012)	New Zealand	To identify the dietary patterns of colorectal cancer survivors, the level of dietary information received, and its impact upon behaviour	Cross-sectional Survey	Original Questionnaire (No Information)	40	NR	NR	53%/ 47%	58%/ 43%	NR	X/ 15%/ 50%/ 30%	NR/ 88%/ 93%
Ramirez et al. (2009)	USA	To examine the experiences of sexual challenges and adaptions made by female colorectal cancer survivors following ostomy formation	Qualitative Interview	Interviews	30	41%	> 5 yrs	0%/ 100%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR

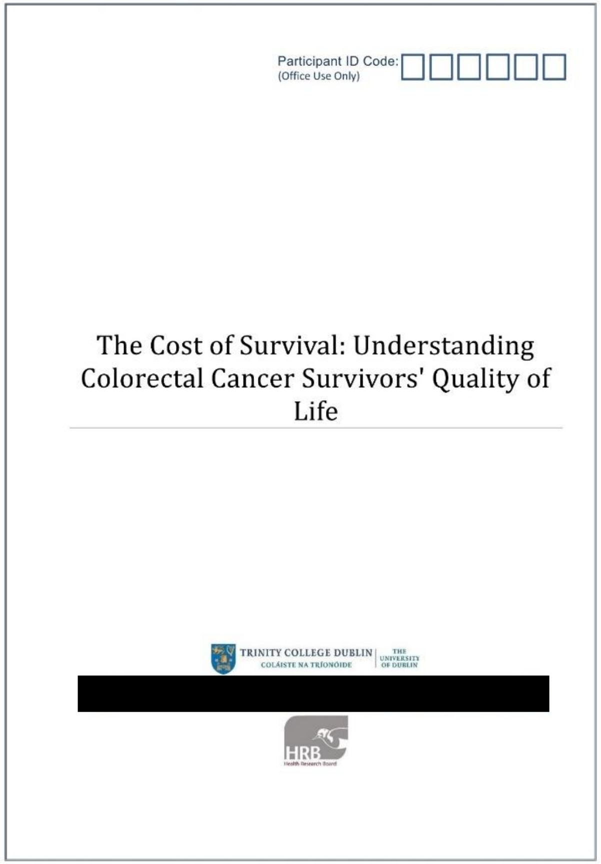
Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
Ramirez et al. (2014)	USA	To understand the changes in bodily function after colorectal cancer in female survivors with ostomies	Qualitative Phenomenological	Interview	30	NR	> 5 yrs	0%/ 100%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR
Rees et al. (2014)	United Kingdom	To describe the long-term impact of liver surgery for colorectal cancer metastases on patient-reported outcomes	Longitudinal Survey	EORTC QLQ-C30 EORTC QLQ-LMC21	232 68	92% 85%	7-9 yrs	70%/ 30% 62%/ 38%	NR NR	NA NA	5%/ 16%/ 29%/ 42% 6%/ 16%/ 29%/ 41%	NR/ NR/ NR NR/ NR/ NR
Ristvedt & Trinkaus (2009)	USA	To determine the influence of trait anxiety of patient reports of health-related quality of life and post-traumatic stress symptoms	Longitudinal Survey	FACT-C	80	53%	<2.5 years	56%/ 44%	0%/ 100%	24%	46%/ 30%/ 19%/ 1%	NR/ NR/ NR
Ronning et al. (2014)	Norway	To examine the role of frailty indicators as predictors of functional decline in older colorectal cancer patients	Longitudinal Survey	EORTC QLQ-C30 ECOG PS	84	69%	16-28 mths	41%/ 59%	NR	NR	NR/ NR/ NR/ NR	X/ X/ 100%
Salsman et al. (2009)	USA	To describe associations between post-traumatic growth, post-traumatic stress disorder symptomatology and mental health	Longitudinal Survey	Mental Health Inventory	55	20%	6-18 mths	41%/ 59%	NR	NR	40%/ 45%/ 15%/ 0%	NR/ NR/ 66%
Salsman et al. (2011)	USA	To examine the association between spiritual well-being (Faith and meaning/peace) and health-related quality of life	Cross-sectional Survey	FACT-C	258 568	NR 53%	1-193 mths 13-32 mths	57%/ 43% 49%/ 51%	NR NR	22% 14%	19%/ 25%/ 34%/ 22% 28%/ 35%/ 30%/ 8%	NR/ NR/ NR NR/ NR/ NR
Salz et al. (2009)	USA	To identify health beliefs that predict intentions to obtain routine colonoscopies among colorectal cancer survivors	Cross-sectional Survey	Structured interviews	277	51%	4 yrs	47%/ 53%	72%/ 28%	NR	32%/ 29%/ 34%/ X	NR/ NR/ NR
Salz et al. (2010)	USA	To describe the rate of surveillance colonoscopy and its association with geographic, socio-demographic, clinical and health services characteristics	Retrospective Cohort Study	Medical Record Data	1423	39%	14 mths	56%/ 41%	79%/ 18%	NR	29%/ 35%/ 35%/ X	NR/ NR/ NR
Salz et al. (2014)	USA	To understand colorectal cancer survivor's information needs	Cross-sectional Survey	Evaluation Questionnaire	175	53%	6-24 mths	51%/ 49%	58%/ 43%	NR	20%/ 27%/ 53%/ X	30%/ 75%/ 98%
Schlesinger et al. (2014)	Germany	To investigate the association between post-diagnosis lifestyle score and health-related quality of life	Cross-sectional Survey	EORTC QLQ-C30	1389	74%	5-9 yrs	56%/ 44%	47%/ 48%	26%	NR/ NR/ NR/ NR	24%/ 43%/ 100%
Schneider et al. (2007)	USA	Describe the patient-reported symptoms of colorectal cancer survivors, surviving at least four years after diagnosis	Cross-sectional Survey	Adapted Instrument (No report of Validity and Reliability)	474	63%	> 4 yrs	51%/ 49%	69%/ 31%	15%	X/ 52%/ 48%/ X	23%/ NR/ NR
Sendur et al. (2014)	Turkey	To identify the severity and absolute risk factors of erectile dysfunction in male colorectal cancer survivors	Cross-sectional Survey	International Index of Erectile Function	61	75%	14-102 mths	100%/ 0%	54%/ 46%	25%	8%/ 46%/ 34%/ 12%	38%/ 82%/ 100%

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
Serpentini et al. (2011)	Italy	To evaluate the psychological well-being outcomes of disease-free rectal cancer survivors	Cross-sectional Survey	Psychological General Well-being Index	117	81%	25-176 mths	63%/ 37%	0%/ 100%	10%	45%/ 19%/ 17%/ 3%	80%/ 80%/ 100%
Shun et al. (2011)	Taiwan	To explore the association between quality of life and type D personality	Cross-sectional Survey	SF-12 Fatigue Symptom Inventory	124	75%	1-123 mths	61%/ 39%	NR	8%	18%/ 35%/ 38%/ 10%	12%/ 66%/ NR
Sigurdsson et al. (2009)	Norway	To examine the utilisation of specialist care in patients with incurable rectal cancer	Retrospective Cohort Study	Registry Data Medical Record Data	287	97%	NR	52%/ 48%	NR	NR	X/ X/ X/ 62%	30%/ 28%/ 64%
Sisler et al. (2012a)	Canada	To examine concordance with the American Society of Clinical Oncology surveillance guidelines among colorectal cancer survivors	Retrospective Longitudinal Cohort Study	Registry Data Repository Data	250	NA	18-42 mths	53%/ 47%	67%/ 33%	NR	X/ 52%/ 48%/ X	21%/ 58%/ NR
Sisler et al. (2012b)	Canada	To examine how colorectal cancer survivors evaluate the continuity and quality of care in primary care models of post-treatment follow-up	Cross-sectional Survey	Patient Continuity of Care Questionnaire FACT-C	246	68%	1-2 yrs	57%/ 43%	62%/ 38%	20%	X/ NR/ NR/ X	29%/ 59%/ 88%
Skeps et al. (2013)	USA	To examine the association between body mass index and ostomy-related problems among long-term colorectal cancer survivors	Cross-sectional Survey	City of Hope QOL – Ostomy	283	53%	> 5 yrs	62%/ 38%	11%/ 89%	100%	NR/ NR/ NR/ NR	41%/ 40%/ 100%
Snyder et al. (2008a)	USA	To examine the physician specialties that long-term survivors visit and how the mix relates to preventative care	Retrospective Longitudinal Cohort Study	Medicare Data	1541	NA	< 5 yrs	43%/ 57%	NR	NR	43%/ 40%/ 17%/ X	NR/ NR/ NR
Snyder et al. (2008b)	USA	To examine patterns of care and preventative care among colorectal cancer survivors in the first year following treatment	Retrospective Cohort Study	Medicare Data	20068	NA	< 1 yrs	45%/ 56%	NR	NR	9%/ 57%/ 35%/ X	NR/ NR/ NR
Standeven et al. (2013)	Canada	To evaluate adherence to surveillance guidelines and outcomes among colorectal cancer survivors enrolled in nurse-led shared follow-up	Retrospective Cohort Study	Medical Record Data	408	NA	< 2 yrs	59%/ 41%	70%/ 72%	NR	X/ 43%/ 57%/ X	30%/ 66%/ 100%
Steginga et al. (2009)	Australia	To assess the influence of medical, socio-demographic, psychological and lifestyle variables on physical, social/family, emotional, functional well-being and colorectal cancer-specific concerns	Longitudinal Survey	FACT-C	1822	53%	6 and 24 mths	60%/ 40%	70%/ 30%	17%	25%/ 35%/ 30%/ 10%	X/ X/ 54%
Stein et al. (2009)	USA	To investigate the prevalence of complementary/alternative medicine use and the medical, demographic and psychosocial correlates among colorectal cancer survivors	Cross-sectional Survey	Profile of Mood States - Short Form	529	36%	1 yrs	48%/ 52%	NR	NR	X/ 45%/ 55%/ 0%	33%/ 61%/ 96%

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
Sun et al. (2013)	USA	To describe persistent ostomy-specific concerns and adaptions in long-term colorectal cancer survivors	Mixed Methods	Qualitative Focus Group Open-ended Survey Question	33 130	NA NA	> 5 yrs (8-19 yrs) > 5 yrs (5-33 yrs)	52%/ 49% 56%/ 44%	NR NR	100% 100%	NR/ NR/ NR/ NR NR/ NR/ NR/ NR	NR/ NR/ NR NR/ NR/ NR
Sun et al. (2014)	USA	To describe the healthcare experiences of long-term colorectal cancer survivors with permanent ostomies	Mixed Methods	Qualitative Focus Group	33	NA	> 5 yrs (8-19 yrs)	52%/ 49%	NR	100%	NR/ NR/ NR/ NR	NR/ NR/ NR
Tan et al. (2014)	Canada	To examine population-based rates of surveillance imaging and endoscopy following curative resection of colorectal cancer	Retrospective Cohort Study	Registry Data	4960	NA	< 5 yrs	NR	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR
Taylor et al. (2011)	United Kingdom	To explain how fear of recurrence can affect individuals recovering from curative colorectal cancer surgery	Qualitative Grounded Theory	Interview	16	NA	NR	NR	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR
Thomas et al. (2014)	Ireland	To investigate the relationship between remoteness from hospital and quality of life	Cross-sectional Survey	EORTC QLQ-C30	496	39%	1-3 yrs	63%/ 38%	62%/ 38%	22%	18%/ 29%/ 36%/ 8%	16%/ 28%/ 86%
Thong et al. (2011a)	The Netherlands	To assess the impact of chemotherapy on general and disease-specific health status of colon cancer survivors	Cross-sectional Survey	SF-36 EORTC QLQ-CR38	848	75%	< 10 yrs	52%/ 48%	100%/ X	NR	22%/ 43%/ 29%/ 6%	2%/ 30%/ 99%
Thong et al. (2011b)	The Netherlands	To assess the impact of pre-operative radiotherapy on general and disease-specific health status of rectal cancer survivors up to 10 years post-diagnosis	Cross-sectional Survey	SF-36 EORTC QLQ-C30 EORTC QLQ-CR38	340	73%	< 10 yrs	66%/ 34%	X/ 100%	33%	16%/ 39%/ 44%/ 1%	71%/ 20%/ 99%
Thong et al. (2013)	The Netherlands	To assess the effect of fatigue on long-term colorectal cancer survivors	Cross-sectional Survey	Fatigue Assessment Scale	2320 1419	79%	< 5 yrs > 5 yrs	57%/ 43% 53%/ 47%	64%/ 36% 59%/ 41%	NR NR	27%/ 36%/ 29%/ 7% 33%/ 38%/ 26%/ 2%	29%/ 31%/ 99% 30%/ 25%/ 100%
Tofthagen et al. (2013a)	USA	To evaluate relationships between neuropathic symptoms, health-related quality of life, depressive symptoms and sleep in colorectal cancer survivors treated with Oxaliplatin	Cross-sectional Survey	SF-36	111	26%	1-7 yrs	51%/ 48%	NR	NA	0%/ 0%/ 71%/ 29%	X/ 100%/ X
Tofthagen et al. (2013b)	USA	To evaluate medications and non-pharmacologic self-management strategies that cancer survivors with Oxaliplatin-induced peripheral neuropathy use to control neuropathic symptoms	Mixed Methods	SF-36 Modified CIPN Assessment Tool Open-ended Survey Question	111	94%	1-8 yrs	51%/ 49%	NR	NR	X/ X/ 71%/ 29%	NR/ 100%/ NR
Vadaparampil et al. (2010)	USA	To evaluate colorectal cancer survivors' level of knowledge about hereditary colorectal cancer	Cross-sectional Survey	Original Hereditary Colorectal Cancer	93	59%	< 5 yrs	61%/ 39%	NR	NR	12%/ 16%/ 59%/ 12%	NR/ NR/ NR

Author / Year	Country	Aim	Method	Instrument	# Partici-pants	RR	Survivorship Period	Male/ Female	Colon/ Rectal	% Ost-omy	Stage I/ II/ III/ IV	RT/ CT/ SX
				Knowledge Questionnaire								
Vallance et al. (2014)	Canada & Australia	To determine the association between moderate-vigorous physical activity and 1) health-related quality of life, 2) physical function and 3) well-being	Cross-sectional Survey	FACT-C	178	19%	6 mths - 3 yrs	56%/ 44%	100%/ 0%	NA	31%/ 30%/ 39%/ X	X/ 45%/ X
Watanabe-Galloway et al. (2014)	USA	To establish the relationship between geographic residence and end-of-life care outcomes	Retrospective Cohort Study	Medicare Data	34975	NA	NR	47%/ 53%	NR	NR	NR/ NR/ NR/ NR	NR/ NR/ NR

Appendix 5.1: The Cost of Survival: Understanding Colorectal Cancer Survivors’ Quality of Life Questionnaire



Participant ID Code: ☐☐☐☐☐☐
(Office Use Only)

The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life

TRINITY COLLEGE DUBLIN | THE UNIVERSITY OF DUBLIN
COLÁISTE NA TRÍONÓIDE

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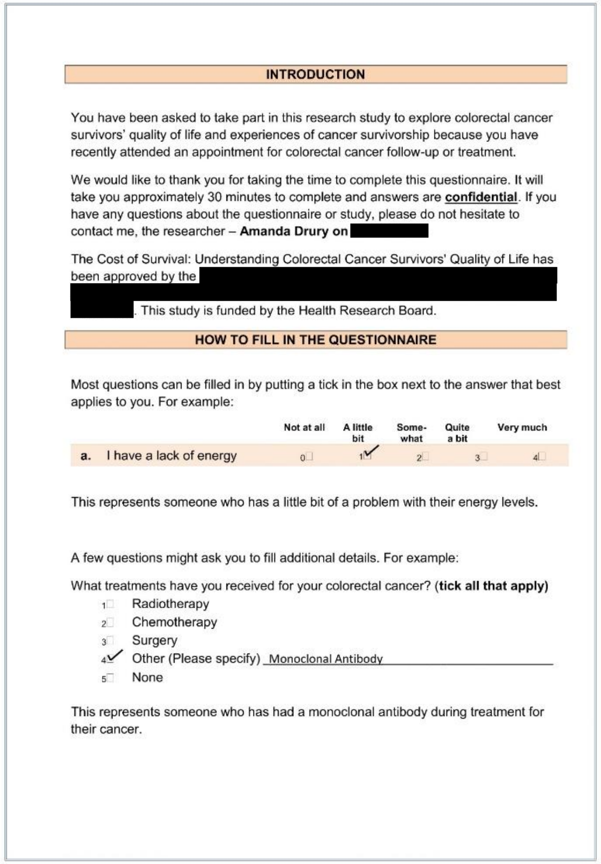
HRB
Health Research Board



INTRODUCTION

You have been asked to take part in this research study to explore colorectal cancer survivors’ quality of life and experiences of cancer survivorship because you have recently attended an appointment for colorectal cancer follow-up or treatment.

We would like to thank you for taking the time to complete this questionnaire. It will take you approximately 30 minutes to complete and answers are **confidential**. If you have any questions about the questionnaire or study, please do not hesitate to contact me, the researcher – **Amanda Drury on** [redacted]

The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life has been approved by the [redacted]. This study is funded by the Health Research Board.

HOW TO FILL IN THE QUESTIONNAIRE

Most questions can be filled in by putting a tick in the box next to the answer that best applies to you. For example:

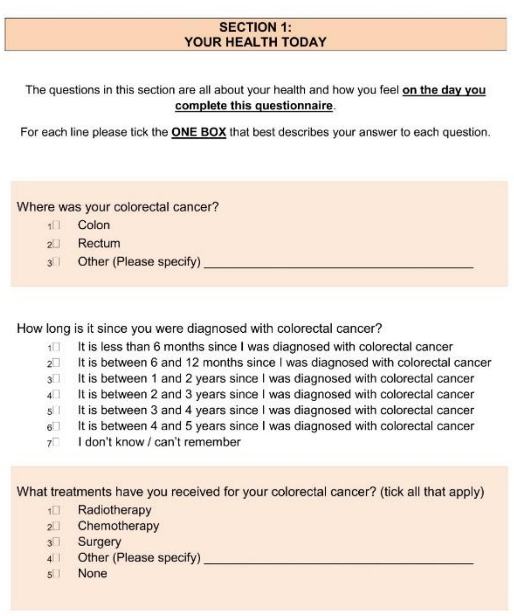
	Not at all	A little bit	Some-what	Quite a bit	Very much
a. I have a lack of energy	0☐	1☑	2☐	3☐	4☐

This represents someone who has a little bit of a problem with their energy levels.

A few questions might ask you to fill additional details. For example:

What treatments have you received for your colorectal cancer? (**tick all that apply**)
1☐ Radiotherapy
2☐ Chemotherapy
3☐ Surgery
4☑ Other (Please specify) Monoclonal Antibody
5☐ None

This represents someone who has had a monoclonal antibody during treatment for their cancer.



SECTION 1:
YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel **on the day you complete this questionnaire**.

For each line please tick the **ONE BOX** that best describes your answer to each question.

Where was your colorectal cancer?
1☐ Colon
2☐ Rectum
3☐ Other (Please specify) ____________________

How long is it since you were diagnosed with colorectal cancer?
1☐ It is less than 6 months since I was diagnosed with colorectal cancer
2☐ It is between 6 and 12 months since I was diagnosed with colorectal cancer
3☐ It is between 1 and 2 years since I was diagnosed with colorectal cancer
4☐ It is between 2 and 3 years since I was diagnosed with colorectal cancer
5☐ It is between 3 and 4 years since I was diagnosed with colorectal cancer
6☐ It is between 4 and 5 years since I was diagnosed with colorectal cancer
7☐ I don't know / can't remember

What treatments have you received for your colorectal cancer? (tick all that apply)
1☐ Radiotherapy
2☐ Chemotherapy
3☐ Surgery
4☐ Other (Please specify) ____________________
5☐ None

Are you currently receiving treatment for your colorectal cancer? (tick all that apply)

1☐ Radiotherapy
2☐ Chemotherapy
3☐ I am waiting for surgery
4☐ I have had surgery within the past 6 weeks
5☐ Other (Please specify) ______________________
6☐ None

How has your colorectal cancer responded to treatment?

1☐ My colorectal cancer has responded fully to treatment (I am in remission)
2☐ My colorectal cancer has been treated but is still present
3☐ My colorectal cancer has not been treated at all
4☐ My colorectal cancer has come back after it was originally treated
5☐ I am not certain what is happening with my colorectal cancer

If you have a stoma (e.g. colostomy) is it:

1☐ Still present
2☐ Reversed
3☐ This does not apply to me

Under each heading, please tick the **ONE BOX** that best describes your health **TODAY**.

MOBILITY

1☐ I have no problems in walking about
2☐ I have slight problems in walking about
3☐ I have moderate problems in walking about
4☐ I have severe problems in walking about
5☐ I am unable to walk about

SELF CARE

1☐ I have no problems washing or dressing myself
2☐ I have slight problems washing or dressing myself
3☐ I have moderate problems washing or dressing myself
4☐ I have severe problems washing or dressing myself
5☐ I am unable to wash or dress myself

USUAL ACTIVITIES (work, study, housework, family or leisure activities)

1☐ I have no problems doing my usual activities
2☐ I have slight problems doing my usual activities
3☐ I have moderate problems doing my usual activities
4☐ I have severe problems doing my usual activities
5☐ I am unable to do my usual activities

PAIN / DISCOMFORT

1☐ I have no pain or discomfort
2☐ I have slight pain or discomfort
3☐ I have moderate pain or discomfort
4☐ I have severe pain or discomfort
5☐ I have extreme pain or discomfort

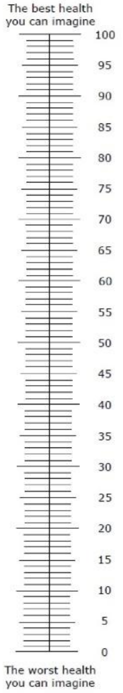
ANXIETY / DEPRESSION

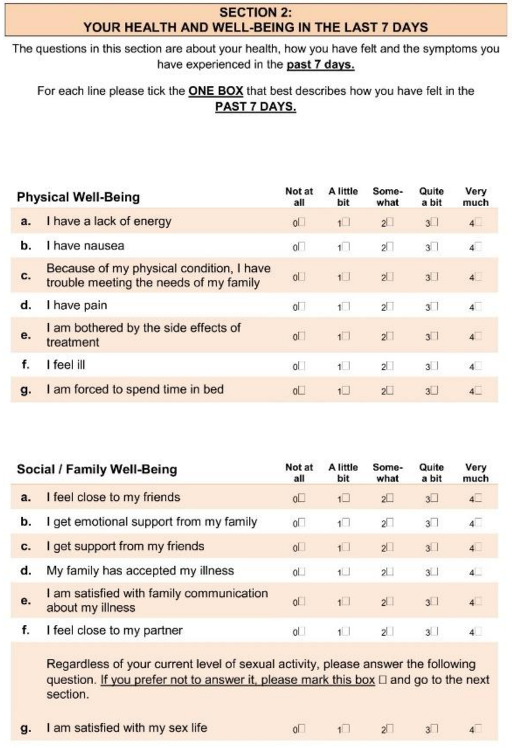
1☐ I am not anxious or depressed
2☐ I am slightly anxious or depressed
3☐ I am moderately anxious or depressed
4☐ I am severely anxious or depressed
5☐ I am extremely anxious or depressed

We would like to know how good or bad your health is TODAY

- This scale is numbered from 0-100.
- 100 means the best health you can imagine.
- 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now please write the number you marked on the scale in the box below:

YOUR HEALTH TODAY = ☐





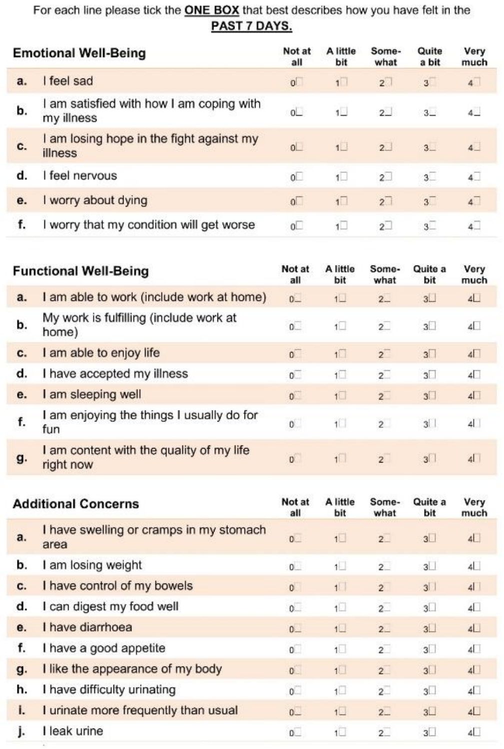
SECTION 2:
YOUR HEALTH AND WELL-BEING IN THE LAST 7 DAYS

The questions in this section are about your health, how you have felt and the symptoms you have experienced in the **past 7 days.**

For each line please tick the **ONE BOX** that best describes how you have felt in the **PAST 7 DAYS.**

Physical Well-Being		**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a.	I have a lack of energy	0☐	1☐	2☐	3☐	4☐
b.	I have nausea	0☐	1☐	2☐	3☐	4☐
c.	Because of my physical condition, I have trouble meeting the needs of my family	0☐	1☐	2☐	3☐	4☐
d.	I have pain	0☐	1☐	2☐	3☐	4☐
e.	I am bothered by the side effects of treatment	0☐	1☐	2☐	3☐	4☐
f.	I feel ill	0☐	1☐	2☐	3☐	4☐
g.	I am forced to spend time in bed	0☐	1☐	2☐	3☐	4☐

Social / Family Well-Being		**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a.	I feel close to my friends	0☐	1☐	2☐	3☐	4☐
b.	I get emotional support from my family	0☐	1☐	2☐	3☐	4☐
c.	I get support from my friends	0☐	1☐	2☐	3☐	4☐
d.	My family has accepted my illness	0☐	1☐	2☐	3☐	4☐
e.	I am satisfied with family communication about my illness	0☐	1☐	2☐	3☐	4☐
f.	I feel close to my partner	0☐	1☐	2☐	3☐	4☐
	Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ and go to the next section.					
g.	I am satisfied with my sex life	0☐	1☐	2☐	3☐	4☐

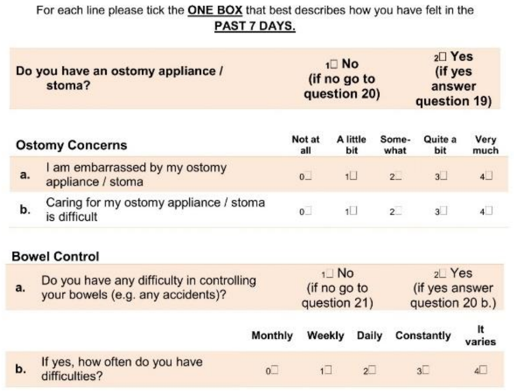


For each line please tick the **ONE BOX** that best describes how you have felt in the **PAST 7 DAYS.**

Emotional Well-Being		**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a.	I feel sad	0☐	1☐	2☐	3☐	4☐
b.	I am satisfied with how I am coping with my illness	0☐	1☐	2☐	3☐	4☐
c.	I am losing hope in the fight against my illness	0☐	1☐	2☐	3☐	4☐
d.	I feel nervous	0☐	1☐	2☐	3☐	4☐
e.	I worry about dying	0☐	1☐	2☐	3☐	4☐
f.	I worry that my condition will get worse	0☐	1☐	2☐	3☐	4☐

Functional Well-Being		**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a.	I am able to work (include work at home)	0☐	1☐	2☐	3☐	4☐
b.	My work is fulfilling (include work at home)	0☐	1☐	2☐	3☐	4☐
c.	I am able to enjoy life	0☐	1☐	2☐	3☐	4☐
d.	I have accepted my illness	0☐	1☐	2☐	3☐	4☐
e.	I am sleeping well	0☐	1☐	2☐	3☐	4☐
f.	I am enjoying the things I usually do for fun	0☐	1☐	2☐	3☐	4☐
g.	I am content with the quality of my life right now	0☐	1☐	2☐	3☐	4☐

Additional Concerns		**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a.	I have swelling or cramps in my stomach area	0☐	1☐	2☐	3☐	4☐
b.	I am losing weight	0☐	1☐	2☐	3☐	4☐
c.	I have control of my bowels	0☐	1☐	2☐	3☐	4☐
d.	I can digest my food well	0☐	1☐	2☐	3☐	4☐
e.	I have diarrhoea	0☐	1☐	2☐	3☐	4☐
f.	I have a good appetite	0☐	1☐	2☐	3☐	4☐
g.	I like the appearance of my body	0☐	1☐	2☐	3☐	4☐
h.	I have difficulty urinating	0☐	1☐	2☐	3☐	4☐
i.	I urinate more frequently than usual	0☐	1☐	2☐	3☐	4☐
j.	I leak urine	0☐	1☐	2☐	3☐	4☐



For each line please tick the **ONE BOX** that best describes how you have felt in the **PAST 7 DAYS.**

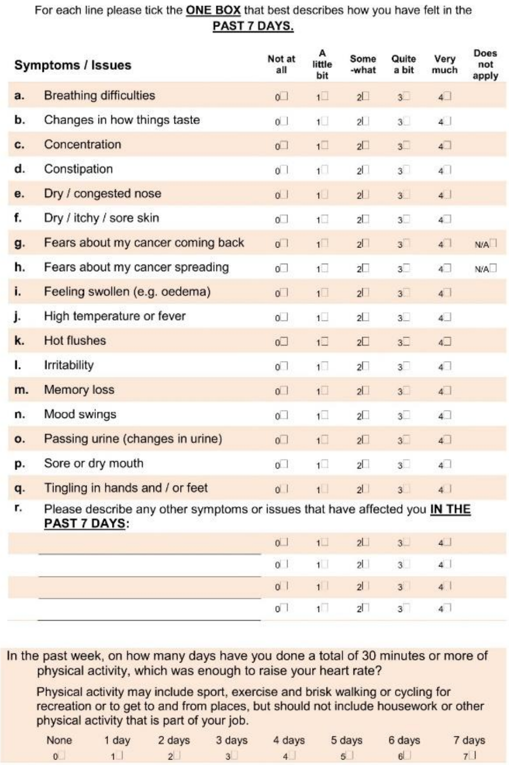
Do you have an ostomy appliance / stoma?	**1☐ No (if no go to question 20)**	**2☐ Yes (if yes answer question 19)**

Ostomy Concerns		**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a.	I am embarrassed by my ostomy appliance / stoma	0☐	1☐	2☐	3☐	4☐
b.	Caring for my ostomy appliance / stoma is difficult	0☐	1☐	2☐	3☐	4☐

Bowel Control

a.	Do you have any difficulty in controlling your bowels (e.g. any accidents)?	1☐ No (if no go to question 21)	2☐ Yes (if yes answer question 20 b.)

		Monthly	**Weekly**	**Daily**	**Constantly**	**It varies**
b.	If yes, how often do you have difficulties?	0☐	1☐	2☐	3☐	4☐



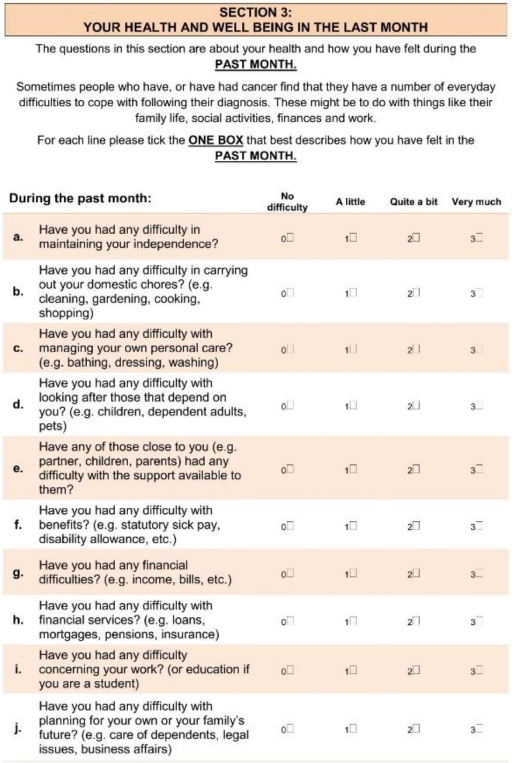
For each line please tick the **ONE BOX** that best describes how you have felt in the **PAST 7 DAYS.**

	Symptoms / Issues	**Not at all**	**A little bit**	**Some -what**	**Quite a bit**	**Very much**	**Does not apply**
a.	Breathing difficulties	0☐	1☐	2☐	3☐	4☐	
b.	Changes in how things taste	0☐	1☐	2☐	3☐	4☐	
c.	Concentration	0☐	1☐	2☐	3☐	4☐	
d.	Constipation	0☐	1☐	2☐	3☐	4☐	
e.	Dry / congested nose	0☐	1☐	2☐	3☐	4☐	
f.	Dry / itchy / sore skin	0☐	1☐	2☐	3☐	4☐	
g.	Fears about my cancer coming back	0☐	1☐	2☐	3☐	4☐	N/A☐
h.	Fears about my cancer spreading	0☐	1☐	2☐	3☐	4☐	N/A☐
i.	Feeling swollen (e.g. oedema)	0☐	1☐	2☐	3☐	4☐	
j.	High temperature or fever	0☐	1☐	2☐	3☐	4☐	
k.	Hot flushes	0☐	1☐	2☐	3☐	4☐	
l.	Irritability	0☐	1☐	2☐	3☐	4☐	
m.	Memory loss	0☐	1☐	2☐	3☐	4☐	
n.	Mood swings	0☐	1☐	2☐	3☐	4☐	
o.	Passing urine (changes in urine)	0☐	1☐	2☐	3☐	4☐	
p.	Sore or dry mouth	0☐	1☐	2☐	3☐	4☐	
q.	Tingling in hands and / or feet	0☐	1☐	2☐	3☐	4☐	
r.	Please describe any other symptoms or issues that have affected you **IN THE PAST 7 DAYS**:						
	____________________	0☐	1☐	2☐	3☐	4☐	
	____________________	0☐	1☐	2☐	3☐	4☐	
	____________________	0☐	1☐	2☐	3☐	4☐	
	____________________	0☐	1☐	2☐	3☐	4☐	

In the past week, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate?

Physical activity may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or other physical activity that is part of your job.

None	1 day	2 days	3 days	4 days	5 days	6 days	7 days
0☐	1☐	2☐	3☐	4☐	5☐	6☐	7☐



SECTION 3:
YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the **PAST MONTH.**

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

For each line please tick the **ONE BOX** that best describes how you have felt in the **PAST MONTH.**

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**
a.	Have you had any difficulty in maintaining your independence?	0☐	1☐	2☐	3☐
b.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	0☐	1☐	2☐	3☐
c.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	0☐	1☐	2☐	3☐
d.	Have you had any difficulty with looking after those that depend on you? (e.g. children, dependent adults, pets)	0☐	1☐	2☐	3☐
e.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	0☐	1☐	2☐	3☐
f.	Have you had any difficulty with benefits? (e.g. statutory sick pay, disability allowance, etc.)	0☐	1☐	2☐	3☐
g.	Have you had any financial difficulties? (e.g. income, bills, etc.)	0☐	1☐	2☐	3☐
h.	Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	0☐	1☐	2☐	3☐
i.	Have you had any difficulty concerning your work? (or education if you are a student)	0☐	1☐	2☐	3☐
j.	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	0☐	1☐	2☐	3☐

For each line please tick the **ONE BOX** that best describes how you have felt in the **PAST MONTH.**

23.	**During the past month:**	**No difficulty**	**A little**	**Quite a bit**	**Very much**
k.	Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	0☐	1☐	2☐	3☐
l.	Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	0☐	1☐	2☐	3☐
m.	Have you had any difficulty concerning sexual matters?	0☐	1☐	2☐	3☐
n.	Have you had any difficulty concerning plans to have a family?	0☐	1☐	2☐	3☐
o.	Have you had any difficulty concerning your appearance or body image?	0☐	1☐	2☐	3☐
p.	Have you felt isolated?	0☐	1☐	2☐	3☐
q.	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	0☐	1☐	2☐	3☐
r.	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	0☐	1☐	2☐	3☐
s.	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	0☐	1☐	2☐	3☐
t.	Have you had any difficulty with your plans to travel or take a holiday?	0☐	1☐	2☐	3☐
u.	Have you had any difficulty with any other area of your everyday life?	0☐	1☐	2☐	3☐

SECTION 4:
OVERALL SUPPORT AND CARE – PART 1

The questions in this section are about the care you received **BEFORE FINISHING YOUR TREATMENT** and / or being discharge from hospital.

For each line please tick the **ONE BOX** that best describes your answer to each statement.

In this section **healthcare provider** refers to the doctor or nurse who is responsible for your care.

BEFORE Discharge		**Strongly Disagree**	**Some-what Disagree**	**Hard to Decide**	**Some-what Agree**	**Strongly Agree**
a.	I was provided with clear information on my diagnosis	1☐	2☐	3☐	4☐	5☐
b.	I was provided with clear information on my prognosis	1☐	2☐	3☐	4☐	5☐
c.	I was told about non-urgent symptoms that may occur and how I should cope with these	1☐	2☐	3☐	4☐	5☐
d.	I was given information on symptoms that may signal a need to seek urgent medical attention and whom to contact for these symptoms (e.g. specialist, general practitioner, homecare)	1☐	2☐	3☐	4☐	5☐
e.	I was given complete information on my medications (e.g. purpose, how given, how often, for how long, how much, side effects)	1☐	2☐	3☐	4☐	5☐
f.	I was given information on follow-up appointments that have been made for me and appointments I have to make for myself	1☐	2☐	3☐	4☐	5☐
g.	I was informed of ongoing treatment that may be required after discharge (e.g. purpose, how, when), and whether I will have ongoing contact with providers of my care (e.g. doctors, nurses, etc.)	1☐	2☐	3☐	4☐	5☐
h.	The different providers appeared to communicate well with each other while I was in hospital/convalescent care	1☐	2☐	3☐	4☐	5☐
i.	A well-developed and realistic follow-up plan was prepared and explained to me	1☐	2☐	3☐	4☐	5☐

SECTION 4:
OVERALL SUPPORT AND CARE – PART 2

The questions in this section are about the care you received **SINCE FINISHING YOUR TREATMENT** and / or being discharge from hospital.

For each line please tick the **ONE BOX** that best describes your answer to each statement.

In this section **healthcare provider** refers to the doctor or nurse who is responsible for your care.

AFTER Discharge		**Strongly Disagree**	**Some-what Disagree**	**Hard to Decide**	**Some-what Agree**	**Strongly Agree**	**Not applicable**
a.	I feel "known" (e.g. current health condition) by my present healthcare provider who has taken over my care since discharge	1☐	2☐	3☐	4☐	5☐	N/A☐
b.	I have confidence in my present healthcare providers who have taken over my care since discharge	1☐	2☐	3☐	4☐	5☐	N/A☐
c.	I am satisfied with the information from my healthcare providers who have taken over my care since discharge	1☐	2☐	3☐	4☐	5☐	N/A☐
d.	I am satisfied with the opportunity to talk and raise questions with my healthcare providers who have taken over my care since discharge	1☐	2☐	3☐	4☐	5☐	N/A☐
e.	As far as I am aware, the different healthcare providers in hospital have communicated well with those in the community about my care	1☐	2☐	3☐	4☐	5☐	N/A☐
f.	As far as I am aware, my general practitioner or other key provider was contacted and informed about the important aspects of care that I received (e.g. diagnosis, prognosis, treatment, medications, etc.)	1☐	2☐	3☐	4☐	5☐	N/A☐
g.	As far as I am aware, necessary forms were all completed	1☐	2☐	3☐	4☐	5☐	N/A☐
h.	As far as I am aware, necessary forms were sent to all appropriate places / providers	1☐	2☐	3☐	4☐	5☐	N/A☐
i.	As far as I am aware, no forms or information were lost when I was discharged	1☐	2☐	3☐	4☐	5☐	N/A☐

SECTION 4:
OVERALL SUPPORT AND CARE – PART 3

For each line please tick the **ONE BOX** that best describes your answer to each question.

Do you have an up-to-date written care plan?

A care plan is a document that sets out your needs and goals for caring for your cancer.

1☐ Yes, definitely
2☐ Yes, I think so
3☐ No
4☐ I do not need a care plan
5☐ Don't know

1. Did you receive a written treatment summary at the end of your cancer treatment?

A treatment summary is a document that contains information about the treatments you received for your cancer (e.g. radiotherapy, chemotherapy, surgery).

1☐ Yes, definitely
2☐ Yes, I think so
3☐ No
4☐ I do not need a treatment summary
5☐ Don't know

Do you have a NAMED NURSE who you can contact if you have a worry about your cancer?

1☐ Yes, definitely
2☐ No
3☐ Don't know

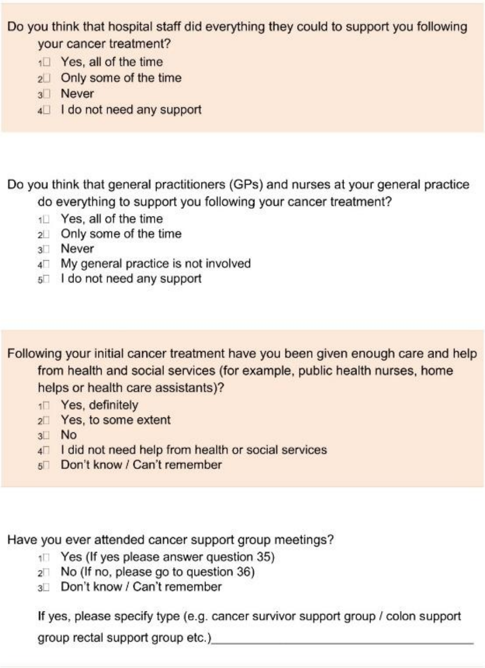
Do you have a NAMED DOCTOR who you can contact if you have a worry about your cancer?

1☐ Yes, definitely
2☐ No
3☐ Don't know

Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1☐ Yes, definitely
2☐ Yes, I think so
3☐ No

If yes, please specify (nurse, doctor, etc.)______________________________



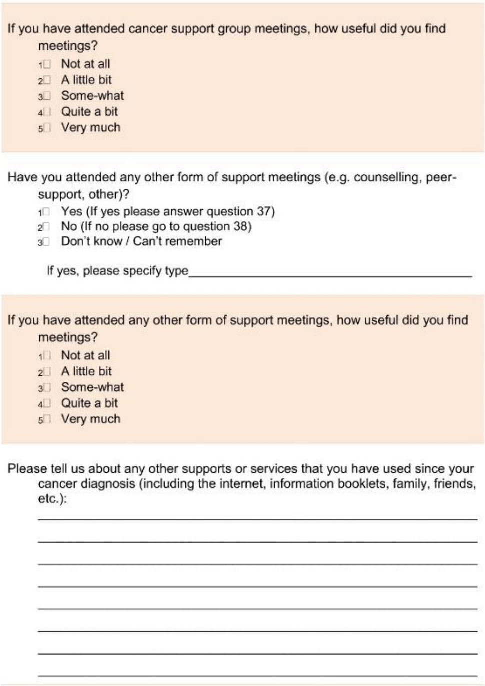
Do you think that hospital staff did everything they could to support you following your cancer treatment?
- 1☐ Yes, all of the time
- 2☐ Only some of the time
- 3☐ Never
- 4☐ I do not need any support

Do you think that general practitioners (GPs) and nurses at your general practice do everything to support you following your cancer treatment?
- 1☐ Yes, all of the time
- 2☐ Only some of the time
- 3☐ Never
- 4☐ My general practice is not involved
- 5☐ I do not need any support

Following your initial cancer treatment have you been given enough care and help from health and social services (for example, public health nurses, home helps or health care assistants)?
- 1☐ Yes, definitely
- 2☐ Yes, to some extent
- 3☐ No
- 4☐ I did not need help from health or social services
- 5☐ Don't know / Can't remember

Have you ever attended cancer support group meetings?
- 1☐ Yes (If yes please answer question 35)
- 2☐ No (If no, please go to question 36)
- 3☐ Don't know / Can't remember

If yes, please specify type (e.g. cancer survivor support group / colon support group rectal support group etc.)______________________________



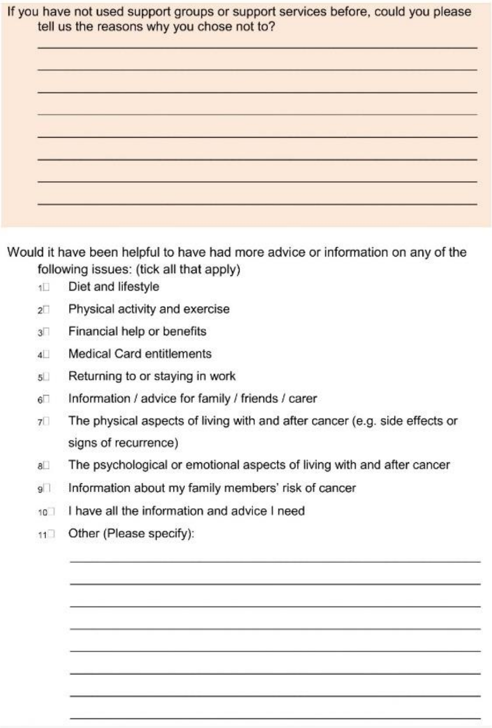
If you have attended cancer support group meetings, how useful did you find meetings?
- 1☐ Not at all
- 2☐ A little bit
- 3☐ Some-what
- 4☐ Quite a bit
- 5☐ Very much

Have you attended any other form of support meetings (e.g. counselling, peer-support, other)?
- 1☐ Yes (If yes please answer question 37)
- 2☐ No (If no please go to question 38)
- 3☐ Don't know / Can't remember

If yes, please specify type______________________________

If you have attended any other form of support meetings, how useful did you find meetings?
- 1☐ Not at all
- 2☐ A little bit
- 3☐ Some-what
- 4☐ Quite a bit
- 5☐ Very much

Please tell us about any other supports or services that you have used since your cancer diagnosis (including the internet, information booklets, family, friends, etc.):



If you have not used support groups or support services before, could you please tell us the reasons why you chose not to?

Would it have been helpful to have had more advice or information on any of the following issues: (tick all that apply)
- 1☐ Diet and lifestyle
- 2☐ Physical activity and exercise
- 3☐ Financial help or benefits
- 4☐ Medical Card entitlements
- 5☐ Returning to or staying in work
- 6☐ Information / advice for family / friends / carer
- 7☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
- 8☐ The psychological or emotional aspects of living with and after cancer
- 9☐ Information about my family members' risk of cancer
- 10☐ I have all the information and advice I need
- 11☐ Other (Please specify):

SECTION 5
ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patients and not your own.

What year were you born?
(Please write in)

e.g. 1 9 4 4

Y Y Y Y

Are you male or female?
1☐ Male
2☐ Female

Which statement best describes your living arrangements?
1☐ I live with partner / spouse / family / friends
2☐ I live alone
3☐ I live in a nursing home, hospital or other long term care home
4☐ Other (Please specify) ____________________

Do you live in an urban or rural area?
1☐ Urban
2☐ Rural

Do you have:
1☐ Private health insurance
2☐ Medical card
3☐ Other health benefit (Please specify)____________________
4☐ None of the above

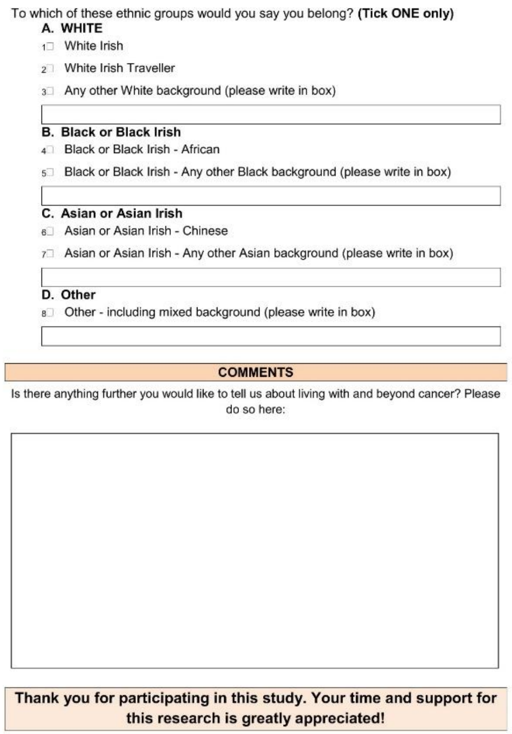
Do you have a long standing health condition other than colorectal cancer?
Please include anything other than your cancer that has troubled you over a period of time or that could affect you over a period of time.
1☐ Yes (If yes please answer question 47)
2☐ No (If no please go to question 48)
3☐ Don't know / Can't say

Which, if any, of the following conditions do you have? (tick all that apply)
1☐ Alzheimer's disease or dementia
2☐ Angina
3☐ Arthritis
4☐ Asthma or other chronic chest problem
5☐ Blindness or visual impairment
6☐ Deafness or hearing impairment
7☐ Diabetes
8☐ Epilepsy
9☐ Heart condition
10☐ High blood pressure
11☐ High cholesterol
12☐ Kidney disease
13☐ Learning difficulty
14☐ Liver disease
15☐ Long-term back problems
16☐ Long-standing mental health problem
17☐ Long-standing neurological problem
18☐ Osteoporosis
19☐ Skin condition
20☐ Stomach ulcer
21☐ Stroke
22☐ Another long-standing condition (Please specify)________________
____
23☐ Another form of cancer (Please specify)____________________
____

What was your employment status <u>before you were diagnosed with cancer</u>?
1☐ Full time employment
2☐ Part time employment
3☐ Homemaker
4☐ Student (in education)
5☐ Retired
6☐ Unemployed and seeking work
7☐ Unemployed and unable to work for health reasons
8☐ Other (please describe) ____________________
____

What is your employment status currently?
If on maternity or sick leave answer in relation to your usual employment status
1☐ Full time employment
2☐ Part time employment
3☐ Homemaker
4☐ Student (in education)
5☐ Retired
6☐ Unemployed and seeking work
7☐ Unemployed and unable to work for health reasons
8☐ Other (please describe) ____________________
____

If you are currently employed, are you:
1☐ Working less hours than before your illness
2☐ Working your usual hours
3☐ Working more hours than before your illness
4☐ Not working at all (due to illness or other reasons)
5☐ This question does not apply to me



To which of these ethnic groups would you say you belong? **(Tick ONE only)**

A. WHITE

1☐ White Irish

2☐ White Irish Traveller

3☐ Any other White background (please write in box)

B. Black or Black Irish

4☐ Black or Black Irish - African

5☐ Black or Black Irish - Any other Black background (please write in box)

C. Asian or Asian Irish

6☐ Asian or Asian Irish - Chinese

7☐ Asian or Asian Irish - Any other Asian background (please write in box)

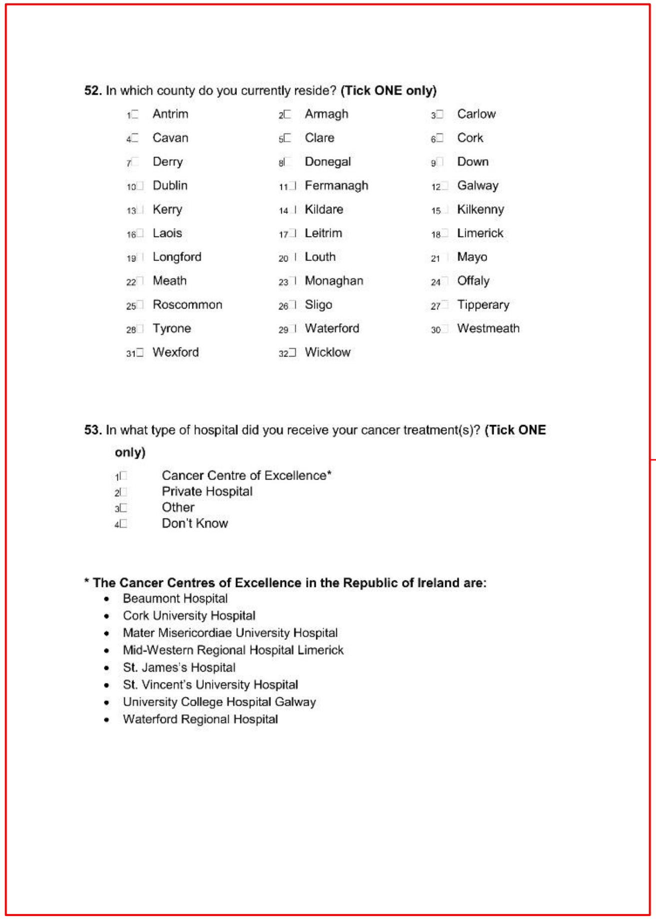
D. Other

8☐ Other - including mixed background (please write in box)

COMMENTS

Is there anything further you would like to tell us about living with and beyond cancer? Please do so here:

Thank you for participating in this study. Your time and support for this research is greatly appreciated!



52. In which county do you currently reside? **(Tick ONE only)**

1☐ Antrim
2☐ Armagh
3☐ Carlow
4☐ Cavan
5☐ Clare
6☐ Cork
7☐ Derry
8☐ Donegal
9☐ Down
10☐ Dublin
11☐ Fermanagh
12☐ Galway
13☐ Kerry
14☐ Kildare
15☐ Kilkenny
16☐ Laois
17☐ Leitrim
18☐ Limerick
19☐ Longford
20☐ Louth
21☐ Mayo
22☐ Meath
23☐ Monaghan
24☐ Offaly
25☐ Roscommon
26☐ Sligo
27☐ Tipperary
28☐ Tyrone
29☐ Waterford
30☐ Westmeath
31☐ Wexford
32☐ Wicklow

53. In what type of hospital did you receive your cancer treatment(s)? **(Tick ONE only)**

1☐ Cancer Centre of Excellence*
2☐ Private Hospital
3☐ Other
4☐ Don't Know

*** The Cancer Centres of Excellence in the Republic of Ireland are:**

- Beaumont Hospital
- Cork University Hospital
- Mater Misericordiae University Hospital
- Mid-Western Regional Hospital Limerick
- St. James's Hospital
- St. Vincent's University Hospital
- University College Hospital Galway
- Waterford Regional Hospital

Phase 1b Questionnaire Supplementary Questions

Appendix 5.2: Questionnaire Permission

1. The Patient Reported Outcome Measures Living with and Beyond Colorectal / GastroIntestinal Cancer Questionnaire

Amanda,

Apologies for not replying sooner.

I am content for you to use the questionnaire for non-profit purposes.

As you are aware, the questionnaires have content which has other copyright owners, e.g. FACIT; SDI and EuroQol. You will need to receive permissions from each owner separately. I note you have already been in touch with these organisations.

Kind regards

David Glover

Economic Adviser | PROMs Analysis | NHS England Analytical Service

2. The FACT-C Questionnaire

Hi Amanda,

Sure, non-commercial use of the FACIT questionnaires is free of charge, so you have our permission. If you make adjustments to the wording of the FACT-C specifically, you'll need to note the revisions in any publications or reports resulting from your study. Let me know if you have any other questions.

Kind regards,
Jason

Jason Bredle
FACIT.org

3. The Social Difficulties Inventory

Dear Amanda
Thank you for your request to use the social difficulties Inventory (SDI-21) which I am happy to agree to as long as any work published references the questionnaire appropriately. I'd be interested in hearing about any changes you make to the questionnaire and how you get on with it.
I have attached some papers which describe the development and evaluation of the questionnaire and list the full set below, if you want one which is not attached let me know. I have also attached the original questionnaire and information on scoring.
Please get in touch if you have any queries.
With kind regards
Penny

4. The EuroQol 5D-5L

Dear Amanda,

As the study you registered involves low patient numbers (350) you may use the EQ-5D-5L instrument (Paper version) free of charge. Please note that separate permission is required if any of the following is applicable:
- Funded by a pharmaceutical company, medical device manufacturer or other profit-making stakeholder;
- Number of respondents over 5000
- Routine Outcome Measurement;
- Developing or maintaining a Registry;
- Digital representations (e.g. PDA, Tablet or Web)

Please find attached the English (Ireland) EQ-5D-5L version (word format). A brief user guide is downloadable from the EuroQol website (www.euroqol.org).
Please note that currently we do not have value sets associated with the EQ-5D-5L system. Valuation studies to elicit values for the EQ-5D-5L are just beginning in a number of countries. In the meantime, the EuroQol Group has developed a "crosswalk" between the EQ-5D-3L value sets and the new EQ-5D-5L descriptive system, resulting in interim value sets for the new EQ-5D-5L descriptive system. Please find all information about the crosswalk from EQ-5D-5L data to the EQ-5D-3L value sets online at the EuroQol website (http://www.euroqol.org/about-eq-5d/valuation-of-eq-5d/eq-5d-5l-value-sets.html).
Kind regards,

Gerben Bakker
User Support Officer
EuroQol Group Foundation

5. Patient Continuity of Care Questionnaire

Hello Amanda,

Yes you have my permission to use this measure and to make modifications. Please be sure to reference my article in your work.

Best wishes with your research,

Heather

Appendix 5.3: Phase 1a Letter of Invitation

COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH | TRINITY COLLEGE DUBLIN
Ollscoil Átha Cliath | The University of Dublin

[redacted]

Research Study: The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life

Dear sir/madam

I am a nurse researcher from the School of Nursing and Midwifery, Trinity College Dublin. I am inviting all patients who have attended [redacted] for colorectal cancer treatment over the past five years to take part in a research study to explore colorectal cancer survivors' quality of life and experiences of cancer survivorship. Your consultant / nurse has identified you as a suitable potential participant for this study, and has invited you to participate in this study.

This study aims to explore colon and rectal cancer survivors' quality of life and the physical and psychological side effects experienced after treatment for colorectal cancer. I hope to use the findings of this study to find ways to improve the health of cancer survivors and improve medical and social services for cancer survivors.

If you choose to participate in this study, you are asked to complete and return the consent form and questionnaire within four weeks. You may be asked to participate in a follow-up interview or future postal questionnaires relating to this study. These interviews will be conducted between September 2015 and February 2016. If you do not wish to participate in these interviews or questionnaires you may inform the researcher.

I have included a detailed information booklet about the study with this letter, please take the time to read this. I have included my contact details in the booklet, if you require any further information, please do not hesitate to contact me at [redacted].

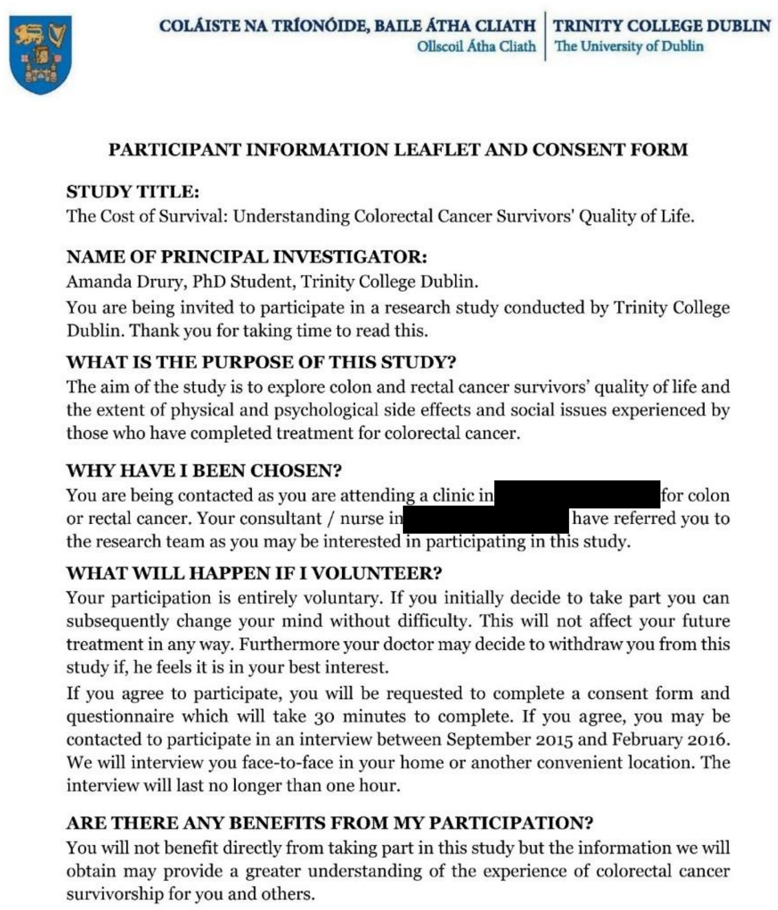
Thank you for taking the time to read this letter and information booklet.

Yours sincerely,

____

Amanda Drury

Appendix 5.4: Phase 1a Participant Information Leaflet and Consent



COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH | TRINITY COLLEGE DUBLIN
Ollscoil Átha Cliath | The University of Dublin

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

STUDY TITLE:

The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life.

NAME OF PRINCIPAL INVESTIGATOR:

Amanda Drury, PhD Student, Trinity College Dublin.

You are being invited to participate in a research study conducted by Trinity College Dublin. Thank you for taking time to read this.

WHAT IS THE PURPOSE OF THIS STUDY?

The aim of the study is to explore colon and rectal cancer survivors' quality of life and the extent of physical and psychological side effects and social issues experienced by those who have completed treatment for colorectal cancer.

WHY HAVE I BEEN CHOSEN?

You are being contacted as you are attending a clinic in [redacted] for colon or rectal cancer. Your consultant / nurse in [redacted] have referred you to the research team as you may be interested in participating in this study.

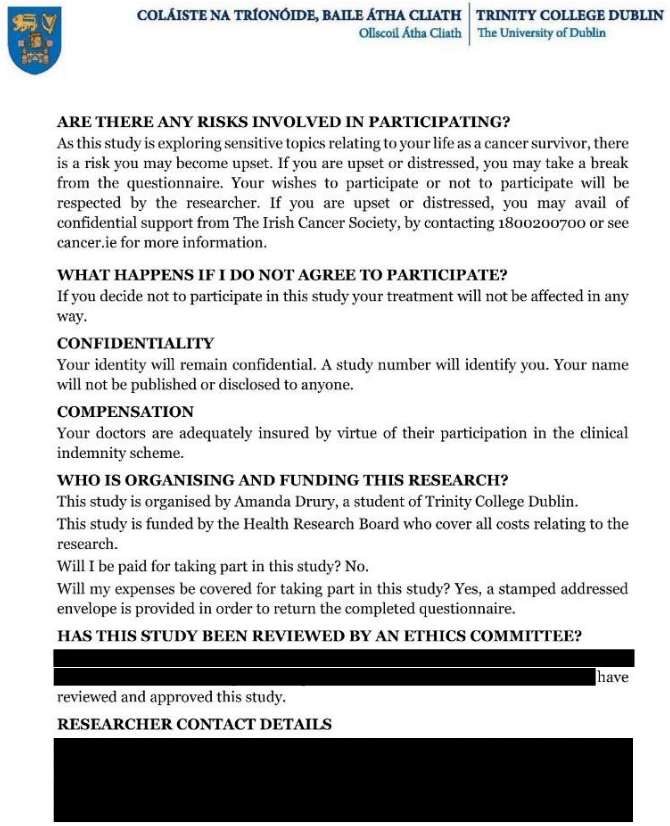
WHAT WILL HAPPEN IF I VOLUNTEER?

Your participation is entirely voluntary. If you initially decide to take part you can subsequently change your mind without difficulty. This will not affect your future treatment in any way. Furthermore your doctor may decide to withdraw you from this study if, he feels it is in your best interest.

If you agree to participate, you will be requested to complete a consent form and questionnaire which will take 30 minutes to complete. If you agree, you may be contacted to participate in an interview between September 2015 and February 2016. We will interview you face-to-face in your home or another convenient location. The interview will last no longer than one hour.

ARE THERE ANY BENEFITS FROM MY PARTICIPATION?

You will not benefit directly from taking part in this study but the information we will obtain may provide a greater understanding of the experience of colorectal cancer survivorship for you and others.



COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH | TRINITY COLLEGE DUBLIN
Ollscoil Átha Cliath | The University of Dublin

ARE THERE ANY RISKS INVOLVED IN PARTICIPATING?

As this study is exploring sensitive topics relating to your life as a cancer survivor, there is a risk you may become upset. If you are upset or distressed, you may take a break from the questionnaire. Your wishes to participate or not to participate will be respected by the researcher. If you are upset or distressed, you may avail of confidential support from The Irish Cancer Society, by contacting 1800200700 or see cancer.ie for more information.

WHAT HAPPENS IF I DO NOT AGREE TO PARTICIPATE?

If you decide not to participate in this study your treatment will not be affected in any way.

CONFIDENTIALITY

Your identity will remain confidential. A study number will identify you. Your name will not be published or disclosed to anyone.

COMPENSATION

Your doctors are adequately insured by virtue of their participation in the clinical indemnity scheme.

WHO IS ORGANISING AND FUNDING THIS RESEARCH?

This study is organised by Amanda Drury, a student of Trinity College Dublin.

This study is funded by the Health Research Board who cover all costs relating to the research.

Will I be paid for taking part in this study? No.

Will my expenses be covered for taking part in this study? Yes, a stamped addressed envelope is provided in order to return the completed questionnaire.

HAS THIS STUDY BEEN REVIEWED BY AN ETHICS COMMITTEE?

[redacted] have reviewed and approved this study.

RESEARCHER CONTACT DETAILS

[redacted]

COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH | TRINITY COLLEGE DUBLIN
Ollscoil Átha Cliath | The University of Dublin

CONSENT FORM

Please complete this form and return it with your questionnaire

PLEASE TICK YOUR RESPONSE IN THE APPROPRIATE BOX

I have read and understood the Participant Information Leaflet	YES ☐	NO ☐
I have had the opportunity to ask questions and discuss the study	YES ☐	NO ☐
I have received satisfactory answers to all my questions	YES ☐	NO ☐
I have received enough information about this study	YES ☐	NO ☐
I understand that I am free to withdraw from the study at any time without giving a reason and without this affecting my future medical care	YES ☐	NO ☐
I agree to take part in the study	YES ☐	NO ☐
I agree to participate in an interview about this study, if required	YES ☐	NO ☐
I agree to receive future questionnaires relating to this study	YES ☐	NO ☐

Participant's Signature: ____________________ Date: _______

Participant's Name in print: ______________________________

Investigator's Signature: ____________________ Date: _______

Investigator's Name in print: ______________________________

Complete if agreeing to be contacted about this study in the future:

I understand that I may be contacted in the future to participate in an interview or questionnaire(s) relating to this study, I understand I have the right to decline such correspondence.

Participant's Name: ______________________________

ID Code: ______________________________

Address: ______________________________

____

____

Phone Number: ______________________________

COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH | TRINITY COLLEGE DUBLIN
Ollscoil Átha Cliath | The University of Dublin

CONSENT FORM

Please complete this form and retain it for your personal records

PLEASE TICK YOUR RESPONSE IN THE APPROPRIATE BOX

I have read and understood the Participant Information Leaflet	YES ☐	NO ☐
I have had the opportunity to ask questions and discuss the study	YES ☐	NO ☐
I have received satisfactory answers to all my questions	YES ☐	NO ☐
I have received enough information about this study	YES ☐	NO ☐
I understand that I am free to withdraw from the study at any time without giving a reason and without this affecting my future medical care	YES ☐	NO ☐
I agree to take part in the study	YES ☐	NO ☐
I agree to participate in an interview about this study, if required	YES ☐	NO ☐
I agree to receive future questionnaires relating to this study	YES ☐	NO ☐

Participant's Signature: ____________________ Date: _______

Participant's Name in print: ______________________________

Investigator's Signature: ____________________ Date: _______

Investigator's Name in print: ______________________________

Complete if agreeing to be contacted about this study in the future:

I understand that I may be contacted in the future to participate in an interview or questionnaire(s) relating to this study, I understand I have the right to decline such correspondence.

Participant's Name: ______________________________

ID Code: ______________________________

Address: ______________________________

____

____

Phone Number: ______________________________

Appendix 5.5: Phase 1b Poster Advertisement

Colorectal Cancer Survival Study

Research Study:

Online Survey for Colon and Rectal Cancer Patients and Survivors

Have you been diagnosed with bowel cancer within the past five years?

Did you receive treatment within an Irish hospital for your bowel cancer?

Are you 18 years of age or older?

We are trying to understand the experiences of bowel cancer survivors, and the physical, psychological and social impacts of bowel cancer and its treatment. We would like your input.

- This online survey will take between 15 and 30 minutes to complete.
- An online version of the questionnaire is available at http://www.colorectalcancerstudy.ie/
- If you would prefer, a paper version of the questionnaire is available. You may contact the researcher, Amanda Drury to request one at [redacted].
- Ethical approval for this study has been granted by Research Ethics Committee of The School of Nursing and Midwifery, Trinity College Dublin.

Study Title: The Colorectal Cancer Survival Study
Researcher Name: Amanda Drury, PhD Student
Organisation: School of Nursing and Midwifery, Trinity College Dublin
Contact Number: [redacted]
Email: [redacted]
Study Website: www.colorectalcancerstudy.ie

Trinity College Dublin
The University of Dublin

HRB
Health Research Board

Appendix 5.6: Phase 2 Interview Schedule

Interview Checklist
Given & explained information leaflet
Any questions?
Sign Consent
Test recording device
Ensure participant's comfort

Warm-Up Question
A. How long has it been since you completed treatment for your colon / rectal cancer?

Central Interview Questions
A. Could you please tell me about your experiences of living with / after colon / rectal cancer? **Broadly Addresses Objectives 1 and 7**
B. Could you tell me about the healthcare you have received since your treatment for colon / rectal cancer? **Broadly Addresses Objectives: 3, 4, 5 and 7.**

Possible Prompts:

Quality of Life / Symptom Experience: **Addresses Objectives: 1 and 7**
1. Physical Well-being:
A. Tell me about the main symptoms/side-effects you have experienced since completing your initial cancer treatment? How do these symptoms affect your daily life?
2. Social / Family Well-being
A. How have your family and friends helped you since completing your initial cancer treatment?
B. Has having cancer had any impact on your relationships with your family and friends?
3. Emotional Well-being
A. With regard to your cancer, could you tell me about the worries you have for you or your family?
4. Functional Well-being
A. Could you tell me about any positive changes or experiences in your life since completing your cancer treatment?
B. Could you tell me about any negative changes or experiences in your life since completing your cancer treatment?

Follow-up Care / Unmet Needs: Supportive Care Needs **Addresses Objectives: 3 and 4**
1. Support Provided by Healthcare Professionals
A. Could you tell me about the support you have received from healthcare professionals to manage your symptoms / side-effects / worries about your cancer since completing your treatment?
2. Support Provided by Advocacy Organisations
A. Could you tell me about support you have received outside the hospital from other organisations, family, friends or others?
4. Overall Experience of Support
A. What do you feel has best helped you to cope with the symptoms / side-effects of your cancer treatment?
B. Do you feel you needed any additional care or support that you did not receive?

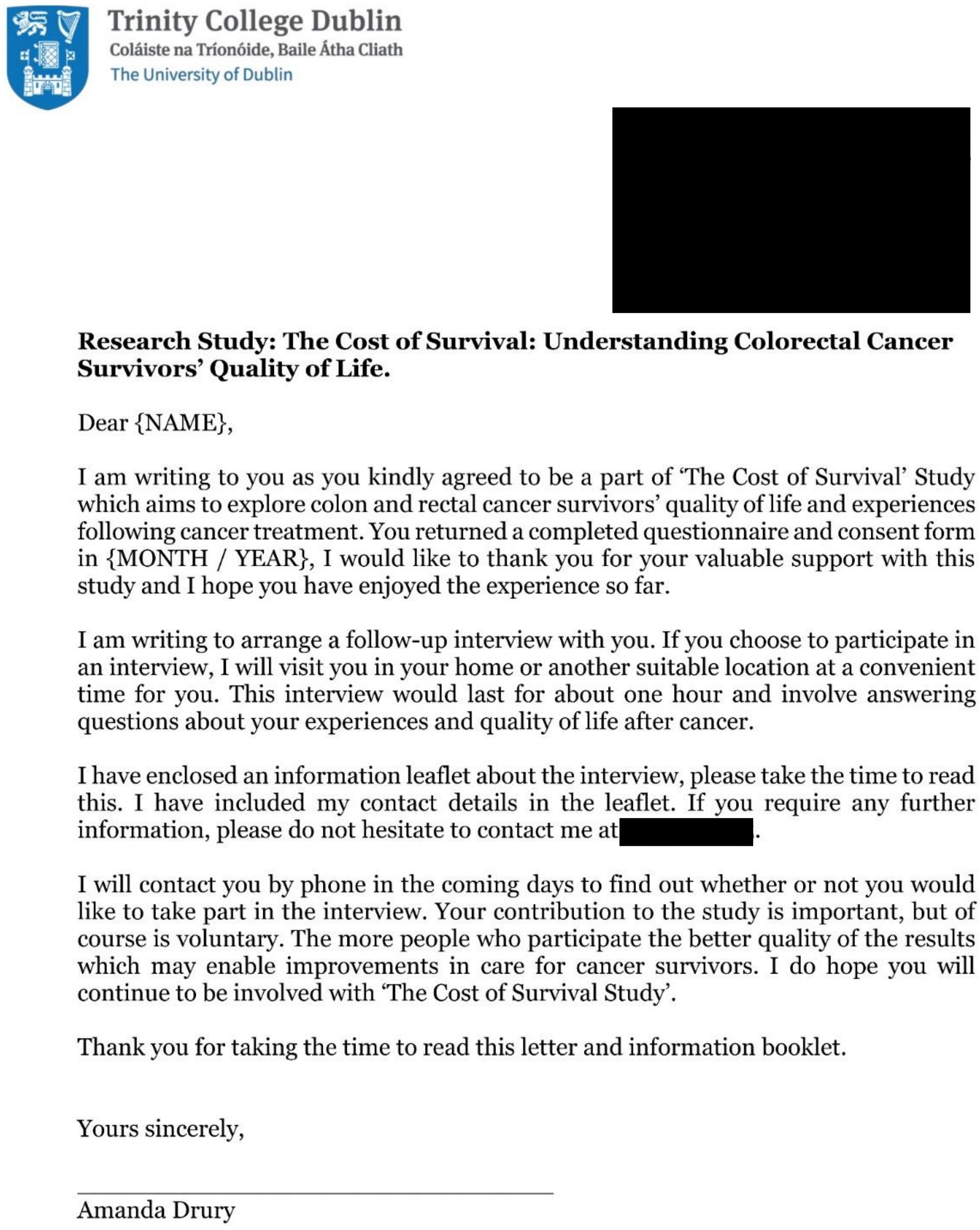
Follow-up Care / Unmet Needs: Information Needs **Addresses Objectives: 4, 5 and 7.**
1. Information Provided by Healthcare Professionals
A. Could you tell me about the information you received from healthcare professionals in the hospital about colon / rectal cancer and its treatment? How do you feel about that information?
2. Information Provided by Advocacy Organisations
A. Did you seek information about colon / rectal cancer outside of the hospital? Could you tell me about where you sourced that information? How did you feel about that information?
3. Overall Impression of Information Received
A. Considering you situation now, do you feel you should have received any additional information about colon / rectal cancer treatment?

Follow-up Care / Unmet Needs: Other Concerns **Addresses Objective 4, 5 and 7**
1. Additional Concerns
A. Do you think there are any areas of care for colon / rectal cancer that might be improved?

Wind-Down Question
A. Is there anything else you would like to tell me?

Additional probing questions may also include:
A. Please tell me more about it
B. What does that mean to you?
C. Could you please give me an example?
D. Could you describe what that was like for you?

Appendix 5.7: Phase 2 Letter of Invitation



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

[redacted]

Research Study: The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life.

Dear {NAME},

I am writing to you as you kindly agreed to be a part of 'The Cost of Survival' Study which aims to explore colon and rectal cancer survivors' quality of life and experiences following cancer treatment. You returned a completed questionnaire and consent form in {MONTH / YEAR}, I would like to thank you for your valuable support with this study and I hope you have enjoyed the experience so far.

I am writing to arrange a follow-up interview with you. If you choose to participate in an interview, I will visit you in your home or another suitable location at a convenient time for you. This interview would last for about one hour and involve answering questions about your experiences and quality of life after cancer.

I have enclosed an information leaflet about the interview, please take the time to read this. I have included my contact details in the leaflet. If you require any further information, please do not hesitate to contact me at [redacted].

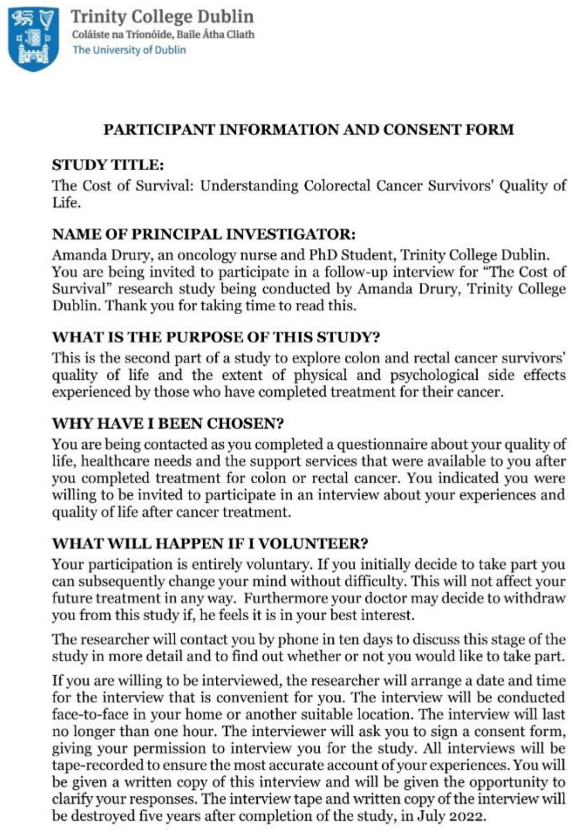
I will contact you by phone in the coming days to find out whether or not you would like to take part in the interview. Your contribution to the study is important, but of course is voluntary. The more people who participate the better quality of the results which may enable improvements in care for cancer survivors. I do hope you will continue to be involved with 'The Cost of Survival Study'.

Thank you for taking the time to read this letter and information booklet.

Yours sincerely,

Amanda Drury

Appendix 5.8: Phase 2 Participant Information Leaflet and Consent



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

PARTICIPANT INFORMATION AND CONSENT FORM

STUDY TITLE:

The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life.

NAME OF PRINCIPAL INVESTIGATOR:

Amanda Drury, an oncology nurse and PhD Student, Trinity College Dublin.
You are being invited to participate in a follow-up interview for "The Cost of Survival" research study being conducted by Amanda Drury, Trinity College Dublin. Thank you for taking time to read this.

WHAT IS THE PURPOSE OF THIS STUDY?

This is the second part of a study to explore colon and rectal cancer survivors' quality of life and the extent of physical and psychological side effects experienced by those who have completed treatment for their cancer.

WHY HAVE I BEEN CHOSEN?

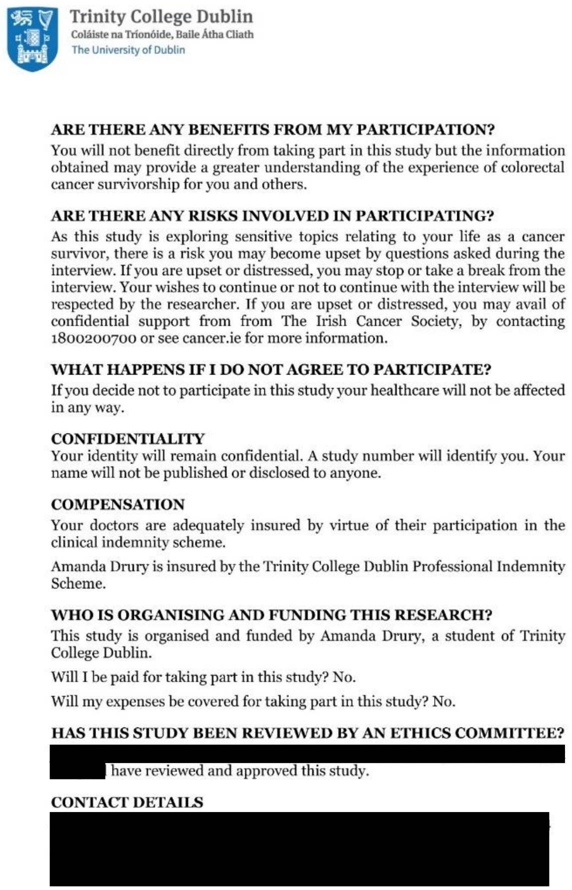
You are being contacted as you completed a questionnaire about your quality of life, healthcare needs and the support services that were available to you after you completed treatment for colon or rectal cancer. You indicated you were willing to be invited to participate in an interview about your experiences and quality of life after cancer treatment.

WHAT WILL HAPPEN IF I VOLUNTEER?

Your participation is entirely voluntary. If you initially decide to take part you can subsequently change your mind without difficulty. This will not affect your future treatment in any way. Furthermore your doctor may decide to withdraw you from this study if, he feels it is in your best interest.

The researcher will contact you by phone in ten days to discuss this stage of the study in more detail and to find out whether or not you would like to take part.

If you are willing to be interviewed, the researcher will arrange a date and time for the interview that is convenient for you. The interview will be conducted face-to-face in your home or another suitable location. The interview will last no longer than one hour. The interviewer will ask you to sign a consent form, giving your permission to interview you for the study. All interviews will be tape-recorded to ensure the most accurate account of your experiences. You will be given a written copy of this interview and will be given the opportunity to clarify your responses. The interview tape and written copy of the interview will be destroyed five years after completion of the study, in July 2022.



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The University of Dublin

ARE THERE ANY BENEFITS FROM MY PARTICIPATION?

You will not benefit directly from taking part in this study but the information obtained may provide a greater understanding of the experience of colorectal cancer survivorship for you and others.

ARE THERE ANY RISKS INVOLVED IN PARTICIPATING?

As this study is exploring sensitive topics relating to your life as a cancer survivor, there is a risk you may become upset by questions asked during the interview. If you are upset or distressed, you may stop or take a break from the interview. Your wishes to continue or not to continue with the interview will be respected by the researcher. If you are upset or distressed, you may avail of confidential support from from The Irish Cancer Society, by contacting 1800200700 or see cancer.ie for more information.

WHAT HAPPENS IF I DO NOT AGREE TO PARTICIPATE?

If you decide not to participate in this study your healthcare will not be affected in any way.

CONFIDENTIALITY

Your identity will remain confidential. A study number will identify you. Your name will not be published or disclosed to anyone.

COMPENSATION

Your doctors are adequately insured by virtue of their participation in the clinical indemnity scheme.

Amanda Drury is insured by the Trinity College Dublin Professional Indemnity Scheme.

WHO IS ORGANISING AND FUNDING THIS RESEARCH?

This study is organised and funded by Amanda Drury, a student of Trinity College Dublin.

Will I be paid for taking part in this study? No.

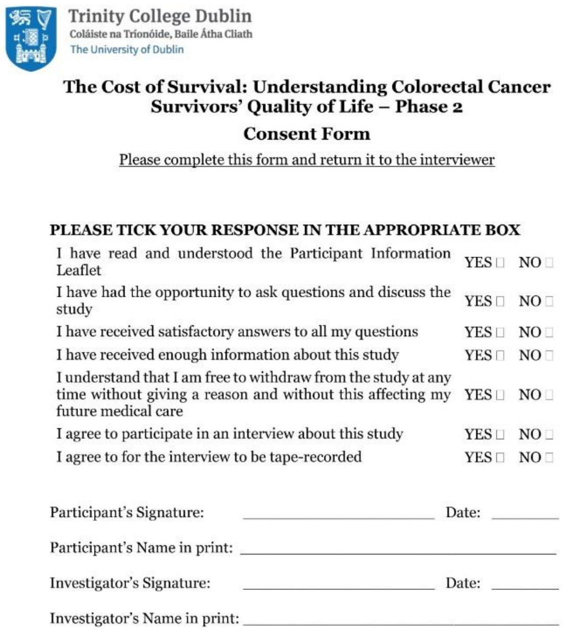
Will my expenses be covered for taking part in this study? No.

HAS THIS STUDY BEEN REVIEWED BY AN ETHICS COMMITTEE?

[redacted] have reviewed and approved this study.

CONTACT DETAILS

[redacted]



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Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life – Phase 2

Consent Form

Please complete this form and return it to the interviewer

PLEASE TICK YOUR RESPONSE IN THE APPROPRIATE BOX

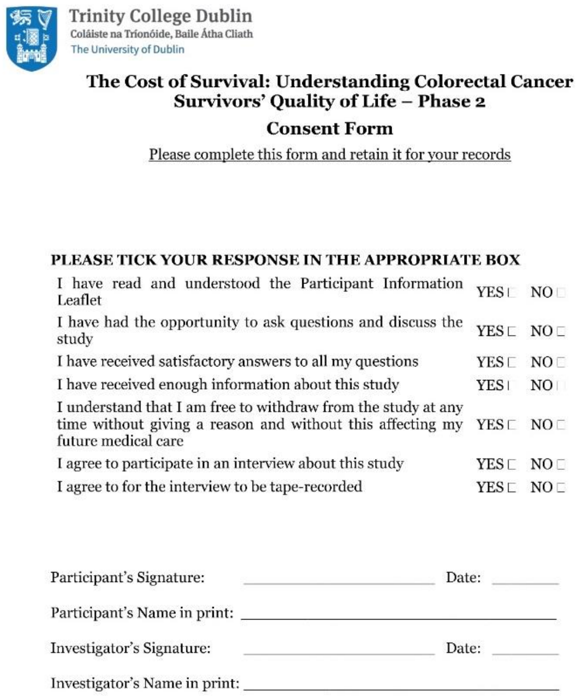
I have read and understood the Participant Information Leaflet	YES ☐	NO ☐
I have had the opportunity to ask questions and discuss the study	YES ☐	NO ☐
I have received satisfactory answers to all my questions	YES ☐	NO ☐
I have received enough information about this study	YES ☐	NO ☐
I understand that I am free to withdraw from the study at any time without giving a reason and without this affecting my future medical care	YES ☐	NO ☐
I agree to participate in an interview about this study	YES ☐	NO ☐
I agree to for the interview to be tape-recorded	YES ☐	NO ☐

Participant's Signature: ______________________ Date: ________

Participant's Name in print: ____________________________________

Investigator's Signature: ______________________ Date: ________

Investigator's Name in print: ____________________________________



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life – Phase 2

Consent Form

Please complete this form and retain it for your records

PLEASE TICK YOUR RESPONSE IN THE APPROPRIATE BOX

I have read and understood the Participant Information Leaflet	YES ☐	NO ☐
I have had the opportunity to ask questions and discuss the study	YES ☐	NO ☐
I have received satisfactory answers to all my questions	YES ☐	NO ☐
I have received enough information about this study	YES ☐	NO ☐
I understand that I am free to withdraw from the study at any time without giving a reason and without this affecting my future medical care	YES ☐	NO ☐
I agree to participate in an interview about this study	YES ☐	NO ☐
I agree to for the interview to be tape-recorded	YES ☐	NO ☐

Participant's Signature: ______________________ Date: ________

Participant's Name in print: ____________________________________

Investigator's Signature: ______________________ Date: ________

Investigator's Name in print: ____________________________________

Appendix 5.9: Feedback from the Clinical Expert Panel

Participant	Feedback	Action
Member 9	Length and time to complete underestimated	Review by research partners /pilot
	Not sure if it will identify the survivorship specific resources used other than support groups / GP / Hospital Other forms of support including online information resources	New Question: “Please tell us about any other supports or services that you have used since your cancer diagnosis”
	Make clearer breaks between the sections for different timelines	Done
	Ask about private insurance	New Question: Do you have: 1☐ Private health insurance 2☐ Medical Care 3☐ Other health benefit (please specify) _______________ 4☐ None of the above
	Open question, what issues have the most impact on their quality of life and what they feel would be most beneficial in terms of service.	This will be addressed in qualitative phase
Member 2	Question 15 – no option if someone is not working	Clarified
	Length and time to complete questionnaire	Review by research partners /pilot
Member 5	Questions are wordy	Review by research partners /pilot
	Length and time to complete questionnaire	Review by research partners /pilot
Member 8	No changes to suggest	
Member 6	Questions 46-53 (PCCQ) – American – define health care provider	Healthcare professional definition included
	Question 58 – care plans – patients do not receive them – potential for confusion or feelings they don’t have something they should have	Need to ask this question
Member 4	Question 3. How long is it since your treatment started – rather than finished?	Decision to go with treatment finished – to ensure they are not experiencing acute symptoms.
Member 1	Length and time to complete questionnaire	Review by research partners /pilot
Member 7	Questionnaire Length – suggest putting demographic questionnaire first to promote adherence.	Review by research partners /pilot
Member 3	Feedback not received	

Appendix 5.10: Feedback from the Stakeholder Panel

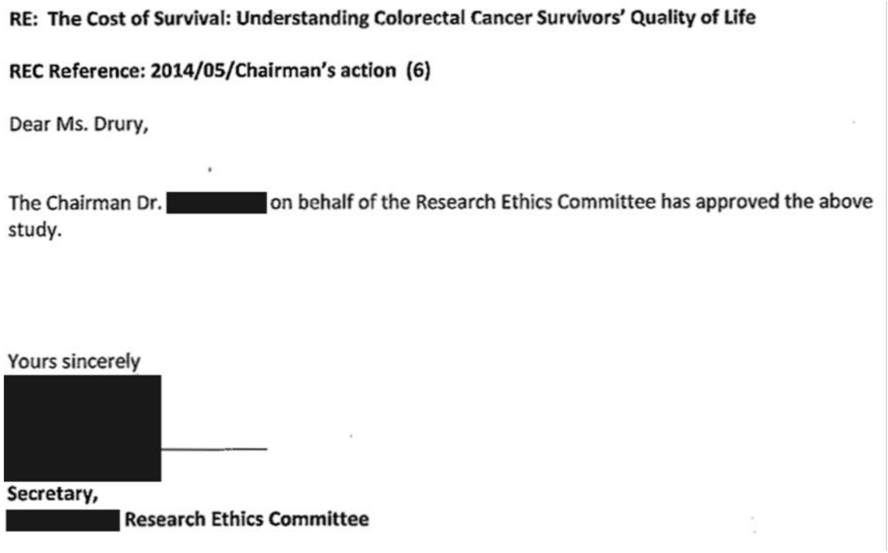
Participant	Feedback	Suggested Changes	Action
Participant 1, 2 and 3	Layout good, Coloured lines helpful		
Participant 1	Time to complete questionnaire 30 minutes approximately	Time for questionnaire changed p.ii.	Done
Participant 2	Use of italic style text may cause difficulty reading	Italic text removed	Done
Participant 2	Use of the term remission – would participants understand	Will be assessed in pilot study.	
Participant 1	Item 13c. – Could this question cause distress	Has been validated previously – will discuss with supervision team.	No change – assess in Pilot study
Participant 2	Item 14f. – What if participant is single?	Suggestion: Because of my physical condition, I have trouble participating in family life.	No change – assess in pilot study
Participant 2	Item 14g. – What if participant is single?		
Participant 3	Item 15c. – use of war terminology, is it appropriate? Could it cause offence	Suggestion: I have felt in despair?	No change
Participant 1	17h. and 17i. – Would participants understand the term urinating?		No change – assess in pilot study
Participant 2 and 3	Item 23b. – would participants understand the term chore?	Suggestion “Tasks”	Assess in pilot study
Participant 1	Item 23e. – Participants may not be aware of family difficulties with supports		Assess in pilot study
Participant 1	Item 23g. – Explain the term ‘Financial Difficulties’ Potential similarity with 21h.	Suggestion “(e.g. income, bills, etc.)”	Done
Participant 2	Item 24b. – Would participants understand the term ‘prognosis’		Assess in pilot study
Participant 1 and 2	Item 24e. – a long item	Suggest break up or reduce wording.	Done
Participant 3	Item 24f. – Would participants understand the term ‘schedule’	Suggest ‘make’.	Done
Participant 2	Item 25h. - How would participants know if forms delivered to appropriate people?		Assess in Pilot Study
Participant 1 and 2	Item 35 and 37 – use of ‘A little bit’ and ‘Somewhat’ – what is the difference?		No change – assess in pilot study
Participant 1	Would like to see a structured question about online services and information booklets.		New Question 38 addressed
Participant 4	Communication: would it be useful to ask if survivors would like to talk more to family and friends about their condition?		New Question 38 addressed
Participant 1 and 4	Support; could a query be included as to whether they would like to speak to someone who had gone through a similar experience?		New Question 38 addressed
Participant 4	In the After Discharge section, would it be helpful to include a query as to whether the local pharmacy was able to meet their need for supplies--bags, sprays, lotions etc.?		Not included

Appendix 5.11: Amendments to Phase 1 Study Protocol Post-Pilot Study

Amendments Arising from Pilot Study		
Challenge	**Action**	**Outcome**
Difficulties with distribution of questionnaires and referral into study in week one of pilot study	Gatekeeper Questionnaire Distribution: Deliver questionnaires on the morning of clinics Gatekeeper referral: Discuss recruitment process and progress in the early stages of the study	Continue but modify protocol
Positioning of researcher contact details	Provide investigator contact details in the patient information leaflet	Continue but modify protocol
Failure to return consent forms	Position consent form inside the cover of the questionnaire.	Continue but modify protocol
Expert Panel and Stakeholder Panel Concerns about Questionnaire Length	Participants appear to complete the questionnaire to the end, and the response rate was reasonable.	Continue without modifications, but monitor closely
Pattern of missing data (pages 8 and 9; pages 14 and 15)	Increase paper quality in printed booklets.	Continue but modify protocol
Difficulty answering Patient Continuity of Care Questionnaire	No changes	Continue without modifications, but monitor closely
Difficulty completing question 14 G, “I am satisfied with my sex life”	Include opt-out box for 14G as in the original FACT-C questionnaire.	Continue but modify protocol
Participants outside inclusion criteria referred to study	Clarify the inclusion criteria (<5 years since diagnosis) with gatekeepers. Investigator clarifies amount of time since the patient was diagnosed at recruitment.	Continue but modify protocol
Social Difficulties Inventory Scoring	Recode variables on questionnaire to match those of (Wright et al. 2011). Remove the “Not Applicable” option from the questionnaire	Continue but modify protocol
Question 22 Physical Activity Coding	Recode variable to match how many days they have participated in physical activity	Continue but modify protocol

Appendix 5.12: Ethics Approval

1. Ethics Approval for Hospitals One and Two



RE: The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life

REC Reference: 2014/05/Chairman's action (6)

Dear Ms. Drury,

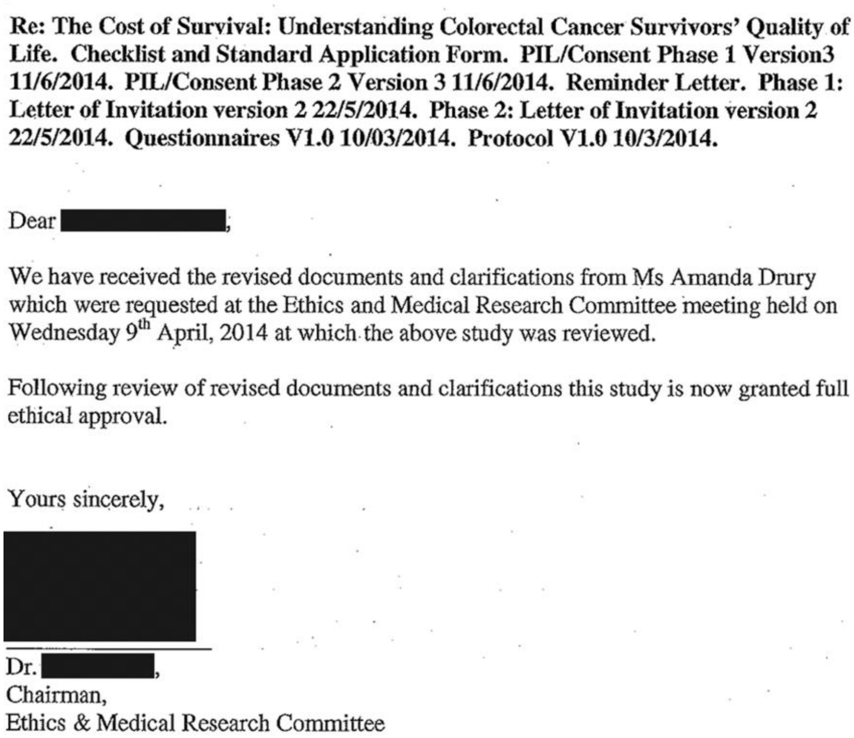
The Chairman Dr. [redacted] on behalf of the Research Ethics Committee has approved the above study.

Yours sincerely

[redacted]

Secretary,
[redacted] **Research Ethics Committee**

2. Ethics Approval for Hospital Three



Re: The Cost of Survival: Understanding Colorectal Cancer Survivors' Quality of Life. Checklist and Standard Application Form. PIL/Consent Phase 1 Version3 11/6/2014. PIL/Consent Phase 2 Version 3 11/6/2014. Reminder Letter. Phase 1: Letter of Invitation version 2 22/5/2014. Phase 2: Letter of Invitation version 2 22/5/2014. Questionnaires V1.0 10/03/2014. Protocol V1.0 10/3/2014.

Dear [redacted];

We have received the revised documents and clarifications from Ms Amanda Drury which were requested at the Ethics and Medical Research Committee meeting held on Wednesday 9th April, 2014 at which the above study was reviewed.

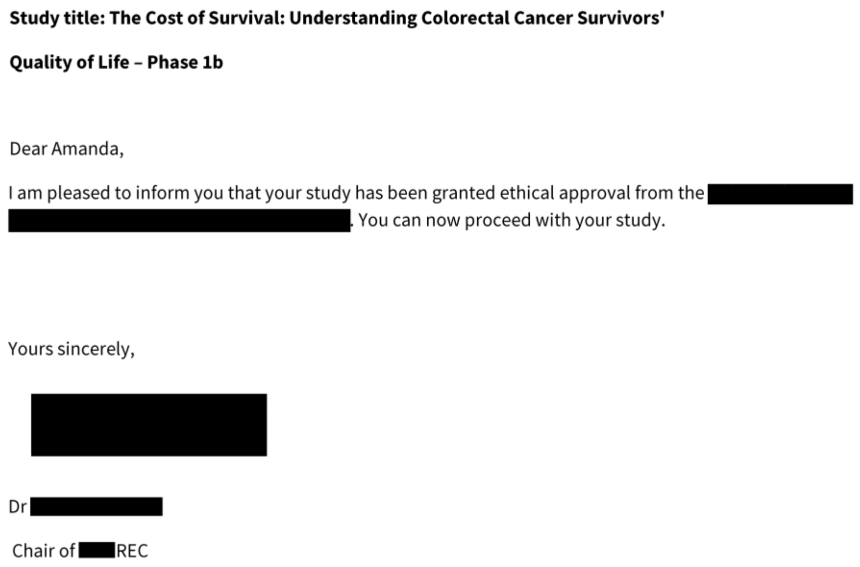
Following review of revised documents and clarifications this study is now granted full ethical approval.

Yours sincerely,

[redacted]

Dr. [redacted],
Chairman,
Ethics & Medical Research Committee

3. Ethics Approval for Cancer Support Groups and Online Study



Study title: The Cost of Survival: Understanding Colorectal Cancer Survivors'

Quality of Life – Phase 1b

Dear Amanda,

I am pleased to inform you that your study has been granted ethical approval from the [redacted]. You can now proceed with your study.

Yours sincerely,

[redacted]

Dr [redacted]

Chair of [redacted]REC