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**Evaluate the effectiveness and sustainability
of OptiMal as a self-management intervention
for cancer survivors**

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Occupational Therapy in Trinity College Dublin

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Declaration

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Summary

Background: The National Cancer Registry Ireland (NCRI, 2014) has projected that cancer diagnoses will double by 2040 in particular incidences of lung, rectal, colon cancer and melanoma are set to increase substantially. The risk of dying from cancer has decreased by 1% per year leading cancer survival rates to increase (NCRI, 2013). This infers that the number of cancer survivors in Ireland will increase. There are currently 150,000 cancer survivors in Ireland (Department of Health (DOH), 2017). Due to early detection and effective treatment, cancer is considered more a chronic rather than a fatal illness (McCorkle, Ercolano, Lazenby, Green, Schilling & Lorig, 2011).

Many cancer survivors experience problems such as pain, fatigue, cognitive difficulties, anxiety and depression following treatment (Shneerson, Taskila, Holder, Greenfield, Tolosa, Damery & Gale, 2014). This can impact upon survivors' abilities to perform everyday activities and affect quality of life (Silver & Gilchrist, 2011). Research recommends that self-management and rehabilitation models used with long-term chronic conditions should be evaluated with cancer survivors, as similar health issues exist and both require long-term follow-up (Elliott, Fallows, Staetsky, Smith, Foster & Maher et al. 2011). Occupational therapists are familiar with the content delivered in self-management programmes (Hwang, Lokietz, Lozano & Parke, 2015).

OptiMal is a six-week, occupation-based, self-management intervention originally designed for people with chronic conditions to develop self-management knowledge and skills (O'Toole, Connolly & Smith, 2013; Garvey, Connolly, Boland & Smith, 2015). The aim of this research is to evaluate OptiMal's effectiveness and sustainability with cancer survivors.

Methodology: Three studies were undertaken as part of this research. Study I consisted of a systematic review to explore the type, content and effectiveness of self-management interventions previously provided to cancer survivors. This review was guided by the PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). Study II consisted of a mixed-methods study to compare the effectiveness and sustainability of OptiMal, in a group of adult cancer survivors and compare with a control group of cancer survivors. The primary outcome measure was frequency of activity participation. Secondary measures included health-related quality of life, self-efficacy, perception of occupational performance, anxiety, depression, cognitive difficulties and fatigue. Data collection took

place at baseline, post-intervention and at three months follow-up. Focus groups were held with participants who attended OptiMal, post-intervention and at three months follow-up, to explore the acceptability of the programme. Due to slow recruitment rates, Study III, a qualitative study, was conducted to explore reasons for declining to attend OptiMal.

Results: Six studies were included in the final analysis of the systematic review. Three studies reported significant differences between groups, however these interventions lacked sustainability. Due to the diversity of the interventions, it was not possible to draw definitive conclusions on the impact of self-management interventions previously carried out with cancer survivors. In Study II, 80 participants were recruited into the mixed-methods study. Four OptiMal programmes were facilitated over a 15-month period. Eighteen participants (22.5%) were lost at follow-up. Sixty-two participants completed self-reporting questionnaires at all three time points and were included in the final analysis. No significant results were observed in the primary outcome measure; frequency of activity participation. Significant results were observed from baseline to three months follow-up, between the control and intervention group, in health-related quality of life ($p < 0.001$, $p = 0.035$) and anxiety ($p = 0.04$). Cancer survivors reported a lack of follow-up care post-treatment to manage persistent symptoms. OptiMal was considered an acceptable intervention but many reported preferring to receive it within the first year of finishing treatment. In Study III, 12 cancer survivors who previously declined to participate in Study II, participated in semi-structured interviews to explore reasons for non-participation in the mixed-methods study. Survivors reported developing their own self-management strategies to manage continuing symptoms or reported a lack of perceived need for self-management education.

Conclusion: Cancer survivors can experience continuing symptoms, particularly psychosocial symptoms, post-treatment which can impact on their participation in daily activities and affect quality of life. Cancer survivors report a need for follow-up care following treatment. OptiMal was considered an acceptable intervention. It empowered survivors with self-management knowledge and skills to increase their participation in daily activities and assist with the transition from cancer treatment to survivorship. Further research is required to conduct a definitive randomised controlled trial with a larger group of mixed cancer survivors earlier post-treatment, to determine the effectiveness and sustainability of OptiMal. However, some cancer survivors reported a lack of need for self-management interventions. Further research is required to identify those in need of self-management.

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1. Introduction

1.1 Background and Need

Early diagnosis and improved access to treatments, has meant that survival from cancer has improved by 1% per year as reported by the National Cancer Registry of Ireland (NCRI) in 2013 (NCRI, 2013). There are currently over 150,000 cancer survivors in Ireland (DOH, 2017). A 'cancer survivor' is any individual who has survived their cancer without a recurrence of cancer within the five years following diagnosis or treatment (Leigh, 1996; Center for Disease Control (CDC) & Lance Armstrong Foundation (LAF), 2004). Cancer survivors experience continuing symptoms such as pain, fatigue, anxiety, depression and cognitive difficulties following treatment (Shneerson et al., 2015). These symptoms can impact on survivors' performance of daily activities or occupations, thus preventing them from engaging in activities of importance to them (Player, MacKenzie, Wills & Loh, 2014). This can affect survivors' quality of life and overall health and wellbeing (Silver & Gilchrist, 2011; Shneerson et al., 2015).

In Ireland there are no standard post-treatment programmes for individuals to help manage continuing symptoms following treatment. This is primarily left to the survivors, their family and voluntary organisations (Ivers, Dooley & Bates, 2009). With economic and time constraints affecting the provision of post-treatment services, it is becoming difficult for hospital-based services in Ireland to meet the needs of cancer survivors (Naidoo, Hayes, Teo, Calvert, Horgan & O'Connor, 2013). Due to these pressures, the responsibility is now with survivors to self-manage their health, however, many are unaware of how to do this (Shneerson et al., 2015).

Cancer is now regarded more as a chronic than a fatal condition due to the improved survival with these persistent symptoms following treatment (CDC & LAF, 2004). Self-management programmes post-treatment are recommended as they can help survivors manage their symptoms as they return to their normal roles and routines (McCorkle, Ercolano, Lazenby, Green, Schilling & Lorig, et al., 2011). However, some survivors can experience social isolation, decreased participation in self-management, financial and familial strain which all have an impact on their health outcomes (Foster & Fenlon, 2011).

Self-management is considered key in bridging the gap between cancer survivors' needs and the ability of health services to meet those needs (McCorkle et al., 2011). There is no

'gold standard' definition for self-management, however, it is considered as the "individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002, p178). Self-management typically incorporates five core skills of problem-solving, decision making, resource utilisation, effective communication with healthcare professionals and action planning (Lorig & Holman, 2003). It distinguishes itself from traditional health education by its emphasis on the application of these five core self-management skills to one's own situation. It has been recommended that self-management and rehabilitation models used for supporting people with other long-term chronic conditions, should be evaluated with cancer survivors, as similar health issues exist and both require long-term follow-up (Elliott et al., 2011; McCorkle et al., 2011).

Recommended content for self-management programmes include fatigue management, energy conservation, sleep hygiene, lifestyle redesign, which are within the scope of practice of occupational therapists (Clark, Jackson, Carlson, Chou, Cherry, Jordan-Marsh et al., 2012; Hwang et al., 2015). Self-management programmes incorporate goal setting creating a client-centred approach which are elements consistent with occupational therapy practice (Hirsche, Williams, Jones & Mann, 2011). Occupational therapy follows a holistic perspective of promoting an individual's independence through the engagement of meaningful activities (Crepeau, Schell & Cohn, 2009). A systematic review of rehabilitation interventions used with cancer survivors reported that many interventions lacked a focus on occupation and participation (Hunter, Gibson, Arbesman & D'Amico, 2017a). Occupational therapy interventions aim to improve participation in daily activities which in turn improves health and wellbeing (Burkhardt & Schultz-Kroh, 2013). Therefore, there was a need to evaluate an occupation-based, self-management intervention with cancer survivors.

OptiMal is a six-week, occupation-based, self-management intervention designed for people with chronic conditions (O'Toole et al., 2013; Garvey et al, 2015). It is a group-based intervention and each session consists of an education and goal-setting component which facilitates individuals to apply the education components of the programme into their daily and weekly routines. Topics covered in OptiMal include fatigue management, pain management, anxiety and stress management, exercise and activity, nutrition, medication management, cognitive strategies and effective communication with health professionals. A pilot study evaluated the programme with individuals with multimorbidity and reported significant changes in activity participation, occupational performance and self-efficacy

post intervention and at eight weeks follow-up, despite a small sample size (O'Toole et al., 2013). In 2015, a randomised control trial (RCT) reported significant improvements in frequency of activity participation, self-efficacy and quality of life in individuals with multimorbidity compared to a control group post intervention (Garvey et al., 2015).

1.2 Aim and Objectives of the Research

The overall aim of this research study was to evaluate the effectiveness and sustainability of OptiMal as a self-management intervention for cancer survivors. To achieve this aim, three separate studies were carried out;

Study I: A systematic review of the type, content and effectiveness of self-management interventions for cancer survivors

Objectives:

- Review the evidence for self-management interventions for adult cancer survivors
- Determine the content of these interventions (i.e. topics covered, duration, facilitators)
- Review the outcomes of the interventions including activity participation, quality of life, self-efficacy, symptom management (fatigue, anxiety, depression)

Study II: A mixed-methods study evaluated the effectiveness and sustainability of a self-management support intervention and its acceptability to Irish cancer survivors.

Objectives:

- Evaluate the effectiveness and sustainability of OptiMal, an **occupation-based**, self-management support intervention for adult cancer survivors and compare with a control group of adult cancer survivors in increasing activity participation, health-related quality of life, self-efficacy, perception of occupational performance and reducing anxiety, depression, cognitive difficulties and fatigue
- Explore participants' perceptions and acceptability of the OptiMal programme for cancer survivors

Study III: As a result of slow recruitment to Study II, a qualitative study explored reasons for non-participation in OptiMal.

Objectives:

- Explore cancer survivors' reasons for non-participation in a self-management intervention

1.3 Overview of Studies Design

Systematic Review:

For the systematic review, search terms were developed in consultation with a medical librarian. Six databases, including EMBASE, Scopus, PubMed, CINAHL, PsycInfo and Cochrane were searched. Limitations were employed specific to each database. Upon removal of duplicates, full-text papers were obtained of included studies. Two reviewers independently reviewed these studies based their relevancy on the inclusion criteria table listed above. The systematic review was guided by the PRISMA guidelines to assess the risk of bias of included studies and ensure accurate reporting of the findings (Moher et al., 2009).

Mixed-Methods Study

A mixed-methods design was chosen to address the evaluate the effectiveness and sustainability of the OptiMal programme. A pragmatic, exploratory randomised controlled trial (RCT) compared adult cancer survivors, who participated in a six-week, self-management intervention with a control group of adult cancer survivors receiving usual care. Usual care consisted of survivors continuing to attend medical appointments. Focus groups were conducted with participants who attended OptiMal to explore their perceptions and acceptability of OptiMal. A qualitative descriptive design was chosen to ensure a rich, straight description of participants' experience of the OptiMal programme (Sandelowski, 2000; Neergaard, Olesen, Andersen & Sondergaard, 2009).

Qualitative Evaluation of Non-Responders

Due to slow recruitment in the mixed-methods study, participants who declined to participate in the mixed-methods study were contacted to participate in a semi-structured interview to explore reasons for non-participation.

In all three studies, it is assumed that participants answered questions honestly throughout the research and that the methods of assessment undertaken accurately measured the concepts under investigation.

1.4 Overview of the Thesis

In this thesis, Chapter Two will outline the current literature and rationale for this research study. Chapter Three will discuss the results and findings of the systematic review evaluating the international literature for self-management interventions that have been carried out with cancer survivors. Chapter Four will outline the methodology used for conducting the mixed-methods study evaluating the effectiveness and sustainability of the OptiMal programme with cancer survivors. Chapter Five will discuss the quantitative and qualitative results from the mixed-methods study. Chapter Six will discuss the results and findings from the qualitative study carried out with cancer survivors to explore reasons for declining to participate in the mixed-methods study. Chapter Seven aims to provide an overall discussion of the results from the three studies.

1.5 Conclusion

The incidence of cancer survivors is increasing in Ireland due to early diagnosis and more effective treatments (NCRI, 2013). However, following treatment, many cancer survivors report persistent symptoms such as pain, fatigue, anxiety and cognitive difficulties. As cancer is now seen as a chronic condition due to increased survival rates and continuing symptoms post-treatment, self-management and rehabilitation models used with long-term chronic conditions should be evaluated with cancer survivors, (CDC & LAF, 2004; Elliott et al. 2011).

Self-management programmes can increase an individual's knowledge of problems arising post-treatment, allowing strategies to be implemented to reduce levels of distress and encourage empowerment in managing symptoms (Schjolberg, Dodd, Henriksen, Asplund, & Smastuen et al., 2014). However, many survivors are unaware how to manage their physical and psychological health post-treatment (Shneerson et al, 2015).

The aim of this research was to evaluate the effectiveness and sustainability of OptiMal, as a self-management intervention for cancer survivors. A mixed-methods study was undertaken to achieve this aim. The international literature was reviewed to establish type and content of self-management interventions already carried out with cancer survivors.

Finally, due to slow recruitment, this research explored reasons for non-participation in the self-management intervention amongst cancer survivors.

2. Literature Review

2.1 Introduction

This chapter provides an overview of the literature on cancer survivorship and self-management. In recent years, several reports have outlined the increasing number of cancer incidences in Ireland and the growing cancer survivorship population (NCRI, 2013, 2014, 2016). The risk of dying from cancer in Ireland has decreased by 1% for females and 1.4% for males a year, leading to improvements in cancer survival rates (NCRI, 2013). The five year survival rate for all invasive cancers in females rose from 52% between 1994 and 1999 to 61.5% between 2004 and 2009 (NCRI, 2013). In men, greater improvements were seen with survival rates rising dramatically from 42% between 1994 and 1999 to 60% between 2004 and 2009. Preventative screening and early diagnosis are attributed to these increases (NCRI, 2013). This infers that as cancer diagnoses increase in Ireland, so will the number of cancer survivors.

The NCRI later reported that by the end of 2014 the number of cancer survivors was approximately 139,526 concluding that cancer support services needed to expand to meet these growing figures (NCRI, 2016). In Ireland, cancer services include medical treatment and follow-up appointments post-treatment carried out by hospital-based consultants. Economic and time constraints are affecting the provision of these services therefore, it is becoming difficult for hospital-based services in Ireland to meet the needs of cancer survivors (Naidoo et al., 2013). As a result, there are no standard post-treatment programmes following treatment, therefore survivors, their families and voluntary organisations must manage the transition from active treatment to life post-treatment. However, many are unaware of how to achieve this (Ivers et al., 2009). This lack of psychosocial and supportive care has been acknowledged in governmental reports but little action has been taken (National Cancer Forum (NCF), 2006). However, the recently published National Cancer Strategy has sought to address this gap in service needs (DOH, 2017).

As pressure grows on cancer support services both in Ireland and internationally, there is now a role for self-management in helping cancer survivors manage their own health and any ongoing symptoms of their cancer (McCorkle et al., 2011; Hammer, Ercolano, Wright, Dickson, Chyun, & Melkus., 2015; Shneerson et al., 2015).

This chapter reviews current literature on cancer survivorship, provides an overview of treatment regimens used to treat certain cancers such as breast and lymphoma, discusses the impact of cancer survivorship, occupational therapy and self-management programmes in cancer survivorship and national and international policies on cancer survivorship.

2.2 Definition of Cancer Survivorship

The term 'cancer survivor' has changed in meaning over the years. Previously, when cancer was generally regarded as an incurable disease, a 'survivor' was considered to be any family member who survived the loss of a loved one to cancer (Leigh, 1996; CDC & LAF, 2004). As treatments have progressed and outcomes improved, a 'cancer survivor' is now considered as any individual surviving their cancer without a recurrence of cancer within the five years following diagnosis or treatment (Leigh, 1996; CDC & LAF, 2004). Presently, cancer survivorship is considered to begin at the time of diagnosis and continue until end of life (National Cancer Institute (NCI), 2017).

The term 'cancer survivor' rather than 'cancer patient' is more relevant to health care practitioners and those affected by cancer, directly and indirectly, as it highlights symptoms still encountered post-treatment (Bell & Ristovski-Slijepcevic, 2013). The impact of these symptoms can continue for several years affecting survivors' quality of life and activity participation, (Shneerson et al., 2015), as described in the following sections.

2.3 Impact of Cancer

Following a diagnosis of cancer, an individual will undergo various forms of treatment. The form of treatment an individual undergoes is directly related to the type and staging of the cancer i.e. how far the cancer has progressed. However, most individuals will undergo local and/or systemic treatment. Each form of treatment is accompanied by side effects as described below (Tobias & Hochhauser, 2010).

2.3.1 Local Therapy

Local therapy refers to treatment focused only on the specific area where the cancer has occurred. Treatments include surgery or radiation therapy (Neal & Hoskin, 2009).

2.3.1.1. Surgery

Surgery is used for biopsies or to remove the cancerous tumour and any affected lymph nodes from the body or to 'debulk' the tumour i.e. to remove parts of the tumour (Neal &

Hoskin, 2009). For example, breast cancer is one of the most common cancers both in Ireland and worldwide with the majority of breast cancer patients undergoing surgery as part of their treatment (Neal & Hoskin, 2009; NCRI, 2013). The type of surgery depends on the tumour type and staging itself with less invasive procedures resulting in fewer side effects. A wide local excision is suitable for small tumour types where the tumour is excised with a small margin of surrounding breast tissue. This type of surgery preserves the bulk of the breast and is minimally invasive (Neal & Hoskin, 2009). In contrast, a mastectomy involves the complete removal of the breast. Immediate reconstruction can take place during this surgery or at a later stage (Neal & Hoskin, 2009).

In addition to surgery at the primary cancer site, lymph node dissections are also common as cancers can metastasize through the blood or the lymphatic system. As a result, a sentinel lymph node (SLN) surgery is a common and more conservative procedure for breast cancer and melanoma. The sentinel lymph node is the first node to receive lymph from the tumour-bearing tissue (Neal & Hoskin, 2009). In this surgery, a dye is preoperatively injected around the tumour. The dye is taken up by the sentinel lymph node. This is then removed and if it is found not to contain cancerous cells, it is highly unlikely other lymph nodes are affected and no further surgery is necessary. If further nodes are affected, a full clearance of the lymph nodes is required. This is a more extensive surgery for auxiliary clearance, impacting on arm and hand function. It can also affect speech and swallow functions if clearance of lymph nodes in the neck is required (Neal & Hoskin, 2009). Chemotherapy or radiation can be administered before surgery to shrink the size of the tumour (neoadjuvant therapy) or after surgery (adjuvant therapy) to kill any remaining cancerous cells (Bower & Waxman, 2015).

2.3.1.2 Radiation Therapy

High-energy ionizing radiation damages the DNA of, and ultimately kills, tumour cells while normal tissue is shielded from similar damage (Bower & Waxman, 2015). Radiation therapy can be delivered in three ways; external beam radiotherapy where radiation is delivered from a distance; brachytherapy involving a solid radioactive nuclide placed within or near the tumour and radioisotope therapy which is administered orally or intravenously (Bower & Waxman, 2015). Radiation therapy is administered daily or intermittently (Tobias & Hochhauser, 2010).

Local therapy is often given in combination with systemic therapy such as chemotherapy (Tobias & Hochhauser, 2010). The former reduces the recurrence rate at the primary

tumour site while the latter attacks cancer cells that may have metastasized outside of the primary tumour site (Neal & Hoskin, 2009).

2.3.2 Systemic Therapy

In contrast to local therapy, systemic therapy treats the whole body for cancer and is non-specific. It is used to target cancer cells that may have left the original cancer site and to reduce the risk of recurrence. As a result, it can damage healthy cells along with cancer cells (Neal & Hoskin, 2009).

2.3.2.1. Chemotherapy

Chemotherapy involves the administration of a combination of cytotoxic drugs to improve treatment efficacy and reduce tumour resistance (Neal & Hoskin, 2009; Bower & Waxman, 2015). It is delivered in cycles to allow normal cells to recover without tumour cells repopulating (Neal & Hoskin, 2009; Bower & Waxman, 2015). Cytotoxic drugs are classified according to their impact upon cell division and normal cell replication (Neal & Hoskin, 2009). For instance, antimetabolites such as 5-Fluorouracil (5FU) and alkylating agents such as cyclophosphamide, attack the structure of the cell's DNA (Bower & Waxman, 2015). Other classification of drugs includes spindle poisons such as vincristine, signal transduction inhibitors such as imatinib, drug-inducing apoptosis or cell death such as bortezomib and antiangiogenic drugs such as bevacizumab, which prevent the growth of new blood vessels, thereby affecting the tumour's growth (Neal & Hoskin, 2009). For the majority of cancers, cytotoxic drugs are given in combination, rather than individually, as they are more effective in targeting different areas of the cancer cells in the one dose (Tobias & Hochhauser, 2010). Immediate side effects of these drugs can include nausea, vomiting and hair loss (Bower & Waxman, 2015).

2.3.2.2 Hormone Therapy

Hormone therapy is an important treatment for cancers where growth depends on hormones as in the case of breast and prostate cancers (Bower & Waxman, 2015). The aim of hormone therapy is to block or reduce the levels of these hormones, thereby preventing the cancer's growth or return. In breast cancer, oestrogen is the hormone targeted by drugs such as Tamoxifen, with the aim of binding oestrogen receptors therein preventing its production. Drugs such as Tamoxifen are accompanied with their own side effects including hot flushes, night sweats and menopausal symptoms (Neal & Hoskin, 2009; Bower & Waxman, 2015). In prostate cancer, hormone therapy targets androgens by binding androgen receptors preventing their production. This therapy is also associated

with side effects such as hot flushes, impotence and loss of libido (Neal & Hoskin, 2009; Bower & Waxman, 2015).

In combination with side effects from individual therapies, the overall impact from these treatments can result in cancer survivors experiencing a cluster of physical and psychosocial symptoms. These symptoms may persist for several years after treatment and can impact on survivors' participation in roles that make life meaningful including productive and social roles, which subsequently affects quality of life (Foster & Fenlon, 2011; Shneerson et al., 2015). The next section considers the impact of symptoms such as fatigue, pain, distress and cognitive issues on cancer survivors upon completion of treatment.

2.3.3 Cancer-Related Fatigue

Cancer-related fatigue is defined by the National Comprehensive Cancer Network (NCCN) as a 'distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning' (NCCN, 2017). Cancer-related fatigue is a common symptom experienced by cancer survivors which impacts upon daily activities and quality of life (Silver & Gilchrist, 2011). The exact cause and persistent nature of fatigue is unknown; many have attributed it to the type of tumour, treatments received, physical symptoms caused by the condition e.g. pain or as part of a psychological response to the cancer itself e.g. depression (Bower, Ganz, Desmond, Rowland, Meyerowitz, & Belin, 2000; Grimmer, Armes, Breckons, Calman & Corner et al., 2013).

Fatigue can persist for years after finishing treatment thus impacting on physical and psychosocial functioning (Grimmett, et al., 2013; Aaronson, Mattioli, Minton, Weis & Johansen et al., 2014). Curt, Breibart, Cella, Groopman and Horning et al., (2000) conducted telephone interviews with 379 cancer survivors who had completed treatment within the last two years or more and of whom 301 (79%) reported fatigue. Of these 301 participants, 91% reported that fatigue prevented them from leading their everyday lives and 88% reported having to change their routine to accommodate their fatigue i.e. sleeping during the day. Specific activities identified as being difficult to perform while experiencing fatigue included household tasks, house cleaning, food preparation and social activities. In addition, 62% of participants reported decreased motivation to perform tasks and 53% reported sadness and frustration. Lack of understanding of fatigue and strategies to manage it can increase feelings of distress (Wu & McSweeney, 2007). Jones, Olson, Catton, Catton, Fleshner & Krzyzanowska et al., (2016) conducted a study involving 1,294

breast, colorectal and prostate cancer survivors who finished treatment at three different phases; 6-18 months, 2-3 years and 5-6 years' post-treatment. In this study, participants completed self-reported questionnaires which found that up to one third of all participants reported clinically significant levels of fatigue up to six years' post-treatment. Breast and colorectal cancer survivors reported greater levels of fatigue compared to prostate cancer survivors. Participants who underwent more complex treatments i.e. chemotherapy and/or radiation therapy compared to surgery alone reported greater levels of fatigue and, therefore, greater impact on performance of daily activities (Jones et al., 2016).

2.3.4 Pain

Chronic pain is commonly reported by cancer survivors (Aaronson et al., 2014; Shneerson et al., 2015). Pain can arise from several complications caused by the cancer itself or treatments, for example, upper limb pain for individuals with breast cancer following surgery, neuropathic pain from nerve compression or peripheral neuropathy because of chemotoxic drugs as described in section 2.3.2.1, or radiation-induced neural damage (Burton, Fanciullo, Beasley & Fisch, 2007; Silver & Gilchrist, 2011; Aaronson et al., 2014). Pain can be treated by pharmacological means however, a complete resolution of the symptoms may not be possible with medication alone (Silver & Gilchrist, 2011). Pain can impact on the performance of activities such as self-care, carrying heavy objects, driving and gardening, activities which involve sustained elevation of the upper limbs (Zomkowski, Cruz de Souza, Pinheiro da Silva, Moreira & de Souza Cunha et al., 2017). In one study, pain and the subsequent decreased performance negatively affected quality of life in colorectal cancer survivors, by impacting on survivors' participation in hobbies, ability to work and their enjoyment of life (Drury, Payne & Brady, 2017). Similar to fatigue, pain can persist for many years. Lowery, Starr, Dhingra, Rogak, Hamrick-Price and Farberov et al., (2013) conducted a telephone survey with 99 colorectal cancer survivors. The authors found that 23% of participants reported experiencing pain up to 10 years' post-treatment and attributed this to their chemotherapy and/or radiotherapy treatments.

2.3.5 Distress

Distress is an all-encompassing term for panic, anxiety, fear and depression (Andrykowski, Lykins & Floyd, 2008). A diagnosis of cancer is often accompanied by an increase in distress levels associated with ongoing treatments and prognosis (Carpenter, Stoner, Schmitz, McGregor & Doorenbos, 2014). However, post-treatment, anxiety levels, whether immediate or long-term, can continue to remain high for reasons such as the loss of frequent contact with the medical team, financial and functional difficulties, threat of cancer recurrence or new cancers emerging with advancing age (Stanton, Ganz, Rowland,

Meyerowitz, Krupnick & Sears, 2005; Andrykowski et al., 2008). Cancer-related health worries are also strongly associated with depression (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006). The ability of cancer survivors to develop effective coping strategies is linked with distress (Philip, Merluzzi, Zhang & Heitzmann, 2013). In one study, breast cancer survivors who believe they are at an increased risk of experiencing a recurrence and report low confidence in their coping abilities are more likely to have a higher fear of recurrence (McGinty, Goldenberg & Jacobsen, 2012). This is in comparison to survivors who do not believe that they are at risk of recurrence and who report high levels of coping self-efficacy (McGinty et al., 2012). However, the evidence reports that addressing psychosocial issues through stress management, problem-solving or cognitive-behavioural therapy, can improve anxiety, depression and quality of life regardless of the type or stage of cancer or the age of the survivor (Hunter, Gibson, Arbesman & D'Amico, 2017b).

2.3.6 Cognitive Difficulties

Cognitive changes are experienced by cancer survivors including breast and lymphoma survivors (Ahles, Saykin, Furstenberg, Cole & Mott et al., 2002; Vodermaier, 2009). These mild cognitive changes involve memory loss, word finding difficulties and lack of concentration (Player et al., 2014). Evidence suggests that following systemic treatment, as outlined in section 2.3.2., the severity of cognitive difficulties can increase, and can last up to two years or longer (Mulrooney, 2008; Pullens, De Vries & Toukema, 2010; Player et al., 2014). This can affect the quality of life of cancer survivors by impacting on their participation in daily activities such as remembering passwords to pay online bills, misplacing objects and completing paperwork (Player, et al., 2014). The exact cause of these cognitive difficulties is unknown and current research is conflicting. Some researchers attribute it to the effects of chemotherapy, describing it as 'chemobrain' (Boykoff, Moieni & Subramanian, 2009; Player et al., 2014). Other treatments and side effects such as fatigue, pain and distress are also considered to contribute to cognitive difficulties (Pullens, et al, 2010). However, in one recent study, cancer survivors who were six months post-chemotherapy, demonstrated reduced working and recognition memory compared to a control group, after accounting for fatigue, anxiety and depression (Wang, Apple, Schroeder, Ryals, Voss & Gitelman, 2016). The authors reported that cancer survivors found it difficult to encode and maintain initially acquired information. It is important to note that this study had several limitations including a small sample size and the exclusion of survivors who received radiotherapy (Wang et al., 2016).

Phillips, Jim, Small, Laronga, Andrykowski and Jacobsen, (2012) compared cognitive difficulties in breast cancer patients who received chemotherapy and radiotherapy or radiotherapy alone to non-cancer controls. Both groups reported slower processing speed, executive functioning and verbal ability compared to the control group at six months' post-treatment. No improvements were noted three years later in both groups, compared to the control group who did report improvements in cognitive functioning.

In conclusion, a diagnosis of cancer can result in individuals undergoing a combination of different treatments. These treatments are accompanied by their own side effects. As survivors' transition from treatment to survivorship, many continue to experience additional symptoms including fatigue, pain, distress and cognitive difficulties. These symptoms can occur in combination with one another and impact upon survivors' performance of everyday activities. The exact cause of these symptoms is unclear, nevertheless their severity can persist for several years following treatment, generating feelings of frustration in cancer survivors. These continuing symptoms can impact on survivors' ability to return to occupations previously engaged in prior to treatment, as discussed in the following section.

2.3.7 Activity Participation

Participation in everyday activities is regarded as an important goal for cancer survivors to return to (Palmadottir, 2010). Cancer survivors have identified that returning to their daily routine can help maintain control and stability, develop a sense of self-worth and enhance self-development. Returning to productive roles such as employment, caring for grandchildren or volunteering with charities has also been identified as helping survivors develop a sense of self-worth post-treatment (Palmadottir, 2010). However, persisting symptoms can impact on activity participation. In their small study, Fleischer and Howell (2017) interviewed eight breast cancer patients during and after treatment. The authors found that during treatment, participation in activities was limited by side effects such as fatigue. Many participants were hopeful of returning to these activities following treatment. Six months' post-treatment, participants reported that side effects were still limiting their activity participation however at this point, many had developed strategies such as pacing to help them complete activities.

Employment is one activity cancer survivors are highly motivated to return to as part of their usual routine (Foster & Fenlon, 2011; Aaronson et al., 2014). Aside from the financial security, employment also creates a sense of identity, normalcy and social relationships (Peteet, 2000; Gordon, Lynch & Newman, 2008). Returning to work is not just in the

interest of the cancer survivor, but society as well (Aaronson, et al., 2014). Curt et al., (2000) reported that out of the 177 participants that were employed in their study, 75% changed their employment status due to fatigue i.e. discontinued work altogether, availed of a disability allowance or availed of unpaid leave. A meta-analysis comparing 20,366 cancer survivors to 157,603 healthy controls concluded that 33.8% of cancer survivors were more likely to be unemployed compared to 15.2% of the control group (de Boer, Taskila, Ojajärvi, van Dijk & Verbeek, 2009). In particular, breast, gastrointestinal and gynaecological cancer survivors were more likely to be unemployed. The authors concluded in their meta-analysis that “*cancer survivorship is associated with unemployment*” (de Boer et al., 2009, p753). Post-treatment effects, particularly, cognitive difficulties, can impact on survivors’ confidence and self-efficacy resulting in increased distress levels and early retirement (Böttcher, Steimann, Rotsch, Zurborn & Koch et al., 2013). In their systematic review Stone, Ganz, Pavlish and Robbins (2017) concluded that the impact of physical and cognitive difficulties on employment increased the likelihood of survivors reporting depression and distress. Furthermore, employers and work colleagues may not always be aware of continuing symptoms post-treatment, therefore, survivors experience an expectation that they are ‘back to normal’ contributing further to their distress (Raque-Bogdan, Hoffman, Ginter, Piontkowski & Schexnayder et al., 2015). The need for return to work planning for cancer survivors has also been recommended in the literature (Stone et al., 2017).

2.3.8 Social Participation

Continuing symptoms such as fatigue, pain, distress and cognitive difficulties can impact on social and personal relationships. Social participation is viewed as an indicator of health and well-being and has been shown to improve mental health outcomes in cancer survivors (Piškur, 2013). When social participation is affected, it can negatively impact on social relationships and quality of life (Thraen-Borowski, Trentham-Dietz, Edwards, Koltyn & Colbert, 2013). Social support is considered a vital component of survivors’ mental health as it can improve the confidence and coping abilities of cancer survivors (Sapp, Trentham-Diaz, Newcomb, Hampton & Moinpour et al., 2003). Socially isolated breast cancer survivors have reported more problems with physical functioning, role limitations and provision of emotional support (Michael, Berkman, Colditz, Holmes & Kawachi, 2002). In contrast, lymphoma survivors who reported greater social networks and supports reported lower levels of fatigue and improved quality of life (Soares, Biasoli, Scheliga, Baptista, Brabo & Morais et al., 2013).

The impact of continuing symptoms such as fatigue, pain, distress and cognitive difficulties post-treatment can result in survivors reporting unmet needs as they transition to survivorship. The lack of understanding of these symptoms can affect survivors' engagement in productive and social roles and subsequent contribution to society thus impacting on self-efficacy and quality of life. The impact of continuing symptoms is one of the reasons why cancer is now seen as a chronic condition.

2.4. Cancer as a Chronic Condition

Due to the increased survival rates and widespread treatments, cancer is now regarded more as a chronic condition rather than a fatal condition, due to the often persistent symptoms following treatment and the long-term follow-up (CDC & LAF, 2004; Hewitt, Greenfield & Stovall, 2005). Elliott et al., (2011) reported that those who received cancer treatment and had no chronic conditions were similar in health status to those with a chronic condition and no cancer treatment. Additionally, those who received cancer treatment and had a chronic condition were similar to those who had two chronic conditions. Foster and Fenlon (2011) argue that cancer survivors and those with a chronic condition place similar values on returning to 'normal life'. When people struggle with this or it takes longer than expected to return to 'normality' it can lead to issues such as social isolation, decreased participation, financial and familial strain (Foster & Fenlon, 2011; Loh, Packer, Chinna & Quek, 2013). Foster and Fenlon (2011) contend that similar to people with chronic conditions, cancer survivors need to learn how to manage these issues as part of their 'normal life'. In the US, the *National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* report called for increased education regarding post-treatment issues for cancer survivors. It encouraged the concept of survivorship as a chronic condition, in order to understand key issues affecting cancer survivors (CDC & LAF, 2004).

The literature recommends further that self-management interventions from other chronic disease models should be reviewed and applied to cancer survivors as both experience persisting symptoms and require long-term follow-up (CDC & LAF, 2004, Elliott et al. 2011; McCorkle et al., 2011).

2.4.1 Chronic Care Model (CCM)

The CCM was originally designed to propose organisational changes in healthcare delivery to improve quality of care for patients with chronic illnesses (Wagner, Austin, Davis, Hindmarsh, Schaefer & Bonomi, 2001; Coleman, Austin, Brach & Wagner, 2009).

These changes consist of increased support for self-management, utilising community resources, creating better connected teams and supportive information technology including registries (Coleman et al., 2009). A Cochrane review found that implementing multicomponent changes such as improving physicians' knowledge, educating and supporting patients, making care delivery more team-based and utilising registry-based information systems, improved patient health outcomes in the management of diabetes (Renders, Valk, Griffin, Wagner, van Eijk & Assendelft, 2000). Wagner et al., (2001) reported that implementing the changes recommended by the CCM improved patient care in conditions such as diabetes and asthma. Currently, research is underway to examine the effectiveness of the CCM in obesity and weight management which is now considered to be an emerging chronic condition (Sheesley, 2016).

Therefore, as cancer is regarded as a chronic condition, researchers believe that the CCM provides a framework to improve the quality of cancer care and the coordination of services (McCorkle et al., 2011). It could also encourage healthcare changes, which may enable and empower cancer patients to actively engage in their cancer care from diagnoses, treatment, survivorship and end-of-life care (McCorkle et al., 2011). However, there are limitations to implementing the CCM into cancer care. Researchers are unsure exactly what changes or combination of changes are effective in promoting change in chronic care delivery. Furthermore, evidence to investigate this is limited due to the complexities of implementing all six changes of the CCM within existing practice (Sheesley, 2016). Finally, as the CCM promotes self-management among patients, the lack of a 'gold standard' definition, creates a difficulty in developing a common language that is usable across professions and with patients (McCorkle et al., 2011).

2.5 Definition of Self-Management

Self-management has recently become more evident in cancer survivorship literature (Sleight & Duker, 2016; Baxter, Newman, Longpre, & Polo, 2017). There is no 'gold standard' definition for self-management however one definition that is used is the *"individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent with living with a chronic condition"* (Barlow et al., 2002, p178). This shifts the focus on patients from passive recipient to active participant in managing their chronic illness (Barlow et al., 2002). Self-management with cancer survivors includes medical management of the continuing symptoms post-treatment, as described in section 2.3, maintaining, changing or creating meaningful roles

following treatment and managing the psychosocial issues related to survivorship (Baxter et al., 2017).

2.5.1 Components of Self-Management Programmes

Self-management typically incorporates five core skills of problem-solving, decision making, resource utilisation, communication with healthcare professionals and action planning or goal setting (Lorig & Holman, 2003). It distinguishes itself from traditional health education by its emphasis on the application of these five core self-management skills to one's own situation. Self-management programmes should aim to address three aspects of chronic conditions that ideally should be managed; medical, role and emotional management (Lorig & Holman, 2003). The theoretical basis of self-management interventions originates from Bandura's Social Cognitive Theory which proposes that increased self-efficacy facilitates behavioural changes. Self-efficacy is considered as the individuals' belief in their own ability to perform the skills necessary to manage a situation (Bandura, 1977). In relation to self-management, it applies to the individual's confidence in achieving goals related to the management of their condition, which can contribute to behavioural changes (Foster & Fenlon, 2011). A higher self-efficacy is associated with a greater persistence to overcome obstacles (Bandura, 1977; Foster & Fenlon, 2011). To enhance self-efficacy, it is recommended that self-management programmes should contain these four key elements (Lorig & Holman, 2003);

1. Performance mastery: This is part of action planning where individuals are encouraged to set a goal they wish to achieve in the coming week and to rate their certainty that they will complete this goal
2. Modelling: Individuals in self-management programmes can act as models through learning from each other
3. Interpreting symptoms: Providing individuals with knowledge or alternative reasons to their symptoms
4. Social persuasion: Peer support and pressure from the presence of other individuals can encourage behavioural changes

The format of self-management programmes can be individualised, group-based or a combination of both. Individualised programmes for chronic conditions can be just as effective as group-based however, the latter is considered more cost-effective and efficient (Barlow et al., 2002; Rickheim, Weaver, Flader & Kendall, 2002). Additionally, previous studies have reported that group-based, self-management programmes, provided an

opportunity for comradeship and emotional support between group members (Adamsen, Rasmussen & Pedersen, 2001; Breau & Norman, 2003; Ahlberg & Nordner, 2006).

Self-management programmes can be lay-led or professional-led. Lay-led programmes generally involve leaders who also have the same chronic condition and are therefore seen as a 'role model' for participants (Foster, Taylor, Eldridge, Ramsay & Griffiths, 2007). Lay-led programmes are considered more cost-effective however, researchers would argue that professional-led programmes can address the factual issues related to an illness, due to their training (Newman, Steed & Mulligan, 2004). Professional-led programmes can target high risk individuals and teach specific disease management skills, that lay-led programmes may not be able to provide (Griffith, Foster, Ramsay, Eldridge & Taylor, 2007). Embuldeniya, Veinot, Bell, Bell, Nyhof-Young and Sale et al., (2013) contended that lay-led programmes can increase social isolation, create negative social comparisons and mimic the power relationships of biomedical models to which they aim to provide an alternative.

2.5.2 Occupational Therapy and Self-Management

Occupational therapy is a client-centred profession concerned with enhancing an individuals' ability to engage in occupations of importance to them which in turn promotes health and well-being (World Federation of Occupational Therapists (WFOT), 2012). Physical and psychosocial issues experienced post-treatment, as described in section 2.3., can impact on cancer survivors' activity participation and quality of life thus compromising their health and wellbeing (Baxter et al., 2017). Occupational therapists work with a vast array of chronic conditions and are accustomed to the occupational performance problems these conditions may present which are similar to issues reported by cancer survivors (Hand, Law & McColl, 2011; Shneerson et al., 2015). Occupational therapy interventions are designed with the aim to improve function and participation in daily activities including self-management, which in turn promotes health and wellbeing, across the cancer care continuum (Burkhardt & Schultz-Krohn, 2013; Vaughn, 2014). The profession follows a holistic perspective of promoting independence through engagement of meaningful activities (Crepeau, Schell & Cohn, 2009). According to Baxter et al., (2017) occupational therapists offer a distinctive perspective on improving functioning and participation in daily activities. Unique skills in activity analysis, combined with background knowledge in medical, psychological, psychosocial and developmental fields, allow occupational therapists to facilitate interventions that enable survivors to return to their daily routine, thus improving their health and wellbeing (Baxter et al., 2017).

Lack of information on how to manage symptoms is a commonly unmet supportive care need of cancer survivors (Dilworth, Higgins, Parker, Kelly & Turner, 2014). Occupational therapists are effective in teaching self-management strategies. Additionally, content covered in self-management programmes are familiar to occupational therapists such as fatigue management, energy conservation, sleep hygiene, lifestyle redesign, coping with emotions and relaxation (Clark et al., 2012; Hwang et al., 2015). The OptiMal programme, discussed in more detail in section 4.2, includes these topics. Self-management programmes incorporate goal setting creating a client-centred approach, elements consistent with occupational therapy practice (Hirsche et al., 2011). Goal-setting was also a core element of the OptiMal programme as each week participants were facilitated to set goals of importance to them to explore how to incorporate the self-management education into their weekly routines.

Self-management interventions have been delivered by occupational therapists to individuals with multimorbidity to promote their health and wellbeing (O'Toole et al., 2013; Garvey et al., 2015). However, there is a paucity of evidence regarding occupational therapists delivering self-management interventions to cancer survivors (Sleight & Duker, 2016). Hunter et al., (2017a) conducted a systematic review on rehabilitation interventions used with cancer survivors and found that many interventions lacked a focus on occupation and participation. Potential ways on how occupational therapy can be integrated into survivorship care is by facilitating occupation-based interventions through problem-solving, energy conservation, education and cognitive-behavioural therapy to promote meaningful participation and health and wellbeing (Hunter et al., 2017a). A non-randomised controlled trial by Loh et al., (2013) involved a four-week, occupational therapy-led programme comprised of self-management and education sessions. Participants formed a 'buddy system' with others who were undergoing similar experiences i.e. undergoing chemotherapy or recently diagnosed. This study reported improvements in quality of life and decreased in stress, depression and anxiety both post-intervention and at four-week follow-up of women with breast cancer.

Despite these promising results, there appears to be a lack of awareness among clinicians and survivors of the potential impact of occupational therapy in cancer survivorship (Cheville, 2005; Hwang et al., 2015; Pergolotti et al., 2016). In North Carolina, Pergolotti, Cutchin, Weinberger and Meyer (2014) reported that among the 87% of older cancer survivors that were considered in need of occupational therapy, only 32% used occupational therapy services within the first two years of their diagnosis. In one systematic review of cancer rehabilitation, various post-treatment side effects were

discussed including fatigue, pain and cognitive issues (Egan, McEwan, Sikora, Chasen, Fitch & Eldred, 2013). Several professions were mentioned to help alleviate these concerns, however, occupational therapy was not one of those included (Egan et al., 2013). The lack of awareness of the potential role of occupational therapy may be attributed to the lack of an evidence base of the facilitation of occupation-based self-management interventions for cancer survivors. There has been a call for more occupation-based interventions with a focus on occupational participation, health and wellbeing for cancer survivors (Slieght & Duker, 2016; Hunter et al., 2017a).

2.5.3 Self-Management Interventions for Cancer Survivors

Self-management programmes have been successful in helping people with chronic conditions manage persistent symptoms that can impact on every day activities and quality of life (O'Toole et al., 2013; Garvey et al., 2015). These symptoms are also experienced by cancer survivors' post-treatment and with the increasing acceptance of cancer as a chronic rather than a fatal condition, there is a clear need to provide evidence on the effectiveness of self-management in cancer survivors (CDC & LAF, 2004; Hewitt et al., 2005).

Self-management is considered important in managing the chronic issues arising from cancer survivorship (Baxter et al., 2017b). Evidence suggests that self-management interventions should be introduced as individuals' transition from treatment to survivorship, as they are returning to their normal roles, while dealing with physical and psychological effects of treatment (McCorkle et al., 2011). The education and coping strategies provided increase the individual's knowledge of issues arising post-treatment (Purcell, Fleming, Burmeister, Bennett & Haines, 2011; Cheville, Shen, Chang & Basford et al., 2013). This enables individuals to implement self-management strategies thereby reducing levels of distress and encouraging empowerment during the rehabilitation phase (Purcell et al., 2011; Cheville et al., 2013; Schjolberg et al., 2014). Self-management is considered key in bridging the gap between cancer survivors' needs and the ability of health services to meet those needs (McCorkle et al., 2011).

However, despite recommendations for providing cancer survivors with self-management strategies, limited evidence is available at present regarding self-management interventions with no definitive conclusions of their effectiveness. Further research and more rigorous investigations are recommended (Gao & Yuan, 2011; Hammer et al., 2015). A systematic review was conducted as part of this research to examine the effectiveness of self-management interventions for cancer survivors. This will be discussed later, in

Chapter Three. There is now a new focus on survivorship in international and national policies through the promotion of self-management.

2.6 Current Policies on Cancer Survivorship

International and national policies have begun to acknowledge the needs of cancer survivors and consider self-management an appropriate intervention to address the needs of cancer survivors.

2.6.1 International Policy

2.6.1.1 United States

Key reports published in the United States have highlighted the topic of cancer survivorship as a formal period of care (McCabe, Faithfull, Makin, & Wengstrom, 2013). The National Health Interview Study was conducted from 1998 to 2000 to gain an understanding of the threats to an individual's function, well-being and subsequent quality of life following cancer treatment (Hewitt, Rowland & Yancik, 2003). This study found that compared to individuals without a history of cancer or other chronic diseases, cancer survivors reported being in poorer health, limited in their daily activities due to functional limitations and were unable to work (Hewitt et al., 2003).

A year later, *The National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* by the Center for Disease Control and Prevention (CDC) was published in the US in 2004. This report called for the development of a cancer survivorship database to follow cancer survivors after the completion of their treatment to explore the long-term effects of cancer and their current needs e.g. emotional, physical etc. The report proposed the development of national clinical guidelines to guide practitioners through each step of cancer survivorship. Guidelines are in place for different cancers but are not comprehensive in detail for the survivorship stage (CDC & LAF, 2004). Another recommendation was to provide education programmes from medical treatment to survivorship to enable people to become active participants and self-managers of their health (CDC & LAF, 2004).

This was followed in 2005 by the Institute of Medicine's (IOM) landmark report, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2005). This report remarked on the increasing survival rates among cancer patients while acknowledging that current health systems are focused on the early stages of cancer management but not on

the survivorship stage (Hewitt et al., 2005). This report recommended the development of Survivorship Care Plans which would outline survivors' follow-up care, guidelines for clinical care, research, communication and encouraged professional training, both at an undergraduate and graduate level, to further understand cancer survivors needs (Hewitt et al., 2005; McCabe et al., 2013). Over a decade since these recommendations, post-treatment follow-up care is considered poorly coordinated across the United States, due to the intricacies of health insurance and healthcare providers unclear of their responsibilities in each state (Rowland, Kent, Forsythe, Havard, Loge & Hjorth, et al., 2013).

2.6.1.2. United Kingdom

In the UK, similar reports recognising the needs of cancer survivors have been published. The UK government's *Cancer Reform Strategy* outlined that the National Cancer Survivorship Initiative (NCSI) would be established to provide support to cancer survivors (Department of Health (DOH), 2007). As a result the NCSI was created by the Department of Health and the charity Macmillan Cancer Support in 2008 (McCabe et al., 2013).

In 2010 the NCSI published their national strategy, the *National Cancer Survivorship Initiative Vision* (DOH, 2010). Similar to the report produced by the Institute of Medicine in the US in 2005, the NCSI's Vision document identified key priorities for the development of cancer survivorship services and research in the UK (McCabe et al., 2013). It recommended the development of survivorship care plans and a focus on self-management as part of follow-up care (DOH, 2010).

The NCSI later released their *Living with and Beyond Cancer* report in 2013 and advocated for survivorship programmes. The NCSI report argued that good survivorship care programs can reduce mortality rates by supporting people in reducing their risk of cancer recurrence, managing or preventing co-morbidities arising from treatment such as osteoporosis or depression thereby improving quality of life. Good survivorship care could improve quality of life for individuals with long-term conditions caused by cancer or treatment. They offer survivors the opportunity to learn how to self-manage the consequences of treatment and reintegrate back into their roles before treatment including education and work (DOH, 2013). This report recommended that the period up to a year after treatment is when people should be guided towards self-management (DOH, 2013). At present, research is ongoing regarding the effectiveness of survivorship programmes (McCabe et al., 2013).

2.6.1.3 Canada and Australia

In Canada, the need for follow-up care for cancer survivors has also been acknowledged. In 2006, the Canadian Partnership Against Cancer (CPAC) was created to deliver action on cancer control in Canada including cancer survivorship (Ristovski-Slijepcevic, Nicholl & Bennie, 2008). The actions of the CPAC informed the National Cancer Strategy in 2007 published by the Canadian government (Ristovski-Slijepcevic et al., 2008). This outlined their key priorities for survivorship care including the development of national and international standards and models of care, promotion of survivorship research and the use of survivorship care plans, similar to the NCSI report (Jefford, Rowland, Grunfeld, Richards, Maher & Glaser, 2013; Keesing, McNamara & Rosenwax, 2015). The impact of the implementation of survivorship care plans is still unknown at present (Jefford et al., 2013).

In comparison, Australia does not have a national cancer strategy and models of care varies across the different states (Jefford et al., 2013; Keesing et al., 2015). Researchers have highlighted that the current follow-up services provided may not meet cancer survivors needs post-treatment (Jefford et al., 2013). Victoria, the second most-populated stated in Australia, launched the Victorian Cancer Survivorship Program (VSCP) in 2011. This is based on the NCSI report in the UK and aims to tests post-treatment models of care between acute and primary care services, to develop resources to support improvements in follow-up care and to facilitate cancer survivor involvement and self-management (Jefford et al., 2013). Six two-year pilot projects are underway evaluating the VSCP involving various cancer types, different regions and age groups (Jefford et al., 2013).

2.6.1.4 Europe

In comparison to their US, UK and Canadian counterparts, European countries lack specific organisations to address cancer survivors' needs (Rowland et al., 2013). A major policy document, *Communication on Action Against Cancer: European Partnership*, was published in 2009 by the European Commission. This report highlighted several areas of improvement in cancer care in Europe including cancer survivorship. The Commission also outlined that all member states publish cancer care plans by 2013. At present, 25 out of the 28 member states have published national cancer plans (European Commission, 2017).

Across Europe, there is variation regarding the recognition of cancer survivorship and addressing cancer survivors' needs. In Sweden, public finances are geared towards

developing cancer aftercare services (McCabe et al., 2013). Its neighbour, Norway, undertook population surveys to inform the design of cancer rehabilitation programmes (Gjerset, Fossa, Courneya, Skovlund, Jacobsen & Thorsen, 2011). Cancer survivors in Italy reported varying access to aftercare services (Mattioli, Montanaro & Romito, 2010). Rowland et al., (2013) reported that cancer survivorship research was limited in Europe due to restricted funding and lack of awareness of this research area, however, developments have been made in progressing the cancer survivorship agenda in Europe. In 2017, Cancon, a cancer control joint action committee formed by the European Commission published a guide to all member states establishing standards of cancer control practice titled *European Guide on Quality Improvement in Comprehensive Cancer Control* (2017). The survivorship section of this document was influenced by reports from the Institute of Medicine in the US and the NCSI in the UK, as detailed in the previous sections. This guide encouraged self-management amongst survivors and early introduction of psychosocial interventions for cancer survivors, particularly regarding return-to-work (Borras & Debrow, 2017). The guide also advocated the use of Survivorship Care Plans as recommended by survivorship strategies in the US and UK, as detailed above.

Within the last two decades, international policies have recognised the needs of cancer survivors and acknowledged that follow-up care should incorporate aspects of self-management (Hewitt et al., 2005; DOH, 2010). The success of these policies has been limited by various factors including funding and a lack of clarity regarding healthcare providers responsibilities (McCabe et al., 2013). Irish policy has also begun to recognise the needs of cancer survivors over recent years.

2.6.2 Irish Policy

The National Cancer Registry of Ireland (NCRI) reported in 2013 that the most common invasive cancers in Ireland are breast, prostate, colorectal and lung cancer excluding non-melanoma skin cancer. A year later, in 2014, the NCRI projected that new cancer diagnoses will double by 2040 particularly those of lung, rectal, colon cancer and melanoma. Future trends in the incidence of breast and prostate cancer may increase by 130% and 104% by 2040. However, the rate of cancer survivorship is increasing and the NCRI reported that by the end of 2014 the number of cancer survivors was approximately 139,526, concluding that cancer support services needed to expand to meet these growing figures (NCRI, 2016). Currently there are now over 150,000 cancer survivors (DOH, 2017). In Ireland, cancer services include medical treatment and follow-up appointments post-treatment carried out by hospital-based consultants. The lack of psychosocial and

supportive care for cancer survivors has been acknowledged in governmental reports but little action has been taken (NCF, 2006). However, the recently published National Cancer Strategy has sought to address this gap in service needs (DOH, 2017).

2.6.2.1 National Cancer Strategy 2017-2026

In 2015, the Minister for Health convened a steering group to inform the National Cancer Strategy for 2017-2026 (DOH, 2015). One of the main aims of this strategy was to improve the quality of life of people recovering from cancer, a significant step in addressing cancer survivorship which had scarcely been mentioned in the previous cancer strategy, produced in 2006 (NCF, 2006).

The National Cancer Strategy 2017-2026 was published in June 2017 (DOH). In this document, cancer survivorship was widely acknowledged and considered a distinct part of the cancer care continuum. In the strategy, the needs of aftercare services for cancer survivors were recognised. The strategy also outlined the intention of developing survivorship programmes. The aim of these programmes will be to provide self-management education on physical and psychosocial factors that impact on health and wellbeing (DOH, 2017).

The latest strategy outlined the main elements of survivorship care including interventions for long-term effects of cancer and the encouragement of self-management and health education. The strategy also outlined that survivorship care should address the needs of survivors with respect to chronic disease management and warned that physical and psychosocial effects not addressed in the first year of post-treatment, can become chronic. The strategy advocated that future survivorship programmes should incorporate self-management support to encourage survivors to take control of their health (DOH, 2017). However, the author warned that for the strategy to be implemented and successful, increased funding in the workforce, particularly in relation to healthcare professionals, will be crucial (DOH, 2017).

Cancer survivors can experience continuing symptoms following treatment which can impact on their daily activities and health and wellbeing. In recent years, the needs of cancer survivors have been acknowledged both internationally and nationally. Interventions to address those needs have been proposed. In particular, self-management has been widely suggested as an appropriate means of addressing post-treatment needs, as it encourages survivors to manage their own health condition, similar to the management of chronic conditions. Occupational therapists are familiar with the content

discussed in self-management programmes. However, evidence is limited regarding the effectiveness of self-management interventions for cancer survivors.

The following chapter will discuss the systematic review conducted as part of this study to determine the effectiveness of self-management interventions for cancer survivors.

3. Systematic Review

3.1 Introduction

As mentioned in the previous chapter, evidence is limited regarding self-management interventions for cancer survivors with no definitive conclusions of their effectiveness and further research is recommended (Gao & Yuan, 2011; Hammer et al., 2015). As part of the research, a systematic review was undertaken. This was published in 2018, in the *Journal of Supportive Care in Cancer*, volume 26, issue 5, pp1585-1595. This chapter maintains the format and content of the article published in the journal (Appendix A).

3.1.1. Aim of the Systematic Review

The aim was to systematically review self-management interventions in cancer survivors in relation to the type, content and the impact of these interventions compared to usual care on at least one outcome of activity participation, self-efficacy, quality of life and symptom management and on at least one occasion during follow-up.

3.2 Methods

The methods are presented according to the PRISMA guidelines (Moher et al., 2009).

3.2.1 Eligibility Criteria

A Population, Interventions, Comparators and Outcomes (PICO) table was created to form inclusion criteria and screen papers based on their title and abstract (Appendix B). Articles were suitable for inclusion if they met the following criteria;

3.2.2 Inclusion Criteria

- (i) Randomised Controlled Trials (RCT) or systematic review/meta-analysis of RCTs
- (ii) Cancer survivors who were aged 18 years or over when diagnosed and completed primary treatments (surgery, chemotherapy and/or radiation therapy)
- (iii) Groups, individual and/or online self-management interventions
- (iv) Viable comparison groups including participants randomised to usual care or waiting list control (WLC)

(v) At least one of the following reported outcomes were measured; activity participation, quality of life, self-efficacy or symptom management

3.2.3 Exclusion Criteria

(i) Non-RCTs or systematic reviews/meta-analysis of non-RCTs

(ii) Cancer survivors who were diagnosed during childhood or participants who were recently diagnosed or undergoing primary treatments

(iii) Interventions conducted at the diagnosis or treatment stage or focused on one component e.g. exercise, return to work

(iv) Studies written in languages other than English

There is no 'gold standard' definition for self-management however Barlow et al., (2002) define it as the 'individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent with living with a chronic condition' (p178). For this review, studies were included if they contained multi-component interventions aimed at facilitating at least one of five core self-management skills (problem-solving, decision making, resource utilisation, communication with healthcare professionals and action planning or goal setting).

3.2.4 Search Methods

Search terms were developed in consultation with a medical librarian and applied to the following databases; EMBASE, Scopus, PubMed, CINAHL, PsycInfo and Cochrane. Search terms included 'self-management' and 'self-efficacy' combined with Boolean terms (and/or) for 'cancer survivor'. Limitations were employed specific to each database ensuring that only RCTs published in English were included. Appendix C contains the full electronic search strategies for the databases used.

3.2.5 Study selection

Each study that resulted from the searches, were screened for suitability based on their title and abstract by one author (LB). Studies were excluded when it was clear from their title and abstract that the article did not relate to the inclusion criteria. Where there was a lack of clarity from the title and abstract, the full text was obtained to determine its suitability.

3.2.6 Data Collection Process

A data extraction tool based on the Cochrane Handbook for Systematic Review of Interventions (Higgins & Green, 2011) was used by two of the authors (LB, KB) to independently extract data from the included studies with the following information;

- Author, year of publication
- Study design, randomisation, allocation concealment, blinding of participants, outcome assessment, attrition bias, reporting bias and other biases
- Participant numbers, cancer types, country and setting, inclusion and exclusion criteria
- Type of Intervention: web-based, group, individual (i.e. face-to-face), content, duration, health professionals as intervention facilitators
- Outcomes – primary and secondary outcomes, follow-up time period

3.2.7 Risk of Bias in Individual Studies

Two reviewers (LB, KB) assessed risk of bias of each study based on the Cochrane Handbook (Higgins & Green, 2011). This tool assesses bias on random sequence generation, allocation concealment, blinding, incomplete outcome data, selective reporting and other sources of bias. In these studies, the risk of bias for each of these domains was determined to be low, high or unclear. Low indicates the domain was performed adequately, high if inadequately performed and unclear if insufficient information was provided to make a judgement. Disagreements were resolved by discussion between the two reviewers, and a third reviewer was available if unresolved.

3.3. Results

3.3.1 Study selection

The electronic searches identified 2,633 studies (Figure 3-1). Upon the removal of duplicates, 2,042 citations were screened and 29 citations were retained. Full texts of these articles were obtained. Nine were immediately excluded including seven citations which were conference abstracts, one article was a literature review and one was a systematic review. The remaining 20 articles were assessed for bias. As a result, six articles were eligible for inclusion in the final analysis.

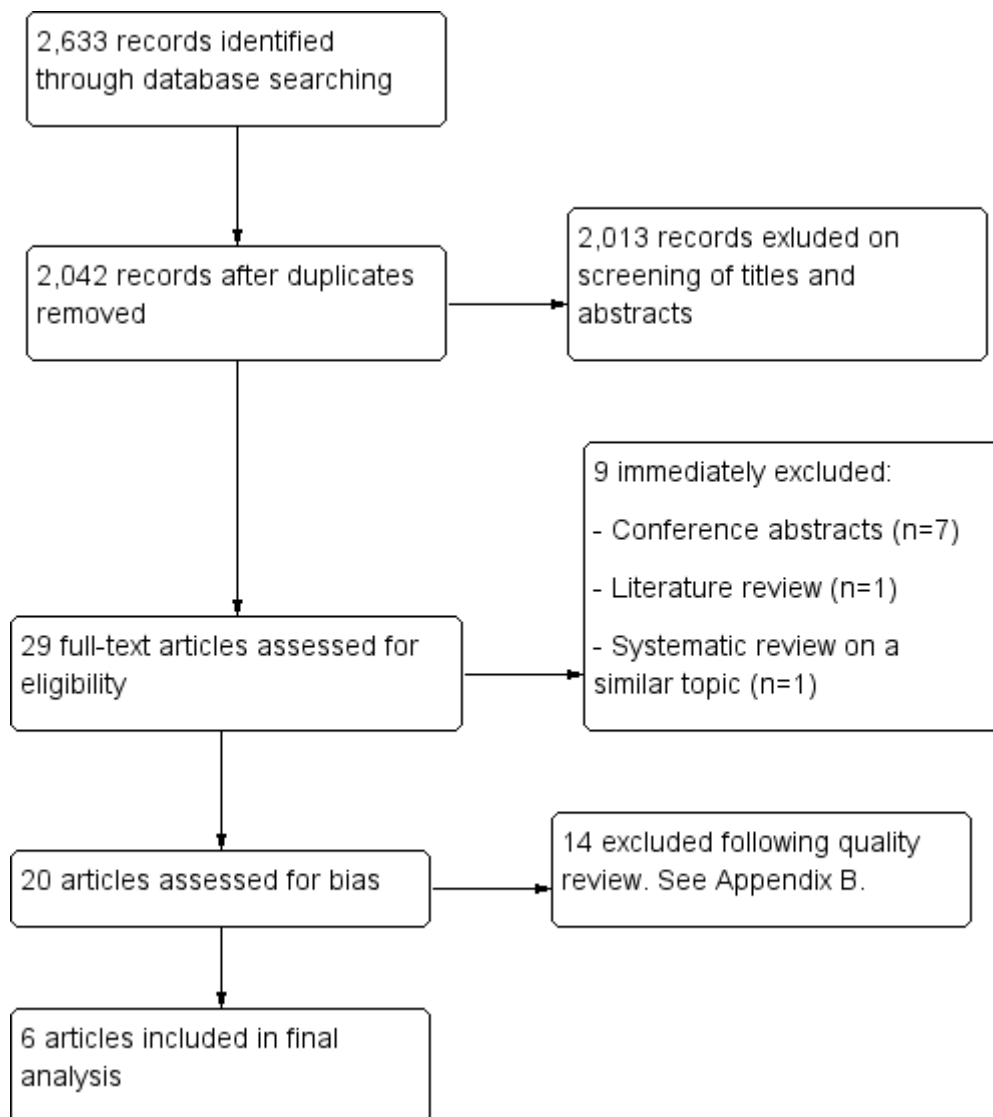


Figure 3-1 PRISMA flow chart of the study selection process

3.3.2 Study characteristics

See Table 3-1 for an outline of study characteristics of the six studies including location, details of the intervention, participant details (including cancer type), duration and facilitators of the intervention.

Table 3-1 Characteristics of Included Studies

Study Name and Country	Participants	Sample Size; Gender; Intervention vs Control	Intervention; Length	Intervention Facilitators	Format	Programme Details
Beatty et al., (2010); Australia	Breast; Women who had completed treatment within the past 3 months Mean Age: 53.05 years SD: 11.44	n = 40; Female: 40 Intervention: n = 20, Control: n = 20	Self-guided workbook; 12 weeks	No health professional involvement	Workbook sent to participants.	<ul style="list-style-type: none"> - Focused on facilitating breast cancer survivors' transition from treatment to survivorship. - Based on 3 major components; education on common medical and psychosocial issues, suggestions and worksheets to address these issues, survivors stories - Relaxation and meditation tape provided to all programme participants
Foster et al., (2016); England	Mixed cancers; Survivors 5 years or less post-diagnosis with self-reported moderate to severe levels of fatigue	n = 159; Male: 37 Female: 122 Intervention: n = 83, Control: n = 76	Self-guided web-based intervention; 6 weeks	No health professional involvement	5 topics in total, each session delivered weekly online	<ul style="list-style-type: none"> - RESTORE, a fatigue management web-based programme; 5 educational topics accessible over a six week period - First 2 sessions introduce cancer-related fatigue (CRF) and goal setting. - Participants could choose to complete all 3 remaining topics or focus on one of those topics for the remaining 3 weeks

Table 3-1 Continued

	Mean Age: 57.8 SD: 9.95					<ul style="list-style-type: none"> - These topics included (i) diet, exercise, sleep, home and work life (ii) thoughts and feelings and (iii) talking to others - Topics incorporated CBT and self-management skills. Goal setting implemented throughout
Lee et al., (2014); South Korea	Breast; Women who completed primary treatment within 12 months prior to the study Mean Age: 42.35 SD: 5.7	n = 59; Female = 59 Intervention: n = 30, Control: n = 29	Self-guided web-based intervention; 12 weeks	Nutritionist contacted participants in intervention group to ensure food diaries were recorded correctly – unclear how often participants contacted	Group members encouraged to use the programme weekly through automated messaging	<ul style="list-style-type: none"> - Participants encouraged to plan their exercise and dietary behaviours in line with current guidelines - Educational sessions included considerations when planning exercise and diet and barriers to sustainability of same - Participants kept a web-based diary throughout recording daily exercise and number of units of each food group consumed. This information provided daily feedback to participants on their goal achievements.
May et al., (2009); Netherlands	Mixed cancers; Last curative treatment completed 3 months before study entry;	n = 147; Male: 24 Female: 123 PT & CBT: n = 76, PT:	Face-to Face; Individual and group-based. Physical	PT guided by 2 physiotherapist, CBT facilitated by a psychologist	PT group - 12 weeks, twice weekly, 2 hour group sessions PT and CBT = same PT	<ul style="list-style-type: none"> - PT group; Personalised exercise programme including aerobic bicycle and muscle strength training followed by group sports (badminton, soccer, swimming or balancing games) - CBT group; Educational sessions on a number of topics including stress, fatigue, exercise, relaxation.

Table 3-1 Continued

	Mean Age: 48.8 SD: 10.9	n = 71	training (PT) and Cognitive Behavioural Training (CBT); 12 weeks	and a social worker	programme but CBT was weekly, 2 hour group sessions	- CBT group assignments provided to facilitate application of self-management skills in everyday life using goal-setting and problem-solving
Mishel et al., (2005); USA	Breast; women who were 5-9 years post-treatment, stages I-III; Mean Age: 64 SD: 8.9	n = 509; Women = 509 Intervention: n = 244, Control: n = 265	Workbook sent to participants; 4 weeks	Nurses	Intervention nurses conducted weekly phone calls for 4 weeks	- Workbook addressed recurrence anxiety of cancer survivors. - Nurses trained in the intervention guided participants through the workbook for 4 weeks - Workbook contained behavioural strategies to develop self-management skills and information on long-term treatment side effects. - Audiotape provided to teach coping responses such as relaxation and visual imagery to triggers of cancer recurrence
van den Berg et al., (2015); Netherlands	Breast; survivors who had finished treatment 2 to 4 months pre-baseline	n = 150; Female: 150 Intervention: n = 70, Control: n = 80	Self-guided web-based intervention; 16 weeks	No health professional involvement	New material released weekly followed by e-mail reminders	- BREATH, web-based programme guided by CBT - Aim was to enable breast cancer survivors to take control of and adjust to survivorship - Content based on 4 phases of adjustment to breast cancer; looking back, emotional processing, strengthening and looking ahead.

Table 3.1 Continued

	Mean Age: 50.81 SDL 8.7					- Participants required to complete assignments, assessments and videos
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3.3.3 Risk of Bias in Individual Studies

A summary of the risk of bias assessment for each study are shown in Figure 3-2. Initially, 20 articles were assessed for bias using the RevMan 5.1 Risk of Bias tool. As a result, 14 studies were excluded from the final review for a variety of reasons (Appendix D). The results of the risk of bias of the remaining six articles are displayed as follows in Figure 3-2.

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Beatty 2010	+	+	+	+	+	+	?
Foster 2015	+	+	+	+	?	+	?
Lee 2014	+	+	+	+	+	+	+
May 2009	+	?	+	+	+	+	+
Mishel 2005	+	?	+	+	+	+	+
Van den Berg 2015	+	?	+	+	+	+	+

Figure 3-2 Risk of bias summary: authors' judgement on each risk of bias item for the six included studies

3.3.4 Synthesis of Results

A meta-analysis of primary and secondary outcomes was planned if sufficient information was available. However, there were differences across the studies in terms of diversity of populations studied, interventions examined, the range of outcomes measures used and follow-up periods. This precluded a statistical synthesis of the included studies results. Therefore, a narrative summary of the data was carried out.

This focused on the nature of the intervention (web-based, group, individual) including content, duration, follow-up, facilitators and the findings from these interventions (Tables 3-1 and 3-2).

3.3.5 Content

Table 3-2 contains detailed information regarding the content of the six interventions. Three out of six studies focused on increasing physical activity (Foster, Grimmer, May, Ewing, Myall, Hulme et al., 2016; Lee, Yun, Park, Lee, Jung & Noh., 2014; May, Korstjens, van Weert, van den Borne, Hoekstra-Weebers, van der Schans, et al., 2009). Two studies (Lee et al., 2014; May et al., 2009) described their exercise interventions which included aerobic and resistance exercise.

Two studies (Foster et al., 2016; Lee et al., 2014) addressed diet. Lee et al., (2014) used an online personalised diet programme which involved participants planning their daily caloric requirements in accordance with BMI values, body weight and daily level of activity. Foster et al., (2016) did not provide any detailed information regarding the diet content.

Three studies focused on psychosocial adjustment of transition to survivorship (Beatty Oxlad, Koczwara & Wade, 2010; Mishel, Germino, Gil, Belyea, Laney, Stewart et al., 2005; van den Berg, Gielissen, Custers, van der Graaf, Ottevanger & Prins, 2015). Two studies used workbooks (Beatty et al, 2010; Mishel et al., 2005) and one used web-based intervention (van den Berg et al., 2015). Mishel et al., (2005) focused on managing recurrence anxiety in long-term breast cancer survivors while Beatty et al., (2010) and van den Berg et al., (2015) focused on the transition to survivorship for individuals who finished treatment within a year. Both Mishel et al., (2005) and Beatty et al., (2010) provided participants with relaxation tapes and education on long-term physical and psychosocial issues (See Table 3-1).

Foster et al., (2016) provided self-management skills to long-term cancer survivors to help manage cancer-related fatigue and was the only study that allowed participants to choose the topics to cover over the six-week intervention.

All six interventions incorporated goal-setting i.e. encouraging participants to incorporate the information obtained into achieving personal goals and behavioural changes through the use of assignments or 'homework' (See Table 3-1).

Table 3.2 Included studies reporting outcomes of self-management intervention post-intervention and follow-up

Study Name	Type of Study, Length	Outcome Measures	Immediate Post-Intervention Results	Longitudinal Follow-Up	Follow-Up Results
Beatty et al., (2010)	2 arm RCT: workbook intervention vs usual care; 12 weeks	Coping Operations Preference Enquiry (COPE), EORTC-QLQ-C30	No significant time by group interactions. Significant improvements within group in venting emotions ($p=.034$) and cognitive functioning ($p=.042$)	6 months	No significant time-by-group interactions. Significant improvements within group in venting emotions and cognitive functioning not maintained.
Foster et al., (2016)	2 arm RCT: Web-based intervention vs leaflet; 6 weeks	Perceived self-efficacy for fatigue self-management, Cancer survivors' self-efficacy scale, Functional Assessment of Cancer Therapy (FACT-G), Personal Wellbeing Index, Patient Health Questionnaire, Brief Fatigue Inventory (BFI)	No significant differences between groups noted. Near-significant improvement between groups in fatigue self-efficacy ($p=0.09$).	12 weeks	No significant differences between groups noted. Between groups difference in fatigue self-efficacy decreased becoming negligible.
Lee et al., (2014)	2 arm RCT: Web-based intervention vs 50pg educational	Exercise and intake of Fruit and Veg, Dietary Quality Index, EORTC-QLQ-C30, HADS, Brief Fatigue Inventory (BFI) Stage of Change	Significant increases for the intervention group compared to control in moderate aerobic exercise ($p<.0001$), eating five servings of fruit and vegetables per day ($p=.0001$),	No longitudinal assessment carried out	N/A

Table 3.2 Continued

	booklet; 12 weeks	Perceived Self-Efficacy	<p>dietary quality ($p=0.001$), self-efficacy for exercise management ($p=.024$) and in self-efficacy to increase fruit and vegetable intake ($p=.023$).</p> <p>Significant improvements reported for the intervention group compared to control in fatigue severity ($p=.032$), physical functioning ($p=.023$) and appetite loss ($p=.034$).</p>		
May et al., (2009)	2 arm RCT: Physical therapy vs physical therapy and cognitive behavioural therapy (CBT); 12 weeks	EORTC-QLQ-C30, Physical Activity Scale for the Elderly (PASE)	No statistically significant difference between the two groups. Statistically significant improvements in quality of life (QOL) ($p<.001$) and physical activity ($p<.05$) was found within both groups	3, 9 months	<p>No statistically significant differences between groups</p> <p>Statistically significant improvements in QOL ($p<.001$) physical activity ($p<.05$) within both groups sustained at 3 and 9 months</p>
Mishel et al., (2005)	2 arm RCT: Workbook intervention vs	Cancer Survivor Knowledge Scale, 5-item Patient/Provider Communication Scale	No immediate post-intervention assessment carried out	10 months	Significant increases for the intervention group compared to control in cognitive

Table 3.2 Continued

	usual care; 4 weeks	Social Support Questionnaire, Cognitive Reframing Subscale of the Self-Control Schedule, Cognitive Coping Strategies Questionnaire Total Information Received and Helpfulness of the Information 25-item measure, Profile of Mood States- Short Form			reframing (p=.01), cancer knowledge (p=.001), social support satisfaction (p=.029), information received (p=.001) and helpfulness of information (p=.001)
van den Berg et al., (2015) [24]	2 arm RCT: Web-based intervention vs usual care; 16 weeks	Symptoms Checklist-90 (SCL-90), Cancer Empowerment Questionnaire, HADS, EORTC-QLQ-C30, Breast Cancer Module (QOL), Distress Thermometer, Illness Cognitions Questionnaire, Remoralization Scale, Master scale, Positive Adjustment Questionnaire (PAQ), Impact of Event Scale, Self Efficacy Scale,	Significant differences between groups observed. Intervention group reported significantly less distress (p<.05) than the control group. Intervention group reported significant improvements in eight of the secondary measures compared to control; general distress (p<.05), fatigue (p<.05), fear of recurrence (p<.001, p<.05), cancer specific distress	6, 10 months	- Only one significant time by group interaction at 6 months reported in the intervention group in fear of cancer recurrence (p=.005). - No significant differences between groups reported in any study measures at 10 months.

Table 3.2 Continued

		<p>Cancer Worry Scale (CWS), Cancer Acceptance Scale (CAS), Checklist Individual Strength - Fatigue, Openness to Discuss Hereditary Cancer in the Family Scale Big Five Inventory, Trimbos/iMTA questionnaire</p>	<p>($p < .01$), general self-efficacy ($p < .05$), general remoralization ($p < .01$) and cancer specific new ways of living ($p < .05$).</p>		
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3.3.6 Impact of Interventions

Out of the six studies, three (Lee et al., 2014; Mishel et al., 2005; van den Berg et al., 2015) demonstrated statistically significant differences between the control and intervention groups at their first follow-up assessment (Table 3-2). Outcome measures varied between the three interventions as did their results with significant improvements noted in several areas including cognitive reframing, cancer knowledge, social support satisfaction (Mishel et al., 2005) dietary quality, fatigue severity, appetite loss (Lee et al., 2014) distress, fear of cancer recurrence and self-efficacy (van den Berg et al., 2015) (Table 3.2). Two of these three interventions contained some form of involvement from health professionals (Lee et al., 2014; Mishel et al., 2005). The workbook-based intervention by Mishel et al., (2005) involved four weekly phone calls by nurses to guide participants through the intervention. The involvement of health professionals by Lee et al., (2014) was minimal in that a nutritionist contacted participants to ensure food records were being maintained properly, but it is unclear how often this was done. The two web-based interventions lasted 12 weeks (Lee et al., 2014) and 16 weeks (van den Berg et al., 2015) respectively in comparison to the four weeks duration of the workbook-based intervention by Mishel et al., (2005).

Of the three studies with significant differences between the control and intervention groups, only one study reported significant differences at longitudinal follow-up. Van den Berg et al., (2015) conducted longitudinal follow-up at six and ten-months post-intervention. Fear of cancer recurrence was the only significant improvement sustained in the intervention group at the six-month follow-up. This significant improvement was not sustained at the ten-month follow-up and no other significant differences between groups were found. Mishel et al., (2005) assessed the sustainability of their intervention with a ten-month longitudinal follow-up. This was to allow participants time to identify and experience triggers of cancer recurrence and use the strategies provided. Several significant differences were noted in the intervention group compared to the control group in areas such as cognitive reframing, cancer knowledge and social support satisfaction (Table 3-2). Lee et al., (2014) did not conduct longitudinal follow-up limiting the ability to assess the sustainability of their intervention.

Two studies with no statistically significant between-group differences, reported significant within-group differences post-intervention. In their small study, Beatty et al., (2010) reported significant improvements from baseline for both the control and intervention groups in venting emotions and cognitive functioning post-intervention. May

et al., (2009) reported significant improvements in physical activity and quality of life within the physical therapy group and the physical therapy and cognitive behavioural therapy group post-intervention. Both studies lasted 12 weeks. Beatty et al., (2010) included only breast cancer survivors while May et al., (2009) included mixed cancer diagnoses.

Both studies conducted longitudinal follow-up assessments. Beatty et al., (2010) conducted follow-up at six months post-intervention. The improvements within both groups in venting emotions and cognitive functioning were no longer significant and no other significant results reported. In comparison, May et al., (2009) reported sustained significant post-intervention improvements in physical activity and quality of life at three and nine-month follow-up within both groups.

The only study to report non-significant differences within or between groups was Foster et al., (2016). This study reported non-significant improvements following the six-week intervention and at the twelve-week follow-up.

3.4 Discussion

The findings highlight the diversity of self-management interventions for cancer survivors, both in format and content, currently available in the published literature. Therefore, it was difficult to provide a conclusive summary of what constitutes a self-management intervention. In addition, the findings of the review highlight the lack of sustainability of self-management interventions.

The content of the six included interventions varied considerably. This may reflect the uncertainty in relation to what constitutes the content of a self-management intervention as identified by Barlow et al., 2002. For example, the impact of exercise on improving fatigue and anxiety in cancer survivors is well-documented (Blacklock, Rhodes, Blanchard & Gaul, 2010; Buffart, Ros, Chinapaw, Brug, Knol, Korstjens & Van Weert et al., 2014). However, only three of the six studies (Foster et al., 2016; Lee et al., 2014; May et al., 2009) focused on increasing physical activity. Both Lee et al., (2014) and May et al., (2009) reported significant improvements in physical activity in their respective studies indicating, that this may be one aspect of a self-management programme that participants follow through on.

In relation to content of self-management interventions, diet is considered an important component to help reduce recurrence (Anderson, Steele & Coyle, 2013). However, only two of the six studies (Foster et al., 2016; Lee et al., 2014) included diet in their intervention. In their study, Lee et al., (2014) reported a significant improvement in dietary quality in the intervention group post-intervention. Evidence suggests that interventions targeting specific outcomes generally result in significant benefits (Howell, Harth, Brown, Bennett, & Boyko, 2017). All six studies targeted specific outcomes including exercise, diet, anxiety, depression, coping and quality of life and significant results were reported post-intervention in five of these six studies. One study reported non-significant effects in their targeted outcomes, Foster et al., (2016). However, in this study participants in the intervention group were given the choice of whether to cover diet and exercise topics which may have affected their outcomes.

Of the three interventions that produced significant between-group differences at their first follow-up assessment, two addressed psychosocial issues (Mishel et al., 2005; van den Berg et al., 2015) including anxiety and depression. This is reflective of the findings of Howell et al., (2017) who in their systematic review reported that self-management education may be beneficial for relieving symptoms of anxiety and depression. A significant amount of literature on the emotional impact of cancer, is focused on the diagnosis and treatment stage, while less is known about the survivorship stage (Philip et al., 2013). Additionally, in the survivorship stage, physical issues are more widely discussed than psychosocial issues (Foster, Wright, Hill, Hopkinson & Roffe, 2009). The findings from our study indicate that there is a clear need to address the emotional impact of cancer post-treatment and self-management may play a key role, thus improving quality of life.

Goal-setting was one element of self-management interventions evident across all six studies. Participants were provided with 'homework' or assignments to facilitate goal-setting. This allowed participants to incorporate the information received into their daily routine thus promoting behavioural changes and encouraged adherence to the interventions (Forrest, 2011). This appears to be a consistent inclusion in self-management interventions.

Two studies that produced significant post-intervention results were both web-based interventions of long duration (Lee et al., 2014; van den Berg et al., 2015). This reflects the change of focus in recent years to utilising technology to provide health interventions. The remaining web-based intervention by Foster et al., (2016) which lasted six weeks,

was affected by a high attrition rate and did not report any significant differences for any outcomes. This suggests that longer duration web-based interventions, may result in participants embedding self-management knowledge and skills into their daily activities. It is important to note that Lee et al., (2014) and van den Berg et al., (2015) conducted many statistical tests which may have increased the chance of a type one error i.e. identifying a false positive. This may have led to misleading conclusions whereby some of the significant effects of the intervention on outcomes were not true effects but chance findings (Kim, 2017). Multiple testing increases the chances of detecting effects of interventions just by chance (Ranganathan, Pramesh & Buyse, 2016).

Although only four weeks in duration, a workbook-based intervention delivered by nurses (Mishel et al., 2005), reported statistically significant improvements in the intervention group compared to the control group. In comparison, the other workbook-based intervention by Beatty et al., (2010) was 12 weeks in duration, with no health professional involvement. Beatty et al., (2010) did not report any significant differences between groups immediately post-intervention or at longer term follow-up. However, the findings in Beatty et al., (2010) were limited by a small sample size (n=40).

On reviewing the impact of health professional involvement in self-management interventions, no clear conclusions can be made based on the studies from this review. Of the six studies, three interventions had some involvement by health professionals (Lee et al., 2014; May et al., 2009; Mishel et al., 2005) which varied from full facilitation of the intervention (May et al., 2009) to minimum telephone contact with participants (Lee et al., 2014; Mishel et al., 2005). Two of these studies reported significant differences between the intervention and control groups (Lee et al., 2014; Mishel et al., 2005), however both studies used different delivery methods. Of the three remaining studies with no health professional involvement (Beatty et al., 2010; Foster et al., 2016; van den Berg et al., 2015), one of these studies using a web-based intervention (van den Berg et al., 2015) reported significant differences between the intervention and control groups. Based on these six studies, it is therefore not possible to conclude whether the involvement of health professionals contributes to any improvement in adherence to self-management strategies. To establish this, studies are required which compare the outcomes of a self-management intervention with two groups, one of which is facilitated by a health professional.

The lack of consensus on the format and content of self-management interventions made it difficult to review and provide definitive recommendations on preferred self-

management interventions for cancer survivors. This has been reported in previous systematic reviews. Coffey, Mooney, Dunne, Sharp, Timmons and Desmond et al., (2016) conducted a meta-synthesis of qualitative studies exploring cancer survivors' experiences of self-management interventions. The authors reported difficulties in selecting studies for inclusion due to the lack of a 'gold-standard' definition. Similarly, Howell et al., (2017) were unable to conduct a meta-analysis to identify the essential components of self-management education due to the variety of interventions and outcome measures used in their included studies.

Conducting longitudinal follow-up is important to determine if interventions can sustain their effectiveness (Stirman, Kimberly, Cook, Calloway, Castro, & Charns 2012). Mishel et al., (2005) and van den Berg et al., (2015) conducted longitudinal follow-ups to assess sustainability of their interventions. Mishel et al., (2005) conducted their first follow-up assessment ten months post-intervention, but not at earlier time points when the impact of the intervention may have been more evident. Van den Berg et al., (2015) conducted follow-up assessments at six months with one significant improvement in fear of cancer recurrence, sustained in the intervention group. However, this was not sustained at the ten-month follow-up and no other significant improvements were noted. It appears that the authors were unable to demonstrate sustainability of the self-management interventions over a long period of time. Self-management is considered a lifelong task, therefore, it may be unrealistic to expect a self-management programme for cancer survivors to sustain these benefits on a long-term basis (Lorig & Holman, 2003). Additionally, the mean age of participants ranged from 42 years to 64 years (Lee et al., 2014; Mishel et al., 2005) which could be a time when other chronic diseases are developing either due to cancer treatments or for other reasons (Anderson et al., 2013). Therefore, life demands are changing which can result in participants needing different self-management strategies to manage these changes. Reiteration of these interventions may be required to provide participants with the skills to self-manage their chronic diseases in addition to post-cancer issues.

3.5 Limitations

Due to the heterogeneity in the study populations and types of interventions included in the six studies, it was not possible to conduct a meta-analysis which may have provided a statistical measure of the impact of self-management interventions with cancer survivors.

Further limitations of this review are the inclusion of RCTs in English only as part of the search strategy which reduces the opportunity to evaluate studies not reported in English. A small number of studies were included in the final review so these findings should be interpreted with caution. The lack of a 'gold standard' definition of self-management and the differing viewpoints on what constitutes a self-management intervention made the initial study screening process difficult (Barlow et al., 2002). This was overcome, in part, by keeping self-management terms broad in the literature search.

3.6 Conclusion

Due to the diversity in the focus of the interventions, their delivery methods, the period of interventions and the presence or absence of facilitators of the interventions, limited recommendations can be made from this systematic review, regarding self-management interventions for cancer survivors. Lack of sustainability of the effectiveness of the six included self-management interventions is an issue raising questions on the long-term impact and cost-effectiveness of self-management interventions. A standardised definition of self-management is also needed which may help to identify the core content components of self-management interventions that are effective in improving health outcomes such as activity participation, self-efficacy, quality of life and symptom management in cancer survivors. Finally, further research is needed to determine if self-management interventions facilitated by health professionals result in more significant and sustainable outcomes than intervention with no health professional involvement.

One of the key findings from this systematic review was the lack of sustainability of self-management interventions for cancer survivors. Therefore, the aim of this research study was to determine the effectiveness and sustainability of the OptiMal programme for cancer survivors. The following chapter will describe the methodology undertaken to conduct the mixed-methods study to achieve this aim.

4. Mixed-Methods Study - Methodology

This chapter will discuss the methods used in a mixed-methods study to evaluate the effectiveness and sustainability of OptiMal, a self-management support intervention for cancer survivors. This chapter will discuss the quantitative aspect of the mixed-methods study including the pragmatic randomised controlled trial (RCT) and will discuss the qualitative aspect which was to explore the acceptability of the OptiMal programme, through focus groups and semi-structured interviews. The following chapter, Chapter Five, will discuss the quantitative and qualitative results from this mixed-methods study.

4.1 Background to the OptiMal programme

OptiMal is a six-week, occupation-based, self-management intervention designed for people with chronic conditions (O'Toole et al., 2013). It is originally based on the Stanford Chronic Disease Self-Management Programme (CDSMP) (Lorig, Sobel, Stewart, Brown, Bandura Ritter et. al., 1999). A pilot study evaluating the programme with individuals with multimorbidity found that significant changes were observed in activity participation, occupational performance and self-efficacy at post-intervention and at the eight week follow-up despite a small sample size (O'Toole et al., 2013). In 2015, a randomised controlled trial (RCT) reported that the programme resulted in significant improvements in frequency of activity participation, self-efficacy and quality of life compared to the control group two weeks post intervention (Garvey et al., 2015).

4.2 OptiMal: Self-management Programme for Cancer Survivors

Two changes were made to the programme content of OptiMal based on recommendations relating to the needs of cancer survivors in the literature (Cimprich, Visovatti & Ronis, 2005; Anderson et al., 2013; Boykoff, 2009; Player et al., 2014). The aim of this was to create a version of the OptiMal programme that was relevant to cancer survivors compared to the original OptiMal programme which was designed for individuals with multimorbidities (O'Toole et al., 2013; Garvey et al., 2015). Content regarding cognition and nutrition were added to the programme content. As per section 2.3.6, cognitive difficulties post-treatment are a key concern for cancer survivors. As cancer survivors are at an increased risk of secondary cancer or other chronic diseases, diet is considered an important factor to reduce recurrence (Anderson et al., 2013).

Each session comprised of an education and goal-setting component. These included fatigue management, mental well-being, cognitive retraining, physical activity, nutrition and communication with health professionals. A physiotherapist and dietician delivered the educational component related to physical activity and nutrition. Individual goal setting was facilitated by the researcher and an occupational therapist based in the oncology department of the acute hospital, to encourage participation and re-engagement in activities (O'Toole et al., 2013). This promotes the behavioural changes required to sustain self-management knowledge and skills (Lorig, et al., 1999). The individual sessions for the OptiMal programme are described in more detail in section 4.10.1.

4.3 Medical Research Council (MRC) Framework

This mixed-methods study was guided by the MRC framework. In 2000, the MRC established a framework for the development, evaluation and implementation of complex interventions to improve health (MRC, 2008). These guidelines were updated in 2008 and have been widely cited since (Campbell, Murray, Darbyshire, Emery & Farmer et al., 2007; MRC, 2008). Complex interventions are described as interventions that contain several interacting components (Craig, Dieppe, Macintyre, Michie & Nazareth, et al., 2008; MRC, 2008). In addition, complex interventions can have a number and variability of outcome measures, a degree of flexibility of the intervention and a number of behaviours required by those delivering and receiving the intervention (Craig et al., 2008). Complex interventions are widely used in the health service, public health and social policy (Campbell et al., 2007). The framework is divided into five stages. It was used to guide this research which is currently in Phase Three of the framework.

Phase 1: Identify Evidence Base and Theory

This phase involves identifying the existing evidence base and exploring the relevant theory. A systematic review was conducted as part of this research to explore self-management interventions previously carried out with cancer survivors (Boland, Bennett & Connolly, 2018). Research suggests that self-management programmes for chronic conditions should be evaluated with cancer survivors as similar health issues exist (Elliot et al., 2011).

Phase 2: Modelling

Pilots of the original OptiMal programme were conducted in 2013 and 2015. The primary outcome measure of those studies was chosen as the primary outcome measure of this mixed-methods study. Some of the secondary outcome measures were also chosen

from this study to meet the overall aim. Two changes were made to the original OptiMal programme but the group-based structure and inclusion of the goal-setting component remained the same as the original studies. A decision was made not to conduct a pilot of the adapted programme as two previous pilot studies were conducted in 2013 and 2015 and reported significant results (O'Toole et al., 2013; Garvey et al., 2015). However, not having conducted a pilot study of the adapted OptiMal was a limitation to this study and is discussed in further detail in section 5.8.

Phase 3: Feasibility/Exploratory Trial

This phase involves gathering evidence for the main trial including testing procedures, calculating appropriate sample sizes and estimating recruitment and retention rates (MRC, 2008). It is recommended that exploratory trials incorporate quantitative and qualitative methods to estimate response rates and barriers to participation (MRC, 2008). This study was in Phase Three of the framework. The starting point for this study is the paucity of evidence regarding effective self-management interventions for cancer survivors. The aim of this exploratory study was to evaluate the effectiveness of OptiMal as a self-management support intervention for cancer survivors, compared to a control group of cancer survivors.

Phase 4: Definitive RCT

This involves a full scale evaluation of a complex intervention. It is recommended that researchers should have an awareness of the range of experimental approaches when making a methodological choice for this phase (MRC, 2008). A definitive RCT is conducted when the results of the feasibility/exploratory trial determine the intervention is feasible and warrants a more robust evaluation (Campbell et al., 2007). Therefore, findings from the exploratory study will determine if a large-scaled multi-centre trial is warranted before progressing to the implementation phase.

Phase 5: Implementation

This phase involves translating the evidence into practice by applying the intervention to real-life practice. This involves monitoring and conducting long-term follow-up to provide information on the practicalities of introducing new interventions into everyday practice and its sustainability (MRC, 2008).

4.4 Research Design

4.4.1 Research Aim and Objectives

The aim of this study was to evaluate the effectiveness of OptiMal as a self-management intervention for cancer survivors. The objectives of this study were to conduct a mixed-methods study to evaluate the effectiveness and sustainability of the OptiMal programme in a sample of adult cancer survivors and compare with a control group of adult cancer survivors. The primary outcome measure was the frequency of activity participation. Secondary outcome measures included health-related quality of life, self-efficacy, anxiety and depression, cognition, fatigue and perception of occupational performance.

The following hypotheses were tested;

1. No significant differences between the intervention and control group would be observed in frequency of activity participation outcomes at three month follow-up
2. No significant differences between the intervention and control group would be observed in health-related quality of life outcomes at three month follow-up
3. No significant differences between the intervention and control group would be observed in self-efficacy outcomes at three month follow-up
4. No significant differences between the intervention and control group would be observed in anxiety and depression levels at three month follow-up
5. No significant differences between the intervention and control group would be observed in cognitive outcomes at three month follow-up
6. No significant differences between the intervention and control group would be observed in fatigue outcomes at three month follow-up
7. No significant differences between the intervention and control group would be observed in self-perceptions of occupational performance outcomes at three month follow-up

4.4.2 Study Design

A mixed-methods design was chosen to address the aim and objectives of this study. Usually, study designs are either quantitative or qualitative (Adamson, 2005). A quantitative approach focuses on objective data and a qualitative approach considers the subjective experience (Pierce, 2013). However, a mixed-methods design combines and implements both quantitative and qualitative aspects, within a paradigm of pragmatism where both methods inform the exploration of the research question

(Creswell & Plano-Clarke, 2007). With regards to health care research, a mixed-methods approach is considered more extensive and holistic (Pierce, 2013). Previous studies concerning self-management in cancer survivors have used a mixed-methods approach (Shneerson & Gale, 2015).

A pragmatic approach is considered suitable for practice research as real world views are being explored (Bowling, 2009). Pragmatic RCTs measures the effectiveness of interventions that are directly related to health service delivery and reflect everyday practice (Bowling, 2009). Therefore, it is considered suitable for health science research and is becoming more popular (Adamson, 2005; Feilzer, 2010; Pierce, 2013). A pragmatic approach focuses on the research question and is not distracted by methods of data collection. The researcher understands through using a pragmatic approach that data is collected in a practical way and there are different aspects to the research question being explored, which accommodates for the emergence of unexpected data (Feilzer, 2010). A convergent parallel design or concurrent triangulation was selected for the collection and analysis of data (Adamson, 2005). This involves quantitative and qualitative data being collected at the same time with analysis of both kept separate. The two are integrated during the interpretation phase of a study and conclusions are drawn (Adamson, 2005; Creswell & Plano-Clark, 2007). This RCT was designed using a pragmatic approach to measure the effectiveness of a self-management programme for cancer survivors versus usual care, using an intention to treat (ITT) analysis. Usual care consisted of cancer survivors continuing to attend scheduled medical appointments.

4.4.3 Randomised Controlled Trials (RCT)

An RCT is considered the gold standard in providing strong evidence on the efficacy of healthcare interventions (Moher, Hopewell, Schulaz, Montori & Gotzsche, et al., 2010). It is recommended when evaluating the effectiveness of a complex intervention as it prevents selection bias from known and unknown factors affecting the outcome (MRC, 2008). Randomisation ensures equal chance of participants assigned to the control or intervention group. Differences between both groups can be more confidently attributed to the effectiveness of the intervention rather than to other factors (MRC, 2008).

CONSORT Guidelines

This study is guided by the CONSORT guidelines which outlines how RCTs should be reported (Moher et al., 2009). They are highly recommended by the MRC and other institutions (MRC 2008; Moher et al., 2009). Since its publication in 1996 with subsequent

updates in 2001 and 2010, the guidelines have been credited with the improvement in reporting of RCTs (Plint, Moher, Morrison, Schulz & Altman, et al., 2006).

The CONSORT guidelines were used at all stages in this RCT from patient selection, randomisation, data collection, analysis and reporting (www.consort-statement.org). A flow diagram is used to depict the flow of participants from enrolment to the final analysis allowing critical analysis of the internal and external validity of the research study (Egger, Juni & Bartlett, 2001). Randomised controlled trials following the CONSORT guidelines are encouraged in occupational therapy research as it contributes to the evidence base of the profession (Nelson & Mathiowetz, 2004).

Process Evaluation

This study also integrates a process evaluation which is recommended in the MRC framework (MRC, 2008). Process evaluations can be used to assess the effectiveness of an intervention by providing insight into how the intervention was implemented, its quality and fidelity (Craig et al., 2008; Moore, Audrey, Barker, Bond & Bonell et al., 2015). It can provide explanations for expected and unexpected outcomes, why an intervention fails or is successful and the role of context in influencing these outcomes (MRC, 2008). This provides important information on an intervention's generalisability or external validity and how it can be replicated (Bonell, Oakley, Hargreaves, Strange, & Rees et al., 2006; Moore et al., 2015). This was integrated into this study by the facilitation of focus group and semi-structured individual interviews to assess participants' perception of the quality of the OptiMal programme. These took place post-intervention and at the three months follow-up with individuals who attended the OptiMal programme.

4.4.4 Sampling

The target population were cancer survivors attending outpatient clinics in an acute hospital or attending a cancer support service located near the acute hospital, in the Dublin area. In order to define the parameters of the population suitable for the study, inclusion and exclusion criteria were applied.

4.4.4.1 Inclusion and Exclusion Criteria

Inclusion Criteria:

- Between 18 and 80 years of age
- Completed cancer treatment including surgery, chemotherapy and radiation therapy within the last three months and up to two years. Patients receiving hormonal therapy for up to five years were considered eligible for inclusion

Exclusion criteria:

- Unable to complete self-reporting questionnaire and/or participate and complete a six-week programme due to a medical condition that affects communication or cognitive difficulties as identified by the medical consultant e.g. Alzheimer's Disease
- Unable to travel independently to the site of study (the acute hospital)
- Undergoing treatment for high grade tumour, significant lymph node involvement, presence of metastasis, high chance of cancer recurrence, terminal/palliative status as identified by the medical consultant/Clinical Nurse Specialist (CNS),
- Significant co-morbidities as identified by the medical consultant/CNS e.g. mental health issues, addiction problems etc. which would prevent their participation.

4.4.5 Sample Size calculation

In this study sample size calculations were based on the primary outcome measure, the Frenchay Activities Index (FAI), which measures activity participation. The outcome measures are discussed in more detail in section 4.6 and 4.7. A biostatistician conducted the sample size calculation. Approximately n=154 participants were required to ensure sufficient power (80%) and detect a statistically significant difference at 5%.

4.4.6 Recruitment

For recruitment to be successful, it requires developing a plan with multiple strategies, maintaining flexibility and establishing interim goals (Friedman, Furberg & DeMets, 1996). The researcher recruited participants from a number of oncology outpatient clinics including breast, lung, lymphoma, melanoma and gynaecological cancer patients.

Before each of these clinics, a thorough chart review was conducted by the researcher to identify eligible patients. If a patient was considered eligible for inclusion in the study, a participation information leaflet (PIL) (Appendix E) was placed in the chart by the researcher. Eligible patients were informed of the study by their doctor who provided them with the PIL. The researcher also attended the outpatient clinics as a reminder to the doctors of the research study thus encouraging recruitment (Friedman et al., 1996). Ethical permission was obtained from the St James' Hospital/Adelaide and Meath Hospital, incorporating the National Children's Hospital (SJH/AMNCH) Research Ethics Committee in December 2014, see section 4.12 and Appendix F for further details. Participants were also recruited through a cancer support service associated with the

acute hospital and located nearby. The researcher attended once a month and provided information on the research study to attendees including participant information leaflets (Appendix E). Ethical permission was obtained from the SJH/AMNCH Research Ethics Committee in July 2016, see section 4.12 and Appendix I.

The contact details of the supervisor and the researcher were included in the PIL so potential participants could contact them directly. If potential participants did not contact the researcher or supervisor, the researcher then conducted a follow-up phone call within one week of the participant receiving the PIL. The researcher provided an overview of the research study and asked participants if they would like to be involved in the study or prefer time to consider their participation or decline participation. If a participant expressed an interest in participating in the study, the researcher organised a meeting with them. The questionnaires, consent form and PIL were sent in advance to allow participants sufficient time to review the details of the study before giving informed consent. In the meeting, the researcher explained the study again, answered any questions and informed the participant that they could withdraw from the study any time. If participants agreed to participate, they signed the informed consent form and completed the study questionnaires. Participants were recruited in blocks of 24 initially. Due to slow recruitment during the study, participants were then recruited in blocks of 16. Half of the participants were randomised to the intervention group and the remainder randomised to the usual care/control group.

Participants in the intervention group were invited to participate in the six-week programme. Participants assigned to the control group were not invited to the six-week programme however continued to receive usual care. Usual care consisted of attending scheduled medical appointments. Following the final data collection period, participants in the control group were provided with the programme booklet, see section 4.10.1. Further details regarding data collection can be found in section 4.5.

4.4.7 Allocation Concealment and Randomisation

Allocation concealment refers to the method used to conceal the allocation sequence so that allocations to the intervention group could not have been foreseen during recruitment (Higgins & Green, 2011). This study was an individually randomised trial where participants were randomly allocated to the intervention or to the usual care group (MRC, 2008). When 24 participants completed the baseline questionnaires, they were randomised to either the control or intervention group. Randomisation was carried out using a computer generated randomisation sequence which ensures all participants

have an equal chance of being assigned to the intervention or control group (Friedman et al., 1996). The researcher generated this sequence once all 24 participants or 16 participants of a block had been recruited and initial assessments completed. Participants were informed of their allocations by the researcher 7-10 days prior to the commencement of the intervention.

4.4.8 Blinding

Randomised controlled trials should ideally have a double-blinded design where the neither the participant nor the researcher are aware of the allocations (Friedman et al., 1996). Blinding can prevent performance bias and detection bias when interpreting the outcome assessments (Higgins & Green, 2011). However, blinding in an RCT in a complex intervention may not be possible when there is ongoing interaction between the therapist/researcher and participant, which is the case in a six-week self-management intervention (Nelson & Mathiowetz, 2004). Additionally, during the process of informed consent, the participants were made aware of the intervention and control groups they may be randomly assigned to limiting further the feasibility of blinding (Nelson & Mathiowetz, 2004; Delaney, Angus, Bellomo, Cameron & Cooper et al., 2008).

4.5 Data Collection

Baseline data were collected before participants were randomised to the control or intervention group. Participants were provided with the option of data collection being completed in their homes, however, all participants preferred this to take place in the acute hospital. Following the six-week programme, the control and intervention groups completed the same self-reporting questionnaires to detect any changes in activity participation, quality of life, self-efficacy and symptom management. Participants of the intervention group, who attended OptiMal, were invited to take part in a focus group to explore its acceptability to cancer survivors. At the three months follow-up, participants in the control and intervention group completed the same study questionnaires in the acute hospital. Focus groups were also held with participants who attended the OptiMal programme to determine the sustainability of it.

A number of primary and secondary outcome measures were chosen to represent the aim and objective of the study (Appendix G). A single primary outcome and secondary outcomes were considered the most practical from a statistical analysis point of view as recommended in the MRC framework (MRC, 2008). It is important to have pre-specified outcome measure before the trial begins as this can prevent selective reporting which

can lead to bias (Higgins & Green, 2011). The outcomes measures chosen will be discussed in the next section.

4.6 Primary Outcome Measure

4.6.1 Frenchay Activities Index (FAI)

In the pilot study of the OptiMal programme in people with multimorbidity, the FAI was the primary outcome measure. Significant differences were observed in scores between baseline and follow-up, particularly in the leisure/work subscale indicating increased participation in leisure and work occupations (O'Toole et al., 2013). Significant differences were also observed between the control and intervention group in Garvey et al., (2015) RCT study, particularly in the domestic subscale. These findings support the use of the FAI as the primary outcome measure to address the main objective of this study which was the frequency of activity participation in cancer survivors. The measure is scored using a modified 0-3 scoring method which provides a total score out of 45 (Appendix G). The higher the total score, the greater the activity participation of the individual (Wade, Leigh-Smith & Langton, 1985).

4.7 Secondary Outcome Measures

A total of six secondary outcomes measures were chosen to explore other outcomes including quality of life, self-efficacy, anxiety and depression, cognition, fatigue, satisfaction and performance of occupations or activities. These measures are discussed in more detail below.

4.7.1 EQ-5D

The EQ-5D was used to measure participants' health-related quality of life, see Appendix G. It is a reliable and valid self-reporting measure used for describing and valuing health-related quality of life (EuroQoL Group, 1990). The EQ-5D is used in clinical and economic evaluations of healthcare (EuroQoL Group, 1990). The measure consists of two parts;

EQ-5D: A descriptive system consisting of five dimensions; mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels; no problems, some problems, extreme problems

EQ-VAS: On a visual analogue scale, participants are asked to rate their health from 0-100

The EQ-5D is analysed by converting the health states from the descriptive system into a single summary index. The EQ-5D can also be presented as the frequency of reported problems (EuroQoL Group, 1990). Both methods were applied in this study.

There are over 171 official language versions of the measure and extensive research supporting its reliability and validity (EuroQoL Group, 1990). The validity of using the EQ-5D with cancer patients has been recommended (Pickard, De Leon, Kohlmann, Cella & Rosenbloom, 2007). One of the objectives of this study was to measure quality of life. This measure is quick and easy to administer which also made it suitable for this study.

4.7.2 Stanford Chronic Disease Self-Efficacy Scale (6 item) (SSE)

The SSE is based on a larger scale developed for a self-management of chronic diseases study, see Appendix G (Lorig, Stewart, Ritter, Gonzalez, Laurent & Lynch, 1996). The six item scale has good internal consistency reliability (Lorig, Sobel, Ritter, Laurent & Hobbs, 2001). The SSE has been used in studies with cancer patients and survivors (Wiljer, Leonard, Urowitz, Apatu & Massey et al., 2010; Foster et al., 2016). In addition, this measure is easy to administer and gains a valuable insight into the individual's perception of their own confidence levels. Therefore, this measure was considered appropriate to reflect the study's objectives to improve participants' self-efficacy.

4.7.3 Hospital and Anxiety Depression Scale (HADS)

The HADS consists of two subscales; Depression and Anxiety with each containing seven items, see Appendix G (Zigmond & Snaith, 1983). Scores from each subscale are summed to produce an anxiety score and a depression score. Each subscale is scored from 0-7 (normal), 8-10 (borderline abnormal) and 11-21 (abnormal) (Zigmond & Snaith, 1983). The HADS has demonstrated good internal consistency, test-retest reliabilities, is sensitive to change and gives valid assessments (Herrmann, 1997). In recent years, it has been used with a variety of different populations including breast cancer, prostate cancer, stroke and myocardial infarction (Johnston, Pollard & Hennessey, 2000; Berglund, Petersson, Eriksson, Wallenius & Roshani, 2007). It is quick and easy to administer making it well accepted amongst patients (Hermann, 1997; Johnston et al., 2000).

4.7.4 Cognitive Failures Questionnaire (CFQ)

This 25-item self-reporting measure assesses minor cognitive mistakes or 'slip-ups' in daily activities in the last six months, see Appendix G (Broadbent, Cooper, FitzGerald &

Parkes, 1982). It covers three main areas including; perception, memory and motor functioning mistakes (Rast, Zimprich, Bostel, & Jolles, 2009). Each item is rated from 0-4 with the total score valued out of 100 with higher scores indicating higher levels of cognitive failures (Broadbent et al., 1982). This measure has demonstrated good psychometric properties including criterion validity, high inter-item consistency, test-retest reliability (Broadbent et al., 1982; Bridger, Johnsen & Brasher, 2013; Rast et al., 2009; Amidi, Christensen, Mehlsen, Jensen & Pedersen et al., 2015). The CFQ is a widely used measure and has been used with breast cancer patients (Schilder, Seynaeve, Linn, Boogerd & Beex et al., 2012; Amidi, et al., 2015).

4.7.5 Functional Assessment of Chronic Illness Therapy-Fatigue short version (FACIT-F)

The FACIT-F forms part of the FACIT Measurement System, see Appendix G. The FACIT-F is a fatigue-specific measure. In this study, the shortened 13-item self-reporting version was chosen. This version measures physical and mental fatigue during the last seven days using ratings 0 (not at all) to 4 (very much). The total score is out of 52 with higher scores representing fewer symptoms of fatigue and higher quality of life (Hagen, Aas, Kvaloy, Eriksen & Soiland, 2016). The shorter assessment was used to avoid further fatigue for the participant. The FACIT-F is easy to administer and has demonstrated reliability, validity and sensitivity to change making it suitable to achieve the objectives of the study (Yellen, Cella, Webster, Blendowski & Kaplan, 1997; Webster, Yellen & Host, 2003).

4.7.6 The Canadian Occupational Performance Measure (COPM)

The COPM measured participants' perceptions of occupational performance and their satisfaction with this in their daily activities, see Appendix G. It is a client-centred measure based on the Canadian Model of Occupational Performance (Law, Baptiste, Carswell, McColl, Polatajko et al., 1998). The COPM is an outcome measure designed for occupational therapists to detect clients change in their self-perception of occupational performance at the beginning and end of occupational therapy intervention (Law et al., 1998).

The COPM is a semi-structured interview where individuals report difficulties in performance in the areas of self-care, productivity and leisure (Law et al., 1998; Jada & Estes, 2010). In this study, participants were encouraged to rate the importance of these activities from 1 (not important) to 10 (extremely important) thus prioritising the five most important problems. Participants then rated their performance of these activities and their

satisfaction with this performance ranging from 1 (unable to do it/not at all satisfied) to 10 (able to perform it extremely well//extremely satisfied). Performance and satisfaction scores are scored separately by adding up the scores of each and dividing by the problem areas. A difference of two or more between scores at baseline and re-assessment is considered statistically significant (Law et al., 1998).

The COPM is a widely used outcome measure in occupational therapy practice and research (Carswell, McColl, Baptiste, Law & Polatajko, et al., 2004). The COPM's psychometric properties have been extensively researched with the measure demonstrating good test-retest reliability (Cup, Scholte op Reimer, Thijssen & van Kuyk-Minis, 2003). It has demonstrated criterion and content validity (Carpenter, Baker & Tyldesley, 2001). The COPM has also demonstrated sensitivity to change (Chen, Rodger & Polatajko, 2002). The versatility of the COPM allows it to be used in a variety of contexts including stroke, neurology, pain management and oncology (Carpenter et al., 2001; Chen et al., 2002; Cup et al., 2003; Lindahl-Jacobsen, Hansen, Waehrens, la Cour & Sondergaard, 2015).

4.8 Qualitative Data

Qualitative methods were used to explore the personal experience and sustainability of the OptiMal programme. Focus groups and semi-structured individual interviews took place immediately post-intervention and at the three months follow-up.

4.8.1 Data Collection

Qualitative data were collected through focus groups and semi-structured interviews with participants who attended OptiMal. These took place immediately post-intervention and at three months follow-up. Focus groups were conducted by an independent researcher while semi-structured interviews were conducted by the researcher. Focus groups are considered an appropriate method of data collection when exploring stakeholders' experiences of a phenomenon (Halcomb, Gholizadeh, DiGiacomo, Phillips & Davidson, 2007). They provide a forum for individuals to express themselves candidly and reduce the influence of the interviewer (Jayasekara, 2012). The facilitation of focus groups in this study allowed participants to express their honest perceptions of the OptiMal programme and its acceptability to cancer survivors. It also provided an opportunity for further discussion of topics as they arose in the groups. Semi-structured interviews were held with individuals who were unable to attend the focus groups. Semi-structured

interviews are a versatile method of data collection as it allows for an in-depth exploration of a topic (Fylan, 2005).

Focus groups took place immediately post-intervention i.e. in the last session of the OptiMal programme and three months later. All focus groups and interviews were conducted using a guide focusing on the impact of the programme on symptom management and quality of life see Appendix H for details.

4.8.2 Post-Intervention

In the last session of the programme, participants in the intervention group were invited to take part in a focus group to discuss the design of the OptiMal programme and the impact of symptoms on activity participation before and after the intervention. Participants could decline to take part in the focus group. Due to the logistics and resources available to this study, conducting a focus group immediately after the intervention, ensured that the perceptions of all group members could be obtained as they were already in attendance, which is common practice (Creswell & Plano-Clarke, 2007). The focus groups were conducted by an independent researcher with a vast experience of facilitating focus groups. At this stage of the programme, participants were familiar with one another and this created a relaxed, accepting atmosphere in which to conduct a focus group and ensured honest perceptions were obtained (Jayasekara, 2012). No participant declined to take part in the focus group. When a participant was unable to attend the focus group, the researcher organised a time with them to conduct a one to one semi-structured interview. Questions asked were the same questions asked in the focus group regarding their perception of the programme (See Appendix H). The focus group or interview was recorded with the participant's consent and later transcribed by the researcher for analysis.

4.8.3 Three Month Follow-Up

At the three month follow-up, participants in the intervention groups were invited to take part in another focus group. The aim of this was to explore the sustainability of the OptiMal programme i.e. to ascertain if participants were continuing to utilise the strategies provided to them in the programme. Questions followed a similar format to those used in the post-intervention focus group and were facilitated by the same independent researcher. Participants could decline to take part in the focus group however, no participant did. When a participant was unable to attend the focus group, an individual interview was organised. The focus group or interview was recorded with the participant's consent and later transcribed by the researcher for analysis.

4.9 Trustworthiness of the study

4.9.1 Reliability

Reliability refers to whether the study's techniques and sampling strategy can be repeated and produce similar results (Newell & Burnard, 2011). Developing a study protocol is crucial to creating a well-designed and replicable trial (Friedman, et al., 1996). Prior to commencement of the study, the researcher developed a clear and thorough study protocol.

4.9.2 Internal Validity

Internal validity for this study was possible through the independent variable of the self-management programme, the use of the control group and randomisation.

In addition, data collection took place at baseline, post-intervention and at the three-month follow-up. These time points were considered to be long enough that participants would not remember their previous responses. Data collection was completed by the researcher and all measures were administered in the same manner, see section 4.5 for further details.

4.9.3 External Validity

This study was a pragmatic RCT held in an acute hospital with the presence of the multidisciplinary team including the medical team, occupational therapy, physiotherapy and dieticians whom feature in the recruitment and delivery of the intervention. The programme was also delivered to each group in a standardised way.

The needs of the participants should reflect the populations' needs (Bonell, et al., 2006). To ensure this, broad exclusion and inclusion criteria were adopted. The research was available to all cancer survivors regardless of type of cancer thus increasing the generalisability of the findings.

4.10 Intervention

4.10.1 OptiMal Programme Content

The groups were facilitated by the researcher and an occupational therapist based in the Oncology Department of the acute hospital. This ensured that participants received greater individual input particularly when setting goals. Each session took place once a week for six weeks and lasted approximately two and a half hours. The first hour

consisted of the educational component. In the second hour participants were facilitated by the researcher and occupational therapist to set goals to apply the educational components of the programme into their daily and weekly routines over the following week. Interactive learning strategies were facilitated in each session through discussion and activity to encourage participants to share their own experiences, knowledge and strategies. The content for the OptiMal programme over the six consecutive weeks included:

Week One: Introduction to Self-Management

The first week was an introduction to self-management and provided an opportunity for group members to meet. The researcher and occupational therapist facilitated this session which provided an overview and the content of the programme. The impact of symptoms on activity participation and quality of life was discussed. The relationship between participating in activities of importance and health and wellbeing was also discussed.

Week Two: Fatigue Management and Sleep Hygiene

Group members were introduced to the impact of fatigue on quality of life and wellbeing by the researcher and occupational therapist. The educational component of this session focused on providing participants with energy management principles. Participants were encouraged to identify activities that resulted in high levels of fatigue and through activity analysis, how to incorporate fatigue management principles into these activities. The aim of the second half of the session was to provide effective strategies to encourage good sleep hygiene. Participants were facilitated, by the researcher and occupational therapist, to set goals incorporating the fatigue management strategies into their daily and weekly routine over the following week.

Week Three: Exercise and Physical Activity

A physiotherapist, with academic and clinical experience in oncology facilitated the first half of this session. The aim of this session was for participants to develop an understanding of the physical and mental health benefits of exercise and the recommended amount of exercise. In the second half of the session, participants discussed how goals set the previous week progressed. Following this, participants were encouraged to set new goals incorporating exercise and physical activity into their daily and weekly routine by the researcher and occupational therapist.

Week Four: Stress Management and Cognitive Retraining

This session aimed to develop participants' understanding of the physiological and psychological impact of stress and anxiety. The researcher and occupational therapist delivered this session. Participants were also educated on coping mechanisms and strategies to manage this. The impact of cognitive difficulties on quality of life and activity participation was discussed. Participants were provided with compensatory strategies to manage cognitive difficulties. In the second half of the session, goals from the previous week were reviewed to discuss their progression. Following this, participants were encouraged to set new weekly goals incorporating stress management and cognitive retraining into their daily and weekly routine by the researcher and occupational therapist.

Week Five: Nutrition

The first half of this session was facilitated by a dietician working in oncology care in the acute hospital. Developing a healthy diet post-treatment was discussed including ways to incorporate healthy eating habits into the daily routine. In the second half, participants discussed how goals set the previous week progressed. Participants were then facilitated, by the researcher and occupational therapist, to set new goals incorporating healthy eating into their daily and weekly routine.

Week Six: Effective Communication Skills

This session focused on identifying barriers in communicating with health professionals, employers or family members. The researcher and occupational therapist provided the participants with strategies in order to encourage good communication skills. Goals set the previous week were reviewed. The second half of the session provided an overview of the programme content covered.

4.10.2 Goal-Setting

Individual goal setting was facilitated each week by the researcher and occupational therapist to ensure a client-centred approach. Goal setting encourages participants to take control of their health by identifying problems and finding solutions (Pollock, 1993). It was incorporated into each session to encourage application of weekly content and re-engagement in activities, promoting the behavioural changes required to sustain self-management knowledge and skills (Lorig et al., 1999; O'Toole et al., 2013). In the pilot study of the original OptiMal programme for participants with multimorbidity, goal setting was seen as a key factor in motivating participants to engage in self-management behaviour (O'Toole et al., 2013).

In each session, time was allocated for goal setting which included participants formulating goals and sharing this with the group. Participants were encouraged to set occupation-focused goals incorporating the educational information into their daily and weekly routine for the week. They were also encouraged to relate these goals back to their long-term goals which were set with the researcher using a goal-setting tool, the Canadian Occupational Performance Measure (COPM), in the baseline assessment.

4.10.3 Programme Booklet

A booklet containing the content of the programme plus additional information on each subject was provided to all participants. Members were encouraged to bring this booklet to every session to monitor goal attainment. Handouts on the presentation for each session were also given to the participants. For individuals who missed a session, the handout and a goal setting sheet was posted to them and they were encouraged to refer to their booklet on the particular session. The following week the researcher and occupational therapist linked in with the individual to ensure they understood the content from the week they missed.

4.10.4 Control Group

The control group consists of participants who are not exposed to the intervention (Bowling, 2009). In this study, control group participants continued to receive usual care. Usual care involved continuing to attend scheduled appointments with the medical team. The control group were contacted by the researcher to carry out the post-intervention and three month follow-up assessments. At the three month follow-up, participants were then provided with the programme booklet.

4.11 Data Analysis

4.11.1 Quantitative Data

Data was collected, prepared for analysis and entered into SPSS Version 21. An intention to treat (ITT) analysis was applied. This is recommended by the CONSORT statement as ITT analysis ensures that every individual that is randomised is included in the analysis regardless of noncompliance, protocol deviations, withdrawal or anything that happens after randomisation (Gupta, 2011). The aim of this mixed-methods study was to evaluate the effectiveness and sustainability of the OptiMal programme. Therefore, only differences between baseline and the three months follow-up scores were analysed to achieve this aim.

Descriptive statistics were used to present data on the characteristics of the participants including age, type of cancer, time since finishing treatment etc. Chi-Square tests were conducted to compare characteristics of the control and intervention group to determine if randomisation was successful. Baseline and three months follow-up of primary and secondary outcome measures scores, between the control and intervention group, were compared.

First, the data were assessed to determine if it were a normal or non-normal distribution. Baseline scores for all outcome measure between the control and intervention group were assessed to determine statistical significance. An independent t-test was used for normal data and a Mann Whitney test was used for non-normal data. The mean, standard deviation and change in mean were assessed for all normal data while the median was assessed for non-normal distribution.

Then, baseline and three month follow-up scores for all outcome measures were analysed for statistical significance. If the data were normal, an independent t-test was conducted to compare the difference in outcomes scores at baseline and three months follow-up, between the control and intervention group. If the data were non-normal, a non-parametric Mann Whitney test was conducted to compare scores at baseline to three months follow-up, between the control and intervention group.

Finally, a repeated measures analysis was conducted on all outcomes to compare the means across all three timepoints at baseline, post-intervention and three months follow-up to observe the overall trend of the data.

4.11.2 Qualitative Data

A qualitative descriptive design as described by Sandelowski (2000), was used for this mixed-methods study. Qualitative description aims to provide a rich, straight description of an experience or event (Neergaard et al., 2009). The qualitative data was analysed to establish the personal experiences of participating in the OptiMal programme and the impact of managing symptoms before and after the intervention. Perceptions on the design, content, delivery and sustainability of the programme were also explored. Thematic analysis was employed to ensure an inductive approach (Braun & Clark, 2006). Recordings from the focus groups conducted immediately post-intervention and at the three months follow up, were transcribed verbatim by the researcher, who subsequently read the transcripts to obtain an overview of the material, encouraging familiarity with the data (Braun & Clarke, 2006). Transcriptions were uploaded to a data analysis software

programme (NVivo10). In this study, focus groups and individual interviews from participants who took part in all four OptiMal programmes were analysed.

A list of initial ideas were generated from the data. Each passage of text was initially coded i.e. passages of text were related to different categories throughout the analysis (Braun & Clarke, 2006). When all codes were identified, the codes were charted by rearranging them, according to the identified themes and to facilitate the comparison of overarching themes and sub-themes (Braun & Clarke, 2006). Themes were then reviewed for structure and a thematic map of the analysis was generated to reflect the perceptions of participants in the OptiMal programme (Braun & Clarke, 2006; Bowling, 2014). Themes were analysed again to refine the specifics of each theme and sub-themes and generate appropriate titles for each theme (Braun & Clarke, 2006). Finally, analysis was related back to the research question which was to evaluate the effectiveness and sustainability of OptiMal as a self-management intervention for cancer survivors. As part of the final phase of thematic analysis, a research article of the qualitative data was accepted to the academic journal, British Journal of Occupational Therapy (BJOT) and is currently in print.

4.12 Ethical Consideration

Ethical approval was sought and obtained in December 2014 from the from Saint James' Hospital/Adelaide and Meath Hospital incorporating the National Children's Hospital (SJH/AMNCH) Research Ethics Committee to recruit participants from outpatient clinics (Appendix F). Due to a slow recruitment rate, an addendum to the approval was sought and obtained to recruit participants from a cancer support centre associated with the hospital in July 2016. See Appendix I for letter of ethical approval.

All participants' identities were protected throughout the course of the study to ensure confidentiality. Documents that could potentially identify participants were coded. The researcher had responsibility for compilation and management of data throughout the study. When completing the outcome measures participants identities were coded with only the researcher having access to the code. Assessments were kept in a locked filing cabinet. A password protected computer and laptop were used to store any electronic data for the purpose of data analysis.

This chapter discussed the mixed-methods approach undertaken to evaluate the effectiveness and sustainability of the OptiMal programme for cancer survivors. The following chapter will discuss the quantitative and qualitative results.

5. Results of Mixed-Methods Study

5.1 Introduction

This chapter presents the quantitative and qualitative results from the mixed-methods study. The recruitment, attrition, attendance and demographics of study participants is provided. Section 5.4 presents the analysis of the primary outcome measure, the Frenchay Activities Index (FAI). Section 5.5 presents the analysis of the secondary outcome measures. Section 5.6 discusses the findings from the qualitative data.

One of the key findings from the systematic review was the lack of sustainability of self-management interventions for cancer survivors (Boland et al., 2018). Therefore, analysis in this mixed-methods study consisted of comparing differences in outcome measures between baseline and three months follow-up of the control and intervention group. This was to evaluate the effectiveness and sustainability of the OptiMal programme for cancer survivors.

5.2 Recruitment, Attrition and Attendance

Four six-week OptiMal programmes were run over a fifteen-month period in the acute hospital. The programmes were run over the following time periods;

- Group 1: September 2015 to October 2015. Five out of twelve invited participants attended. Three months follow-up conducted in January 2016.
- Group 2: April 2016 to May 2016. Nine out of twelve invited participants attended. Three months follow-up conducted in August 2016.
- Group 3: August 2016 to September 2016. Six out of eight invited participants attended. Three months follow-up conducted in December 2016.
- Group 4: November 2016 to December 2016. Six out of eight invited participants attended. Three months follow-up conducted in March 2017.

A total of 246 participants met the inclusion criteria for the study and a total of 80 participants agreed and consented to participate and completed baseline assessments. Out of the 80, seven were recruited from the cancer support service and 73 were recruited from the outpatient clinics. Therefore, 166 individuals were invited to take part in the mixed-methods study, but declined. Reasons for declining to participate in a self-

management intervention will be explored in the following chapter. An overview of recruitment and drop-out rates is presented in Figure 5-1.

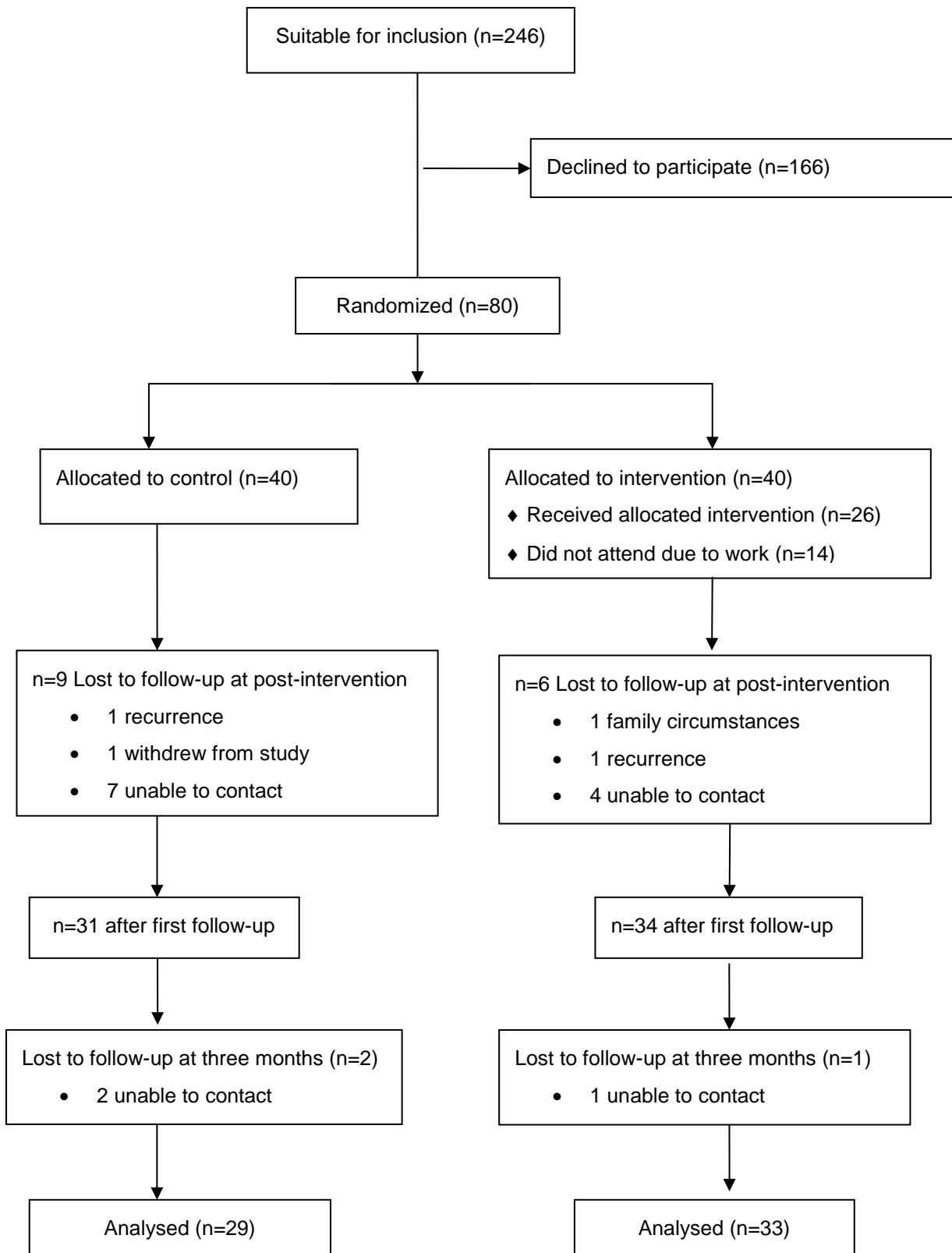


Figure 5-1 Flowchart of Recruitment Process and Attrition Rate

Eleven participants (27.5%) from the control group and seven participants (17.5%) from the intervention group were lost at follow-up. This provided an overall sample of 62 (77.5%) participants with completed baseline, post-intervention and three month follow-up measures; 29 from the control group and 33 from the intervention group. Twenty-five individuals of the 33 from the intervention group, had attended OptiMal. As outlined in the methodology chapter 4.4.2, an Intention to Treat (ITT) analysis was employed in the study and all participants were invited to complete follow-up assessments regardless of the number of sessions attended. Individuals who did not complete post-intervention or three months follow-up assessments were excluded from the primary analysis.

The rates of programme attendance for the intervention group (n=40) are displayed in Table 5-1. Twenty-six (47.5%) participants attended all six sessions and 14 (35%) did not attend any sessions primarily due to work commitments.

Table 5-1 Participants Attendance of Intervention

Sessions Attended	Number of Participants (n=40) (%)
All 6 sessions	19 (47.5%)
5 sessions	5 (12.5%)
4 sessions	2 (5%)
0 sessions	14 (35%)

5.3 Participant Characteristics

Table 5-2 presents characteristics of the 80 participants who completed baseline assessments by the control and intervention groups. The mean age in the control group was 50.4 years and in the intervention group was 51.68. The majority of participants in the study were breast cancer survivors, had undergone surgery, chemotherapy and radiation therapy as part of their cancer treatment, were living with family and had completed college/university education (Table 5-2). There were no significant differences between groups suggesting that randomisation was successful. See Table 5-2 for further information regarding participant characteristics and associated p-values.

Table 5-2 Participant Characteristics at Randomisation

	Control Group (n=40)	Intervention Group (n=40)	p-value
Mean Age (SD)	50.4 (11.75)	51.68 (11.73)	0.48
Gender			
Male (n, %)	3 (7.5%)	4 (10%)	0.69
Female (n, %)	37 (92.5%)	36 (90%)	
Type of Cancer			
Breast (n, %)	30 (75%)	28 (70%)	0.61
Other (n, %)	10 (25%)	12 (30%)	
Type of Treatment			
Surgery, Chemotherapy and Radiation Therapy (n, %)	21 (52.5%)	20 (50%)	0.98
Other (n, %)	19 (47.5%)	20 (50%)	
Marital Status			
Married (n, %)	20 (50%)	24 (60%)	0.36
Other (n, %)	20 (50%)	16 (40%)	
Living Situation			
Family (n, %)	34 (85%)	36 (90%)	0.49
Other (n, %)	6 (15%)	4 (10%)	
Level of Education			
Primary-Leaving Cert (n, %)	21 (52.5%)	24 (60%)	0.49
College/University (n, %)	19 (47.5%)	16 (40%)	
Chronic Condition			
Yes (n, %)	13 (32.5%)	19 (47.5%)	0.17
No (n, %)	27 (67.5%)	21 (52.5%)	
Employment Status Prior to Treatment			
Full-time (n, %)	18 (45%)	18 (45%)	0.63
Part-time (n, %)	6 (15%)	9 (22.5%)	
Other (n, %)	16 (40%)	13 (32.5%)	
Employment Status After Treatment			
Full-time (n, %)	10 (25%)	9 (22.5%)	0.17
Part-time (n, %)	6 (15%)	13 (32.5%)	
Other (n, %)	24 (60%)	8 (20%)	

5.4 Primary Outcome Measure

Firstly, tests were conducted to determine if baseline scores between the control or intervention group were significant. However, no statistically significant differences were observed at baseline between the control and intervention group ($p=0.38$). The data were normally distributed therefore, an independent t-test was used to measure the difference in FAI scores between baseline and three month follow-up. No statistically significant differences were reported for change in scores between the control group and intervention group ($p=0.92$). The mean, standard deviation and p-value between baseline and three months follow-up are displayed in Table 5-3.

Table 5-3 Comparison of changes in mean (SD) of FAI scores at baseline and three month follow-up between the control and intervention group

	Control Group			Intervention Group			Difference; p-value
	Baseline (n=29) Mean (SD)	Three month follow-up (n=29) Mean (SD)	Change in Mean	Baseline (n=33) Mean (SD)	Three month follow-up (n=33) Mean (SD)	Change in Mean	
FAI Scores	32.59 (5.99)	34.59 (3.85)	2	34.06 (5.08)	36.03 (3.90)	1.97	0.92

Table 5-4 compares baseline and three months follow-up scores of the subscales of the FAI (domestic, work/leisure and occupation) between the control and intervention group. Both groups showed small improvements in all three subscales, however, the difference in scores in each subscale, between the control and intervention group were non-significant.

Table 5-4 Comparison of changes in mean (SD) of FAI subscales scores at baseline and three month follow-up between the control and intervention group

FAI Subscales	Control Group		Intervention Group		Difference; p-value
	Baseline (n=29) Mean (SD)	3 month follow-up (n=29) Mean (SD)	Baseline (n=33) Mean (SD)	3 month follow-up (n=33) Mean (SD)	
Domestic	13.52 (2.33)	14 (1.6)	13.55 (2.1)	13.97 (1.61)	0.83
Work/Leisure	8 (3.11)	8.83 (2.36)	9.27 (2.61)	10.21 (2.54)	0.84
Outdoors	11.24 (1.93)	11.59 (1.99)	11.33 (1.83)	11.88 (1.96)	0.54

Analysis was conducted comparing the means of FAI scores between the control group and the intervention group at the three timepoints (T1; Baseline, T2; Post-intervention, T3; Three month follow-up). This was to provide an insight into the trend of the outcome measure over the three timepoints. Figure 5-2 presents the means of the three timepoints. Both groups reported improvements in activity participation over the three timepoints with the intervention group improving at a slightly higher rate.

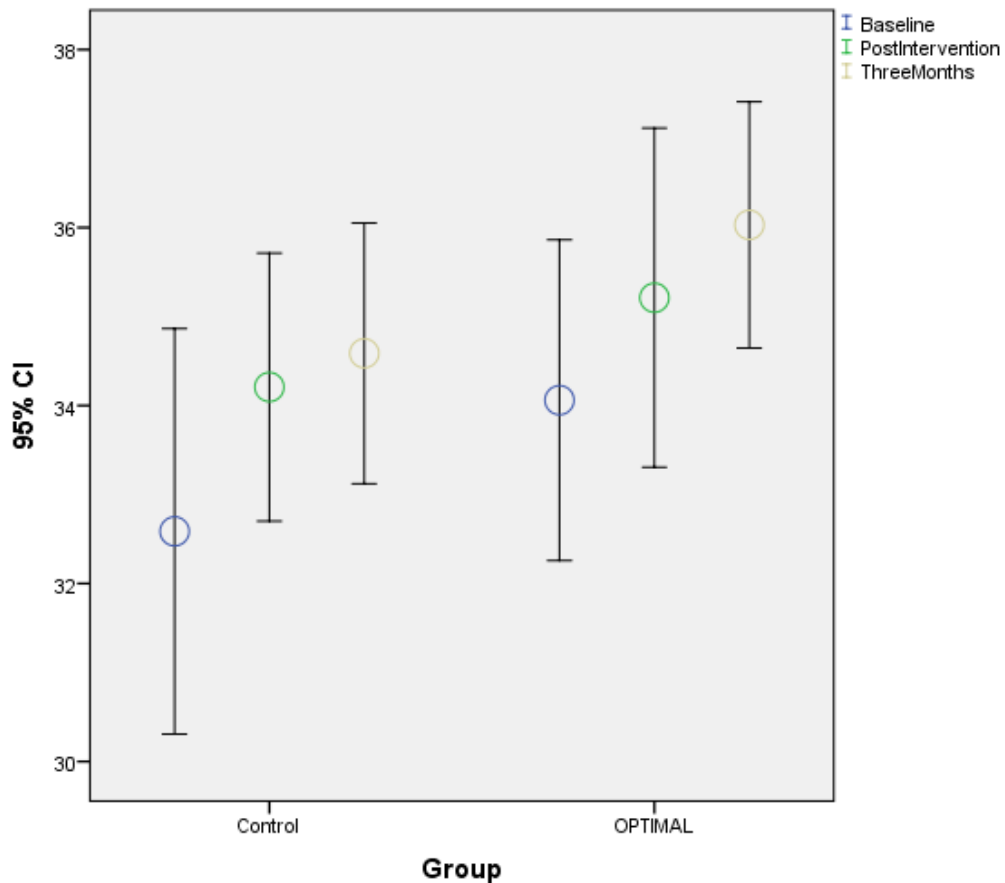


Figure 5-2 FAI means and 95%CI from the control and intervention group from baseline, post-intervention and three month follow-up

5.5 Secondary Outcome Measures

In total there were six secondary outcome measures. Results from the analysis of each outcome measure are presented in the following sections.

5.5.1 EQ-5D

Table 5-5 contains the frequency and % of reported problems at baseline and at three months follow-up in the areas of mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

Table 5-5 Frequency of reported problems between control and intervention group at baseline and three month follow-up

EQ-5D Outcomes	Control Group		Intervention Group	
	Baseline (n=29) (%)	3 month follow-up (n=29) (%)	Baseline (n=33) (%)	3 month follow-up (n=33) (%)
Mobility				
No Problems	23 (79.3%)	17 (58.6%)	20 (60.6%)	24 (72.7%)
Moderate/Severe Problems	6 (20.7%)	12 (41.4%)	13 (29.4%)	9 (27.3%)
Self-Care				
No Problems	28 (96.6%)	28 (96.9%)	30 (90.9%)	31 (93.9%)
Usual Activities				
No Problems	15 (51.7%)	18 (62.1%)	14 (42.4%)	21 (63.6%)
Moderate/Severe Problems	14 (48.3%)	11 (37.9%)	19 (57.6%)	12 (36.4%)
Pain/Discomfort				
No Problems	9 (31%)	9 (31%)	7 (21.2%)	13 (39.4%)
Moderate/Severe Problems	20 (69%)	20 (69%)	26 (78.8%)	20 (60.6%)
Anxiety/Depression				
No Problems	14 (48.3%)	14 (48.3%)	7 (21.2%)	13 (39.4%)
Moderate/Severe Problems	15 (51.7%)	15 (51.7%)	26 (78.8%)	20 (60.6%)

Interestingly, participants in the control group reported increased ‘moderate/severe problems’ with mobility at the three months follow-up. In comparison, the intervention group reported an increase in ‘no problems’ with mobility. Additionally, there was a greater increase in the intervention group reporting ‘no problems’ with usual activities at three months follow-up, compared to the control group. There were no changes in frequency from baseline to three months follow-up in the pain/discomfort and anxiety/depression subscale as reported by the control group. In the intervention group, 78.8% of participants reported moderate/severe problems in pain/discomfort and anxiety/depression at baseline while 21.2% reported no problems. However, at the three month follow-up, only 60.6% reported moderate/severe problems in both subscales and 39.4% reported no problems.

The health states of the EQ-5D were also translated into a single summary index to produce an overall health states score. The data regarding the EQ-5D health scores were non-normal and Mann Whitney tests were performed. A Mann Whitney test was used to first determine if baseline health scores between both groups were significant. A Mann Whitney test showed that there was a near significant difference between the control and intervention groups health scores at baseline but this was not statistically significant ($p=0.08$).

As the data were non-normal, a Mann-Whitney test was used to make comparisons between the median of change scores of the control and intervention group. There was a statistically significant improvement in the EQ-5D health state scores between the control and intervention group ($p<0.001$) (Table 5-6).

Table 5-6 Comparison of the median of change scores of baseline and three month follow-up EQ-5D health states between the control and intervention group

	Control Group (n=29)	Intervention Group (n=33)	
	Median of Change Score from T1-T3 (Interquartile Range)	Median of Change Score from T1-T3 (Interquartile Range)	Difference; p-value
Change in Health Scores	0.00 (0.17)	0.07 (0.20)	<u>0.001</u>

EQ-VAS

Increased scores in the EQ-VAS indicate improvements in self-reported health-related quality of life (HRQOL). One participant allocated to the control group did not complete this scale at any timepoint.

Data regarding the EQ-VAS scores were non-normal and Mann Whitney tests were conducted. First, baseline scores between both groups were analysed for significance. This reported a statistically significant difference between baseline scores of the control and intervention group ($p=0.03$).

A Mann Whitney test compared the change in median scores between the control group and intervention group from baseline to three months follow-up, as per Table 5-7. As a

result, the test showed that there was a statistically significant improvement in the EQ-VAS between the intervention group and control group at three months follow-up (p=0.03) (Table 5-7).

Table 5-7 Comparison of the median of change scores of baseline and three month follow-up EQ-VAS scores between the control and intervention group

	Control Group (n=28)	Intervention Group (n=33)	
EQ-VAS Scores	Median of Change Score from T1-T3 Interquartile Range (IRQ)	Median of Change score from T1-T3 Interquartile Range (IRQ)	Difference; p- value
	0 (15)	5 (10)	<u>0.035</u>

Figure 5-3 compares the means of the control and intervention group at the three timepoints. Of note, is that the intervention group have a continuous increase in EQ-VAS scores over the three timepoints but the control groups scores reduce from T2-T3.

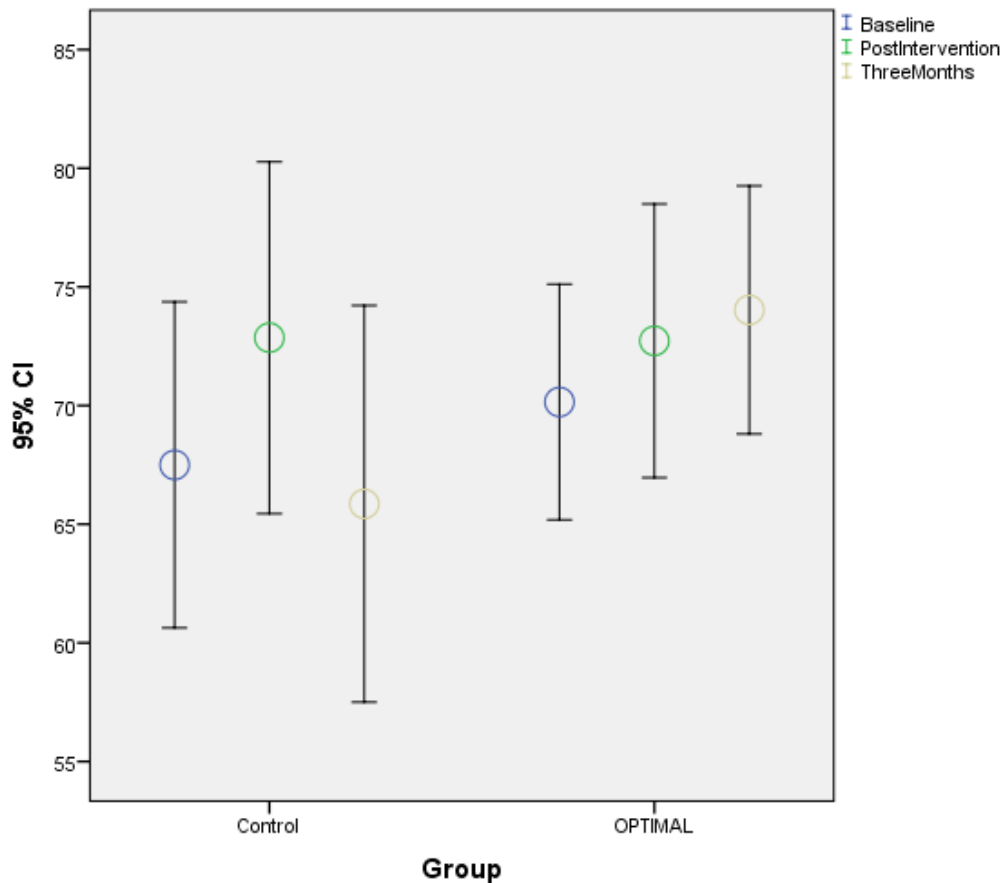


Figure 5-3 EQ-VAS means and 95% CI from the control and intervention group from baseline, post-intervention and three month follow-up

5.5.2 Stanford Chronic Disease Self-Efficacy Scale (6 item) (SSE)

Data regarding the SSE were normally distributed and independent t-tests were conducted. No statistically significant differences were observed between both groups at baseline ($p=0.43$).

An independent t-test then compared changes in mean scores from baseline to three months follow-up, between the control and intervention group, for significance. The t-test indicated no significant differences between the two groups over time ($p=0.35$). The mean, standard deviation and p-value between baseline and three month follow-up are presented in Table 5-8.

Table 5-8 Comparison of changes in mean (SD) SSE scores at baseline and three month follow-up of the control and intervention group

	Control Group			Intervention Group			
	Baseline (n=29) Mean (SD)	Three month follow- up (n=29) Mean (SD)	Change in Mean	Baseline (n=33) Mean (SD)	Three month follow- up (n=33) Mean (SD)	Change in Mean	Difference; p-value
SSE Scores	7.08 (1.54)	7.38 (1.62)	0.30	6.93 (1.62)	7.75 (1.85)	0.82	0.35

Figure 5-4 presents the means and 95% CI of the SSE scores, of the control and intervention group at the three timepoints. Improvements are noted in the intervention group across all three timepoints. In comparison, a slight reduction in self-efficacy scores is observed in the control group from T2-T3.

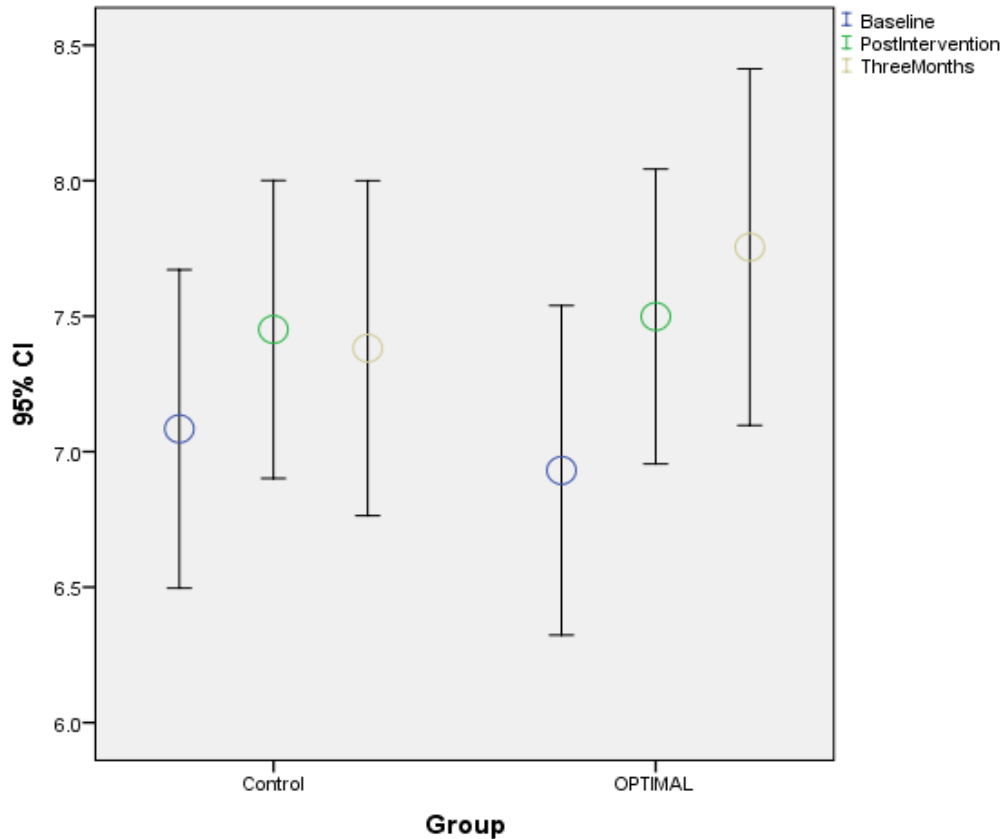


Figure 5-4 SSE means and 95% CI in the control and intervention group at baseline, post-intervention and three months follow-up

5.5.3 Hospital and Anxiety Depression Scale (HADS)

HADS-A

Data regarding the anxiety subscale of the HADS were normally distributed and independent t-tests were conducted. Baseline scores between the control and intervention group were analysed for significance. No statistically significant differences were observed in scores between both groups at baseline ($p=0.24$).

An independent t-test was conducted to analyse change in means scores between the control and intervention group at baseline and three months follow-up. This indicated a statistically significant difference between the control and intervention group regarding the anxiety subscale, with the intervention group reporting greater improvements ($p=0.04$), see Table 5-9.

Table 5-9 Comparison of changes in mean (SD) of HADS-A scores at baseline and three months follow-up between the control and intervention group

	Control Group			Intervention Group			Difference; p-value
	Baseline (n=29) Mean (SD)	Three month follow- up (n=29) Mean (SD)	Change in Mean	Baseline (n=33) Mean (SD)	Three month follow- up (n=33) Mean (SD)	Change in Mean	
HADS- A	7.66 (4.58)	8.00 (4.79)	0.34	9.21 (3.69)	7.76 (3.23)	-1.45	<u>0.04</u>

Figure 5-5 presents the means (95% CI) of the control and intervention group at the three timepoints. Anxiety levels, in the intervention group, continue to decrease at each of the timepoints in comparison to the control group which slightly increased across the three timepoints.

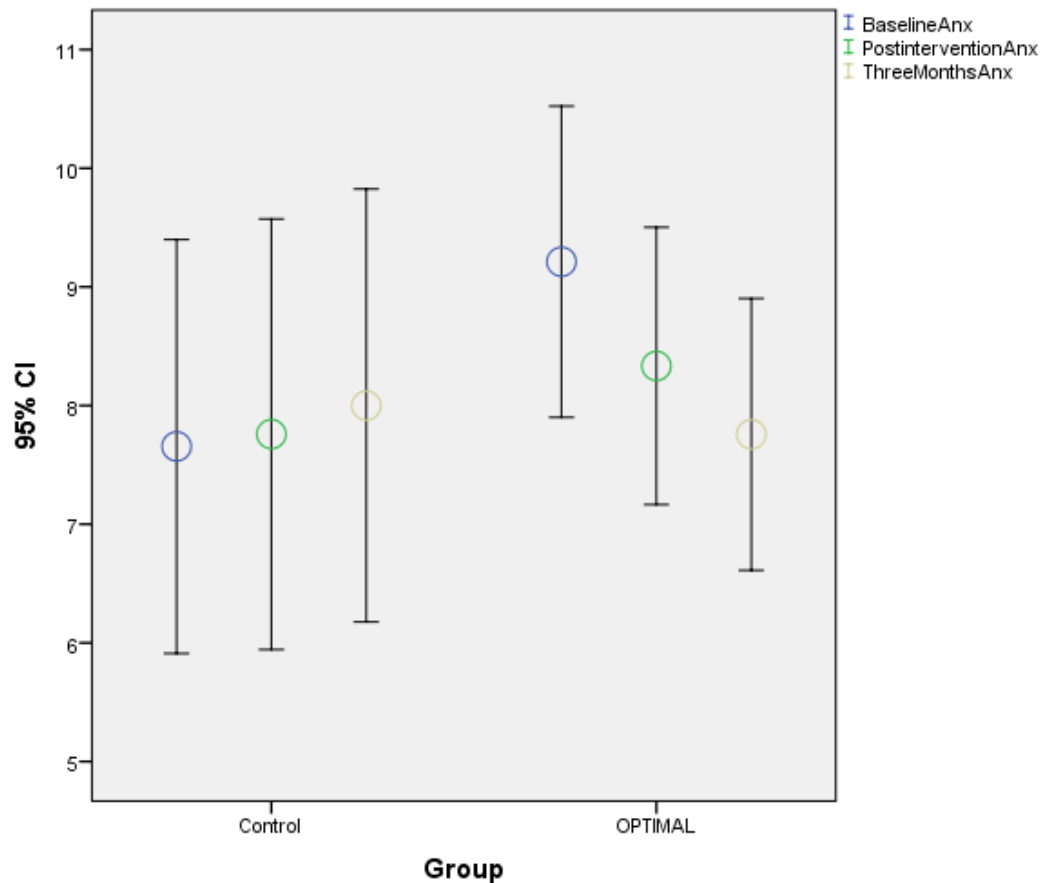


Figure 5-5 HADS-A means and 95% CI from the control and intervention group at baseline, post-intervention and three months follow-up.

HADS-D

Data regarding the depression subscale were non-normal and Mann Whitney tests were performed. Baseline scores between the control and intervention group were analysed for significance. No statistically significant differences were observed between both groups at baseline ($P=0.66$).

A Mann Whitney Test was conducted to detect significance in the median of change scores between the two groups. However, there was no statistically significant differences ($p=0.41$). Table 5-10 presents the change in median between the control and intervention group from T1-T3 and subsequent p-value. Comparison of the change in median of baseline and three month follow-up EQ-VAS scores between the control and intervention group

Table 5-10 Comparison of the median of change score of baseline and three month follow-up HADS-D scores between the control and intervention group

	Control Group (n=29)	Intervention Group (n=33)	
	Median of Change Score from T1-T3 (Interquartile Range)	Median of Change Score from T1-T3 (Interquartile Range)	Difference; p-value
HADS-D Scores	1 (5)	-1 (4)	0.41

Additionally, means (95%CI) from the control and intervention group were compared from baseline to three months follow-up, as per Figure 5-6. Interestingly, levels of depression decreased from T1-T2 in the intervention group and then slightly increased from T2-T3. Levels of depression remained fairly constant in the control group at all three timepoints.

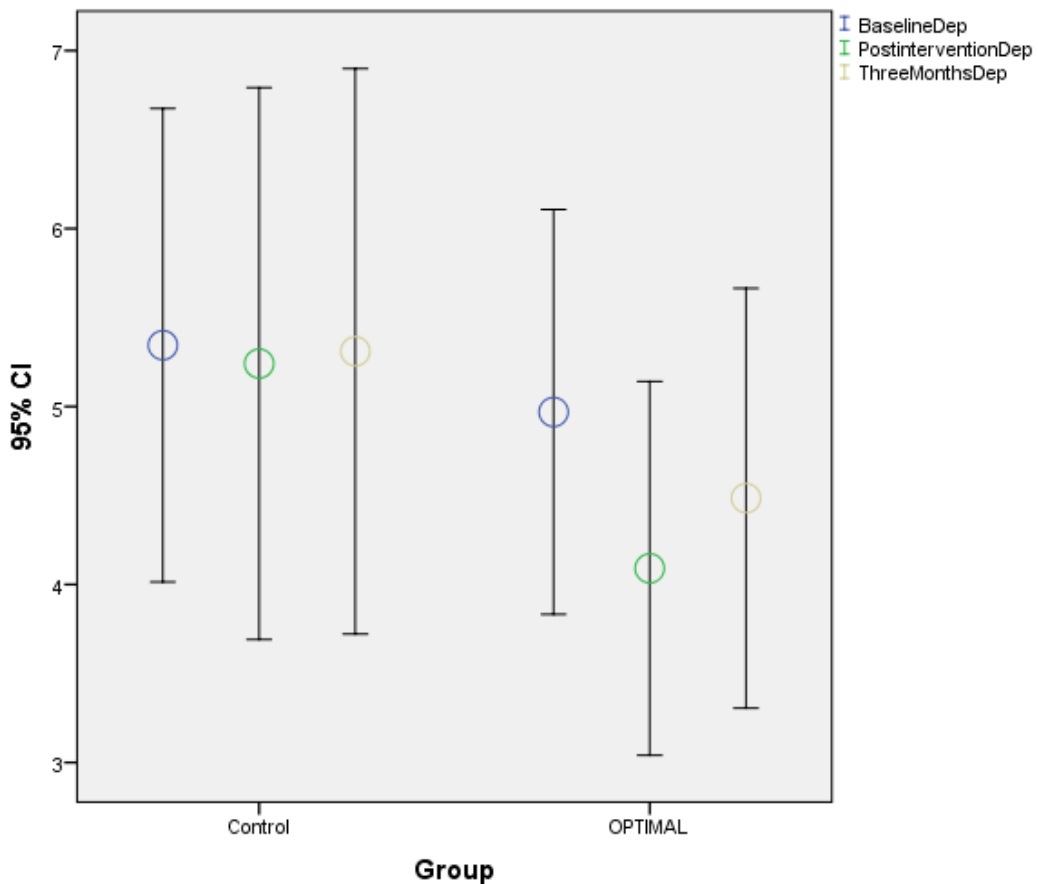


Figure 5-6 HADS-D means and 95% CI from the control and intervention group at baseline, post-intervention and three month follow-up

5.5.4 Cognitive Failures Questionnaire (CFQ)

Data regarding the CFQ were non-normal and Mann Whitney tests were conducted to detect significance between baseline scores from the control and intervention group. No statistically significant differences were observed in baseline scores between both groups ($p=0.3$).

A Mann Whitney test was conducted to detect significance in the median of change scores between the two groups. No statistically significant difference were observed between the control and intervention group ($p=0.26$). The median of change scores and p -value between baseline and three month follow-up are displayed in Table 5-11.

Table 5-11 Comparison of the median of change scores baseline and three month follow-up CFQ scores between the control and intervention group

	Control Group (n=29)	Intervention Group (n=33)	
	Median of Change Score from T1-T3 (Interquartile Range)	Median of Change Score from T1-T3 (Interquartile Range)	Difference; p-value
CFQ scores	1 (11)	-1 (15)	0.26

Figure 5-7 presents the comparison of means (95% CI) between the control and intervention group at the three timepoints. At all three timepoints, participants in the intervention group continued to report higher cognitive difficulties than the control group (Figure 5-7).

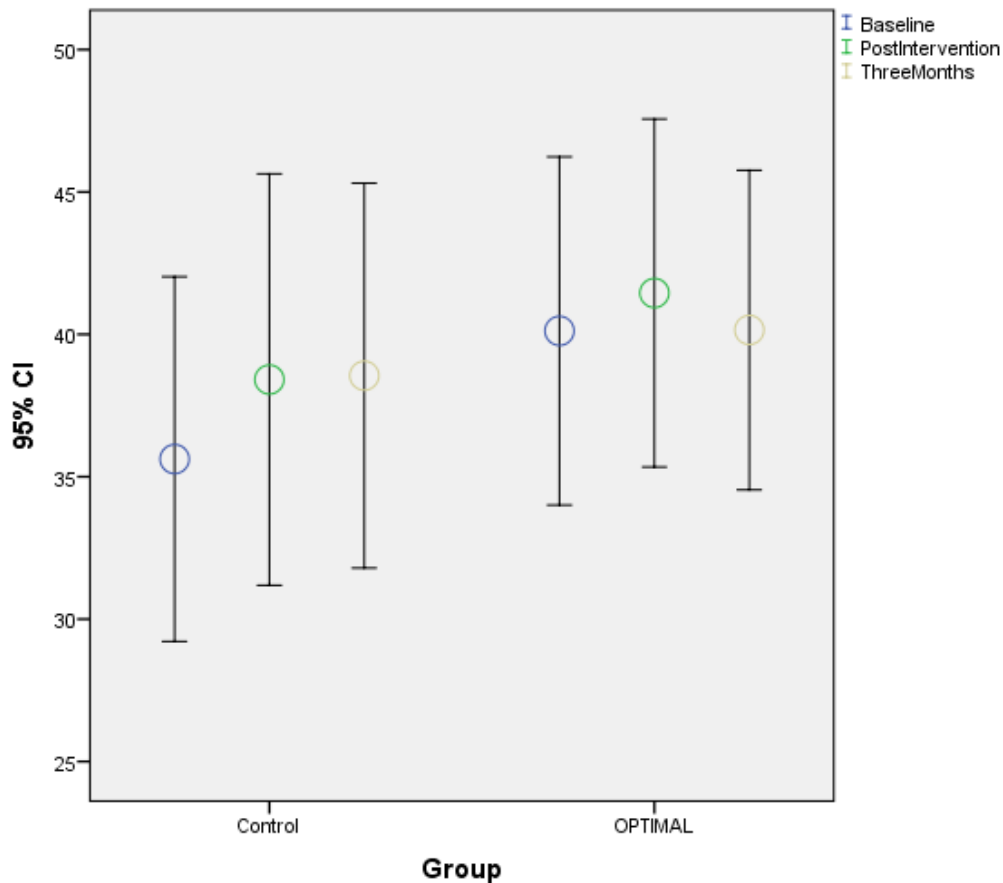


Figure 5-7 CFQ means and 95% CI from the control and intervention group at baseline, post-intervention and three month follow-up

5.5.5 Functional Assessment of Chronic Illness Therapy-Fatigue short version (FACIT-F)

Data regarding the FACIT-F were normally distributed and independent t-tests were conducted. Baseline scores between the control and intervention group were analysed for significance. No statistically significant differences were observed in baseline scores between both groups ($p=0.62$).

No statistically significant differences were identified between baseline and three month follow-up scores of the control and intervention group ($p=0.29$), despite the change in mean scores in the intervention group being higher compared to the control group, see Table 5-12.

Table 5-12 Comparison of changes in mean (SD) of FACIT-F scores at baseline and three month follow-up between the control and intervention group

	Control Group			Intervention Group			Difference; p-value
	Baseline (n=29) Mean (SD)	Three month follow- up (n=29) Mean (SD)	Change in Mean	Baseline (n=33) Mean (SD)	Three month follow- up (n=33) Mean (SD)	Change in Mean	
Fatigue Scores	31.72 (12.74)	32.14 (11.58)	0.42	33.18 (10.71)	35.67 (10.43)	2.49	0.29

Figure 5-8 presents means (95% CI) from the control group and intervention group from the three timepoints. Of interest is from T1-T2 follow-up, both the control and intervention group follow a similar pattern of increased scores i.e. fewer symptoms of fatigue. However, from T2-T3, the intervention group continued to report fewer symptoms of fatigue in comparison to the control group whom reported increased symptoms of fatigue however this difference was not statistically significant between the groups (Figure 5-8).

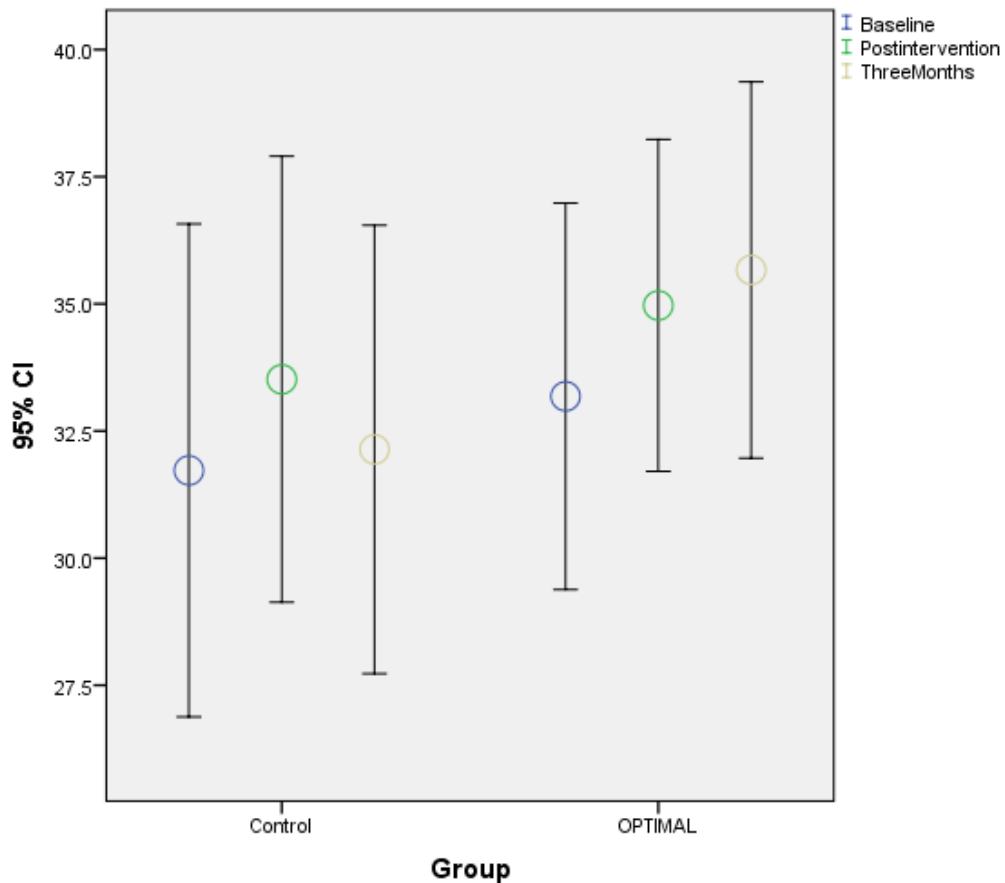


Figure 5-8 FACIT-F means (95% CI) from the control and intervention group at baseline, post-intervention and three months follow-up

5.5.6 The Canadian Occupational Performance Measure (COPM)

The COPM measured participants' perceptions of their occupational performance in their daily activities and their satisfaction with same. Seven people did not complete the COPM at the baseline assessment; five from the control group and two from the intervention group.

COPM-Performance (COPM-P)

Data regarding the performance subscale of the COPM were non-normal and Mann Whitney tests were conducted. Baseline data between the control and intervention group were first analysed for significance. No statistically significant differences were observed in baseline scores between both groups ($p=0.48$).

No statistically significant differences were observed between baseline and three month follow-up scores between the control and intervention group in median of change scores

between the control and intervention group ($p=0.67$). Table 5-13 compares the median of changes scores between the control and intervention groups and subsequent p-value.

Table 5-13 Comparison of the median of change scores baseline and three month follow-up COMP-P scores between the control and intervention group

	Control Group (n=24)	Intervention Group (n=31)	
	Median of Change Score from T1-T3 (Interquartile Range)	Median of Change Score from T1-T3 (Interquartile Range)	Difference; p-value
COPM-P scores	1.2 (3)	2 (2.25)	0.67

Figure 5-9 presents the mean (95% CI) scores from the control group and intervention group from baseline to three months follow-up. Both groups continued to report improvements in occupational performance across the three timepoints.

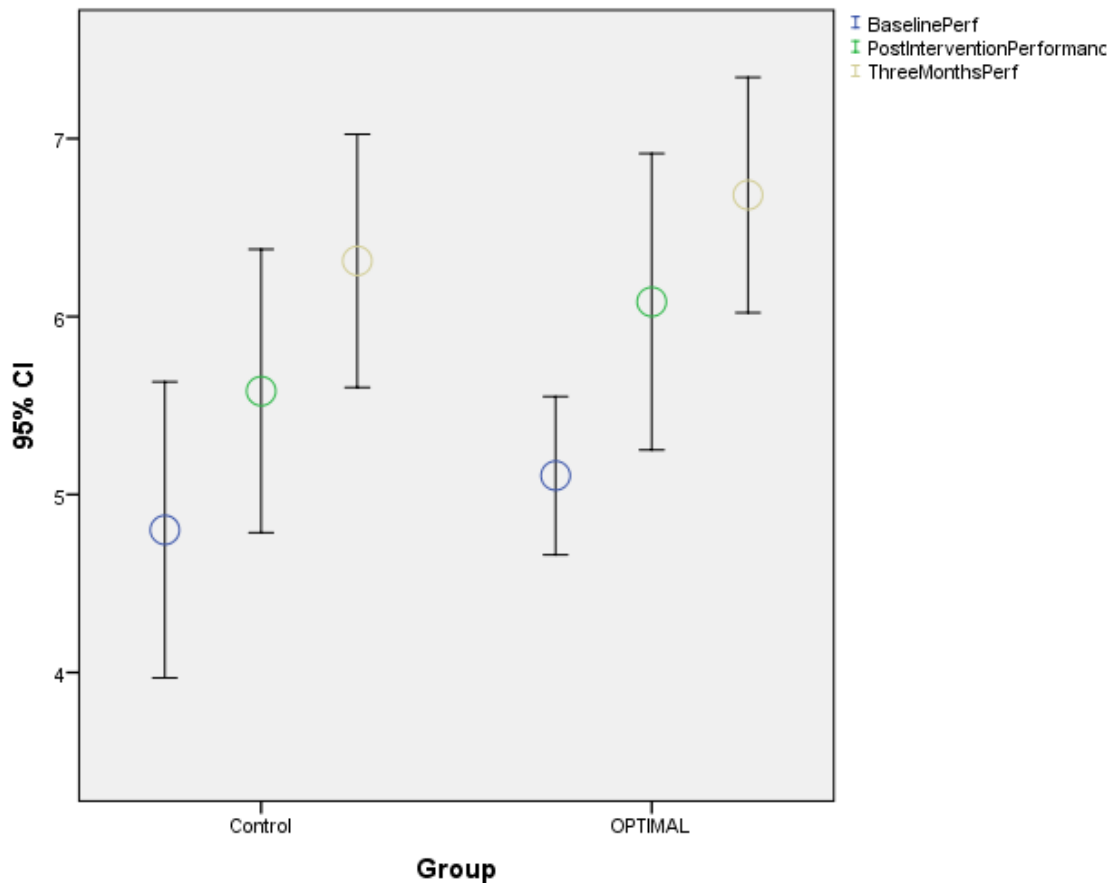


Figure 5-9 COPM-P means (95% CI) from the control and intervention group at baseline, post-intervention and three months follow-up

COPM-Satisfaction (COPM-S)

Data regarding the COPM-S were normal and independent t-tests conducted. Baseline data between the control and intervention group were first assessed for significance. No statistically significant differences were observed at baseline between both groups ($p=0.71$).

No statistically significant differences was observed between the control and intervention group at baseline or three months follow-up ($p=0.52$) (Table 5-14).

Table 5-14 Comparison of changes in mean (SD) of COMP-S scores at baseline and three months follow-up between the control and intervention group

	Control Group			Intervention Group			
	Baseline (n=24) Mean (SD)	Three month follow- up (n=24) Mean (SD)	Change in Mean	Baseline (n=31) Mean (SD)	Three month follow- up (n=31) Mean (SD)	Change in Mean	Difference; p-value
Satisfaction	3.52 (2.76)	5.69 (2.42)	2.17	3.76 (2.12)	6.36 (2.32)	2.6	0.52

Figure 5-10 presents means from the control and intervention groups from baseline to three month follow-up. Similar to COPM-P, both groups continued to report increased satisfaction with their occupational performance over the three timepoints.

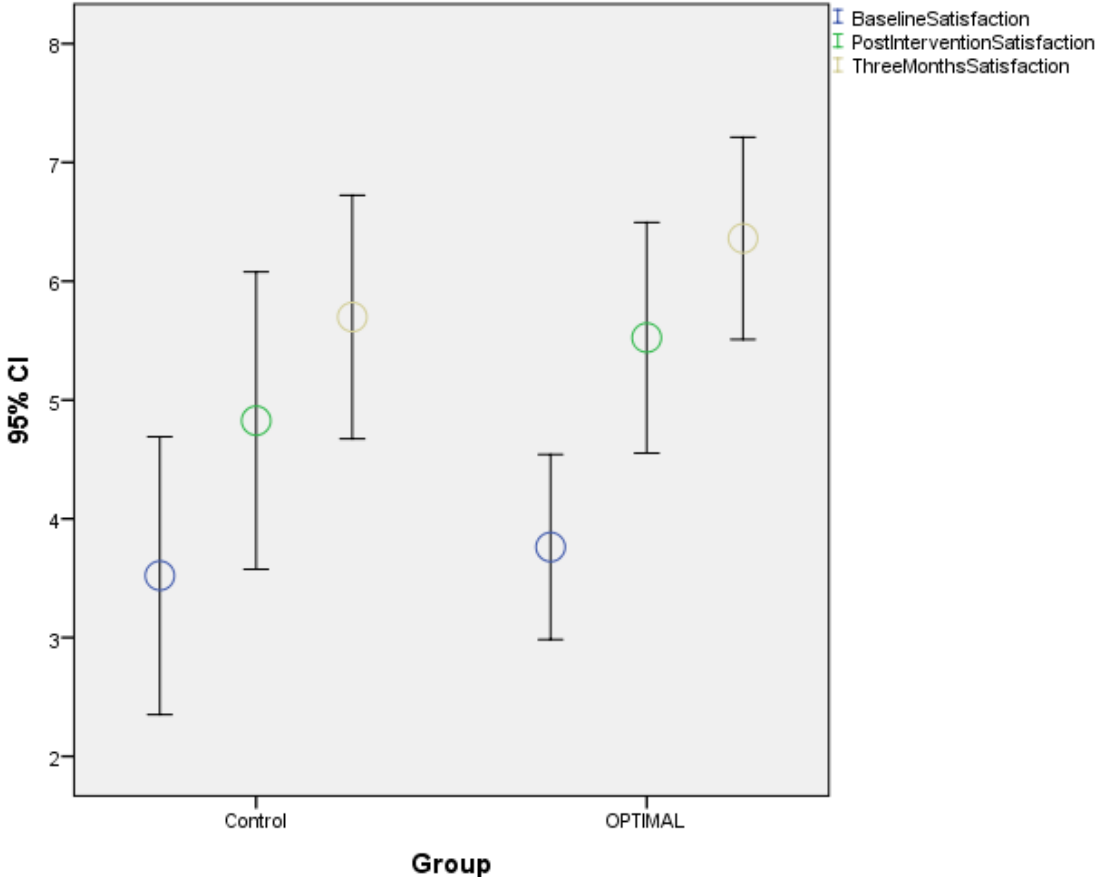


Figure 5-10 COPM-S means (95% CI) from the control and intervention group at baseline, post-intervention and three months follow-up

In conclusion, no statistically significant difference was reported in the primary outcome measure, the Frenchay Activities Index (FAI). However, in the secondary outcome measures, statistically significant results were reported in the anxiety subscale of HADS outcome measure and the EQ-5D. This indicated that the OptiMal programme was effective in decreasing anxiety levels and improving self-reported HRQOL in cancer survivors.

The next section presents the qualitative findings of this study.

5.6 Qualitative Analysis

5.6.1 Introduction

As part of this study, qualitative data was gathered through focus groups and semi-structured interviews to understand the feasibility of the OptiMal programme. Previous studies have recommended qualitative methods to determine the feasibility and acceptability of self-management interventions for chronic conditions (Foster et al., 2007). As mentioned in section 4.3, this research was guided by the Medical Research Council's (MRC) framework for complex interventions. This recommends the inclusion of process evaluations in exploratory trials to assess the acceptability of an intervention through qualitative methods (MRC, 2008). The aim of conducting a process evaluation in this study was to inform future delivery for cancer survivors.

5.6.2 Findings

Eighty cancer survivors were recruited into the study over a 15 month period; 40 randomised to the intervention group and 40 randomised to the control group. Four focus groups were facilitated immediately following the completion of each of the four OptiMal programmes. In total, 26 individuals attended and took part in these four focus groups; five from OptiMal one, nine from OptiMal two, six from OptiMal three and six from OptiMal four. Fourteen individuals did not attend any sessions of the OptiMal programme. At the three month follow-up, four focus groups were facilitated with a total of 20 participants participating in these four focus groups; five from OptiMal one, six from OptiMal two, four from OptiMal three and five from OptiMal four. Six participants took part in semi-structured interviews with the researcher at the three month follow-up. The focus groups and semi-structured interviews lasted between 15 minutes and 1 hour. The average duration of the focus groups were 25 minutes while the average duration of interviews were 20 minutes. The mean age of participants were 52.7 years (SD:11). The majority were female with breast cancer and had completed treatment within the previous year.

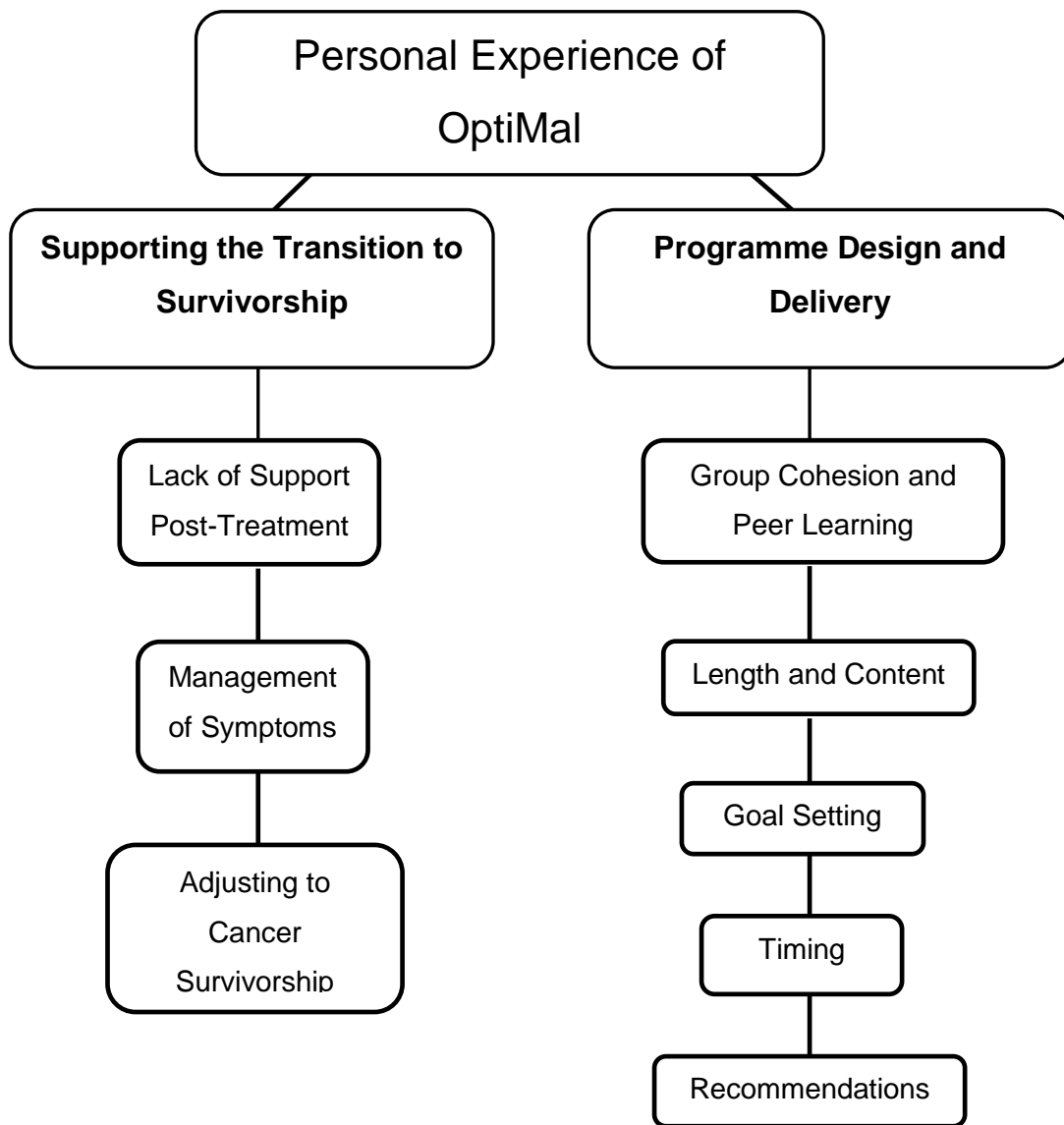


Figure 5-11: Visual Thematic Map of Themes and Sub-Themes from Data Analysis

Two main themes emerged from data analysis: 1) Supporting the transition to survivorship 2) Programme design and delivery

1) Supporting the transition to survivorship

Lack of Support Post-Treatment

Prior to attending the OptiMal programme, many participants described a lack of support from hospital services and a feeling of being abandoned post-treatment:

'When you're sent home you're out of treatment, you're on your own and it's like "Did that really happen?" There are no supports in place, you're living six months to six months for your hospital visit' [P10]

'When you're finished your treatment...you're told to come back in a year's time...you're in limbo for the next year' [P42]

Participants described how following treatment they had many questions regarding persistent symptoms which resulted in them feeling unsure regarding their next step:

'You've so many questions afterwards....you've so many symptoms, you're worrying about everything and there's nothing there to support you and I think that's where the lack was for me...was how to go forward after treatment' [P54]

Many participants spoke of their frustration with family and others at the difficulties encountered in trying to explain their experiences of life post-cancer:

'Everyone seems to think we're all back to normal....They're looking from the outside. You feel like stripping and saying "Tell me now, do I look ok?" [P15]

'Your family try to help you but they don't know your fatigue or your sickness' [P39]

'People that hasn't gone through it, that hasn't been affected by it do not understand. 'Sure your hair's growing back, you're grand' [P5]

Some participants attributed this frustration to the inability of others to discuss the subject of cancer;

'It's a word that some people don't like using...even, my husband doesn't say 'X had cancer'. No he says X "wasn't well" [P15]

'But you're not allowed complain because you're cured' [P54]

Other participants spoke of the impact on symptoms on their daily activities upon finishing treatments:

'If you look at the activities of daily living and the very smallest thing that you do as in putting a sock on and you not actually being physically able to bend down and put a sock on that takes so much away from you' [P37]

'When I went home, I was nothing like my former self. I went from a young to an old woman overnight' [P39]

Management of Symptoms

Participants identified symptoms that persisted post-treatment and described the impact of fatigue, for example:

'You fall into the trap of fatigue...it's that cycle that keeps coming up over and over again. You feed into the fatigue, you get unfit, you're not getting the endorphins, you're not going outside, you're putting on weight' [P10]

'You're over cancer, you've been given the all clear, you're in remission now but...you feel tired and you're not able to do the things that you used to do before' [37]

One participant remarked on the impact of fatigue on their work and family life:

'Well I was back at work and thinking 'Sure, this is great, how have I done all this?' But even though I might have thought it was taking 100% of my energy, work was taking 120%, so I wasn't getting *anything* done for myself or the family and I thought "Now they're just literally being neglected". I just found work took *all* the energy'. [P49]

Participants also spoke of feeling isolated upon experiencing these symptoms:

'You're mind starts going mad. Is this cancer back? Am I the only one feeling this?' [P29]

However, as a result of attending OptiMal, some participants discussed increased understanding of their symptoms. For example:

'I understand now. It's not a big issue. I understand why I'm tired' [P39]

During the three month follow-up, participants reported implementing fatigue management strategies provided during OptiMal:

‘I know now if I do too much...I will be very tired and if I do a lot today I’ve got to rest tomorrow, if I’m going out tonight I have to rest this afternoon’ [P39]

Participants spoke of how increased understanding and management of fatigue alleviated feelings of worry and anxiety;

‘Realising the fatigue is part of it and will go away....and the fuzzy brain is part of it and will also go away. So once told it’s normal, I think you’ve relaxed and it’s ok....and to know all the things you can do then to help yourself and just that it will go away one day...you’re more relaxed’ [P63]

Participants also discussed experiencing cognitive difficulties post-treatment at home:

‘My daughter..she used to slag me all the time when I put the toothpaste in the washing machine, I put the flour in the freezer on different days’ [P13]

‘It was the loss of concentration and focus and trying to read something, trying to watch the television...I...couldn’t concentrate..my mind was flitting all the time’ [P6]

Another participant described the impact of cognitive difficulties in work:

‘...in work especially....I wasn’t as sharp as I was before and you’re trying to think of things and it felt like you have wool in your brain. You’re thinking “I should know this” and you’re just not as sharp as before’ [P63]

The same participant discussed a strategy for managing cognitive difficulties in work through increased awareness of fatigue following OptiMal:

‘I know when I wake up in the morning some days I’m worse than others. So I know now that when I get into work I can’t do certain things first thing in the morning. If it’s complex I have to wait until the afternoon or maybe not today, wait until tomorrow’ [P63].

Other symptoms were mentioned including anxiety around recurrence;

'Probably the biggest thing is the worry of it coming back because I would still be at high risk of it coming back and that's always there' [P48]

The same participant post-intervention described how exercise has helped manage stress and anxiety:

'I would put the runners on and go for a 10 mile walk and come back feeling fine' [P48]

Adjusting to Cancer Survivorship

Post-intervention participants reported a change in attitude to cancer survivorship and described it as an adjustment to a 'new normal' way of life and how attending OptiMal facilitated this:

'It's a new normal and it's managing all the different aspects of that' [P13]

Participants reported allowing themselves to accept this 'new normal' therefore alleviating feelings of guilt:

'You can kind of stop now and say "Actually this is the new me". I'll eventually get there at my own pace, it's ok and forgive yourself' [P54]

Another participant reported how they viewed themselves differently as a result of OptiMal:

'I always thought of myself as a cancer patient, I never thought of myself as a cancer survivor' [P5]

As a result of increased understanding gained in the OptiMal programme, some participants reported re-engaging in productivity-related occupations:

'I think these groups are invaluable, it's got me back to work and I'm finding that with the memory stuff, I really have to think on my feet now, it's actually helping me' [P6]

'I have gone back to college because I think the best way to get my brain working properly again is to use it' [P54]

Other participants reported increasing their physical activity levels post-intervention:

‘I used to always walk but now I try to get at least half an hour walk a day listening to some music so to ease off the day before going home...it’s a small thing but I feel it works’ [P26]

‘I would never have walked in the winter or consciously walked anywhere I would have been too busy to walk but now I consciously walk, I leave the car at home and I walk to work’ [P54]

2) Programme Design and Delivery

One of the key aspects of OptiMal is group participation. This was reflected on by participants who discussed the beneficial effects of meeting and learning from other survivors during the programme.

Group Cohesion and Peer Learning

Participants described a sense of security from within the group creating a safe environment for them to share their own experiences and reducing feelings of isolation:

‘For me it was the comradeship of the group...for five women to sit in a room together is just wonderful and you can’t buy that’ [P10]

‘It can be very lonely when you’re at home and lying down and nobody understands. It’s when you come to a group like this and people understand and they’re nodding “Yeah, I have that as well”. It makes you feel less guilty’ [P29]

Participants spoke of enjoyment gained from interacting with other group members:

‘It’s the socialising part of it as well, you know, knowing people and having a chat and a laugh with people as well just helps, knowing that other people are going through the same thing as you’ [P29]

‘I think it’s therapy in itself, you’re chatting and the laughs we had’ [P48]

Participants discussed learning from other participants:

'When I've heard the other women say "Oh try this, oh this might work"...I felt was hugely beneficial, because these are women who have been through it, they know what they're talking about it isn't someone giving you lip service and trying to humour you, these are women who have gone through exactly what you have gone through' [P54]

'They might have a different way of coping with a problem' [P42]

'It was interesting to hear about other people having anxiety and that this is probably either secondary to the treatment or secondary to the meds that you might take and that was good' [P44]

Length and Content of the Programme

Several aspects of OptiMal were discussed and recommendations were made for future programmes. Focus group participants discussed the length of the programme, input from different health professionals, meeting others with a different cancer diagnoses and the programme handbook. Participants reported that the programme passed very quickly and the content of the programme was relevant:

'It's after flying [the programme]. I thought at the beginning it was going to be long but it's after flying' [P6]

'It's great, the information just keeps coming and coming and coming' [P15]

Out of the 26 participants, fifteen reported that the mix of cancer diagnoses in the group was interesting regarding similar symptoms experienced by many regardless of cancer type:

'That was interesting because with the different types and the different treatments, it was interesting to see that there was common themes' [P44]

Participants expressed how input from other multidisciplinary team members resulted in them feeling valued:

'The professionals like the dietician and the physio take time out to come and meet us, it just proved we are heard and deserve a bit of care somewhere along the way'
[P10]

Participants also viewed this as an opportunity to learn new information:

'The physiotherapist was saying, we should....get about 150 minutes over the course of a week and I never thought of how much we should be doing. Now I'm more conscious of "Did I get in 30 minutes today?" [P44]

The programmes were facilitated either in the morning and afternoon midweek. One participant who was working while attending the programme, found this difficult;

'Just the timing but only for me cause I work' [P10]

Some participants took unpaid and annual leave from their work in order to attend;

'I got unpaid leave' [P48]

'I had to use three days holidays which is big for me because I've two children that I need all my holidays for around their time so it was kind of like, something for yourself' [P36]

Resources were provided to the intervention group including a handbook containing information discussed over the six-week programme. Immediately post-intervention, participants identified the handbook as a valuable resource:

'It's like a little Bible' [P10]

'It's good to have it if you're saying "What was that?" just to go back and have a look' [P5]

However at the three month follow-up, the majority of participants reported that they did not refer to the handbook as often as during the six-week programme but was still available to access if needed:

'I do think about what's in the booklet...I've put it away but it's accessible' [P48]

'I know where it is though...I picked it up a few months ago, I remember there was something in it, it might have been the physio thing and I picked it up. I do know where it is, I didn't bin it' [P44]

Goal Setting

Each week participants were facilitated to set goals related to weekly content which were reviewed the following week. The goal setting element was positively received post-intervention. It encouraged participants to plan specific goals:

'I'll set the plan, Is it going to help? What obstacles are in the way? What's going to help them? What's going to hinder?" It really made you plan, whether it was the shopping for the week..."Well I need to get more fish this time, more veg" ' [P13]

One participant, post-intervention, described how goal-setting helped plan their preparation for a five kilometre race;

'The goal is to do a 5k run and you actually plan it rather than saying "I'll run this week and that week". You put in your goal, how often you're doing it, when you're doing it, how you're doing it, plan everything out so it makes it more defined rather than a thought in your head' [P63]

In the post-intervention focus groups, some participants discussed the motivation that goal setting provided and how it became part of their daily routine;

'Having to set goals, you actually see the results of those goals, like we were doing...how to strengthen the muscles in your legs or whatever. You can see the results of those over a period of time' [P37]

'I felt that once I had written it down I had committed to it and I don't know if it was because I viewed it like homework and I had to do it. Suddenly without even thinking about it, I was finding that it was becoming part of my routine' [P58]

At the three month follow-up, some participants continued to utilise goal setting and subsequent achievement of goals:

'I kept doing it. I was thinking "Okay I am going to try go out walking on my own and I will go out two times this week". You don't think you can do it but if you have it in black and white, I think that helps' [P53]

'I got the spare room cleared out, that was a goal of mine, there was loads of stuff in there. It was a huge deal and took us all day. It gave me a kick in the backside and helped me move on and that came out of this group' [P6]

'One of my goals was that I wanted to stop becoming a Yes person....well I've kept up saying No. I am very proud of myself' [P15]

One participant identified not setting any new goals but instead focused on sustaining goals previously set during the six weeks:

'Not anymore...I'm just doing them now' [P71]

Timing of the Intervention

Participants were asked on the ideal time the programme should be provided, with most reporting within the first year post-treatment, in particular between three to six months:

'After three months. The first three months you're not able..you're sick and tired' [P39]

'Three months would be nice, because you'd be on sick leave from work still' [P10]

'I think six months is a good time for these kinds of groups for people that are over all their treatment and on the step back up again. It would be extremely beneficial' [P37]

'I think if you're too tired you just won't absorb it or you won't read the literature that you're given, you're kind of 'Oh I'm too tired'. Whereas six months to within the year, you've more of an ability to take it on board' [P44]

Recommendations

Some participants recommended additional topics. One participant with breast cancer suggested sessions around sexuality and relationships;

'I suppose two elements of it, number one, was your breasts, there's the sexuality element of that and secondly your relationship at home. You're living with someone and they have expectations of the woman you were beforehand and you're trying to explain and communicate that to your partner. It is quite difficult.' [P10]

Another participant suggested that family members attend:

'I think all of our families should have come with us' [P48]

Suggestions were made around developing some sessions further in the current programme;

'Even with like stress management, maybe incorporate an hour or half hour, to show you how to breathe properly' [29]

'I thought it might have been helpful for people who wouldn't be as into nutrition or diet to maybe have a few meal planners or sample menus' [P36]

The option of a web-based intervention was proposed to participants however many discussed the benefits of the group interaction component, for example;

'I think the computer side is impersonal almost. I think to me personally, it's the bits that are said that are not on the document that are interesting' [P47]

'The main part is the interacting with others in the group' [P42]

5.7 Discussion

OptiMal was found to significantly reduce anxiety levels and increase quality of life in cancer survivors three months after implementation. However, there were no statistically significant differences in the primary outcome measure of activity participation, nor in the secondary measures of fatigue, depression, cognition, perception and satisfaction of occupational performance. This section discusses the meaning of the findings in relation to the primary and secondary outcome measures, and in the context of the qualitative research.

5.7.1 Demographics

The majority of participants recruited into the randomised controlled trial were female breast cancer survivors. As reported in the systematic review in chapter three, most self-management interventions recruited breast cancer survivors (Boland et al., 2018). Previous authors of self-management interventions attributed this to the high prevalence of breast cancer amongst women and high survival rates (Mishel et al., 2005; Lee et al., 2014). Breast cancer survivors tend to utilise healthcare services more frequently compared to other cancer types (van de Poll-Franse, Mols, Vingerhoets, Voogd, Roumen & Coeburgh et al., 2006). In Northern Ireland, Treanor, Santin, Mills and Donnelly, (2013) concluded that survivors who reported long-term effects from treatment were more likely to utilise healthcare services such as primary and hospital care due to increased needs. In their study, breast cancer survivors were also the largest cancer type recruited followed by prostate cancer survivors (Treanor et al., 2013). Female cancer survivors can be more interested in seeking information particularly when they learn that suitable information is available and accessible (Mishel et al., 2005).

A small number of male cancer survivors were recruited into the study. Out of the 26 participants who attended OptiMal, three were male. The slow uptake of self-management programmes by men has been highlighted previously. In their systematic review of qualitative studies evaluating men's experiences of self-management, Galdas Darwin, Kidd, Blickem, McPherson and Hunt et al., (2014) reported that men are reluctant to engage in interventions that 'challenge' their masculine identity. Similarly, Zanchetta, Maheu, Kolisnyk, Mohamed, Sepali and Kinslikh et al., (2017) reported that chronic conditions can threaten men's masculinity and their perceived ability to fulfil roles. Self-management interventions should provide an opportunity for peer learning and are action-orientated thus providing men with practical strategies to manage chronic conditions (Galdas et al., 2014). Goal-setting is a key component of the OptiMal programme as participants are facilitated to set goals incorporating the self-management strategies into their daily routines. OptiMal consisted of groups with mixed cancer diagnoses however male participants who attended the programme reported benefit from meeting survivors regardless of cancer diagnoses or gender. Future research should evaluate men's perceptions of self-management and methods to encourage their recruitment into interventions. Future research should also explore alternative methods to increase recruitment into research studies. Participants in this study were recruited from outpatient clinics in an acute but also from a cancer support service nearby. However, recruitment from the cancer support service commenced at a later stage of the recruitment process and has been acknowledged as a limitation in section 5.8.

5.7.2 Activity Participation

Frequency of activity participation increased for both the control and intervention groups, with the intervention group showing greater improvements, however these improvements were not statistically significant. Based on the qualitative findings, participants utilised self-management strategies such as pacing to engage in activities. As a result, participants reported increasing their participation in activities including returning to employment, college and increased exercise. In previous studies of OptiMal, significant differences have been observed in activity participation (O'Toole et al., 2013; Garvey et al., 2015). However, these previous studies were conducted with individuals with multimorbidity. The mean age of participants in O'Toole et al., (2013) and Garvey et al., (2015) studies were 66 years. However, the mean age of cancer survivors in the control and intervention group of the mixed-methods study conducted as part of this research, were 50.4 and 51.68 years respectively. Multimorbidity is associated with older age (St Sauver et al., 2015). Perhaps individuals with multimorbidity experience lower activity participation levels at their baseline as they are acquiring morbidities at a later age, compared to cancer survivors at their baseline.

The FAI was chosen as the primary outcome measure to evaluate the frequency of participation in daily activities such as leisure, social and housework, in cancer survivors. However, survivors may not participate in these activities as they are not of importance to them rather than as a consequence of post-treatment symptoms. This may have contributed to the non-statistically significant result of the quantitative findings. Therefore, further research should consider alternative outcome measures that captures survivors' participation in activities of importance to them.

The majority of participants in the mixed-methods study were one year post-treatment. Fleischer and Howell (2017) interviewed breast cancer survivors six months post-treatment and found that participants had already developed their own self-management strategies to manage persisting symptoms which in turn increased their activity participation. Perhaps over time, cancer survivors have learned to adjust their activities in order to manage post-treatment symptoms thereby improving their ability to engage in them (Lyons, Lambert, Stefan, Hegel & Bartels, 2013). Focus groups were not conducted with participants in the control group to explore their management of symptoms and subsequent participation in activities. Survivors who declined to participate in the mixed-methods study were interviewed to explore how they managed their post-cancer needs including their participation in activities. This will be discussed in the following chapter.

5.7.3 Fatigue

In the focus groups with participants who attended OptiMal, survivors reported finding the transition from treatment to survivorship difficult due to persisting symptoms such as fatigue. Participants in this study identified fatigue as the most frequent difficulty that impacted on their occupational participation and quality of life. This is reflective of the literature (Silver & Gilchrist, 2011; Shneerson et al., 2015). Participants discussed how they lacked guidance to develop strategies and relied on follow-up appointments with their medical teams. Lack of information on how to manage symptoms such as fatigue is a commonly unmet supportive care need of cancer survivors (Dilworth et al., 2014).

In this study, participants reported increased understanding from the self-management education on fatigue provided in the OptiMal programme. Survivors reported increased awareness of their energy levels following OptiMal and benefitted from implementing strategies such as planning and pacing into their daily activities to manage fatigue. This was not reflected in the quantitative data as no significant differences were observed between the control and intervention group at three months follow-up. However, at the three months follow-up, participants in the OptiMal programme were observed to have a higher quality of life due to lower levels of fatigue, as indicated by the FACIT-F scores, compared to their baseline. The control group were observed to have a lower quality of life due to higher levels of fatigue at three months follow-up compared to their baseline scores.

The lack of significance may be attributed to the FACIT-F not being sensitive enough to measure the severity and impact of fatigue on daily activities but also the low power to detect an effect. The FACIT-F was originally chosen as it is a fatigue-specific assessment measuring mental and physical fatigue in individuals with chronic illnesses (Yellen et al., 1997). Previous self-management support interventions for cancer survivors have reported statistically significant improvements in fatigue (Lee et al., 2014; van den Berg et al., 2015). Fatigue outcome measures in these studies included the Brief Fatigue Inventory (Mendoza, Wang, Cleeland, Morrissey, Johnson & Wendt et al., 1999) and the Checklist Individual Strength-fatigue subscale (Gielissend, Verhagen, Witjes & Bleijenberg, 2006). Perhaps, these measures may be more appropriate for this mixed method study. Additionally, a multidimensional measure such as the Multidimensional Fatigue Inventory (MFI) could also be considered appropriate as it is a more comprehensive assessment of fatigue for cancer patients (Jacobsen, 2004). This 20-item questionnaire evaluates dimensions related to fatigue including general, physical

and mental fatigue, reduced motivation and activity and has been previously tested with cancer patients (Smets, Garssen, Bonke & De Haes, 1995).

5.7.4 Cognition

Cognitive difficulties post-treatment, such as decreased concentration, were widely reported by participants in the mixed-methods study but no significant differences were observed between the control and intervention group at the three months follow-up. Based on the qualitative findings from this current study, participants who attended OptiMal reported difficulties with concentration and information retrieval. Ahles and Root (2018) reported that cognitive difficulties in cancer survivors may be attributed to deficits in attention which in turn affect the registration, encoding and retrieval of information into memory. At present, there is no standardised approach to measure self-reported cognitive difficulties in cancer survivors (Bray, Dhillon & Vardy, 2018). However, based on the qualitative findings, the Cognitive Failures Questionnaire (CFQ) may not have been appropriate as it does not measure attention. The CFQ, as reported in section 4.7.4, measures self-reported failures in perception, memory and motor functioning (Broadbent et al., 1982). It may have been appropriate to use a measure that examines attention as survivors reported this as their main difficulty. The Attentional Function Index may be suitable as it measures levels of perceived difficulties with cognitive activities requiring attention (Cimprich, Visovatti & Ronis, 2011). This measure has been used previously with cancer patients and survivors. Both patients and survivors have previously reported their capacity to direct attention as poor thereby affecting their everyday functioning (Cimprich et al., 2005; Von Ah, Russell, Storniolo & Carpenter, 2009; Cimprich et al., 2011).

Previous evidence supports the use of neuropsychological measures to objectively measure cognition alongside self-reporting cognitive measures, as cancer survivors can report greater cognitive difficulties compared to an objective assessment (Muzzatti, Giovannini, Flabian, Cattaruzza & Annunziata, 2017). It is important to note that in the qualitative findings, participants reported increased understanding of symptoms that contributed to cognitive difficulties post-treatment, such as fatigue and anxiety. Player et al., (2014) discussed how survivors attributed the cause of cognitive difficulties to other symptoms such as stress and implemented strategies to manage stress, in order to improve their concentration. A recent systematic review found that self-reported cognitive difficulties are strongly associated with other self-reported outcomes including fatigue, anxiety and depression (Bray et al., 2018). In our study, some participants implemented fatigue and stress management strategies such as energy conservation

and exercise to manage these symptoms which in turn may have helped manage cognitive difficulties.

5.7.5 Mood and Quality of Life

Changes in anxiety levels differed significantly between the control and intervention group after three months follow-up. However, no statistically significant differences were observed in depression levels between the control and intervention group at three months follow-up. Participants who attended OptiMal reported how self-management education regarding their persisting symptoms of fatigue and cognitive difficulties alleviated feelings of anxiety and stress. Howell et al., (2017) reported that increased understanding and self-management education may be beneficial for relieving symptoms of anxiety and depression which is consistent with findings from previous studies. For instance, Loh et al., (2012) reported that a four-week self-management intervention facilitated by occupational therapists, significantly reduced anxiety, depression and stress levels in recently diagnosed breast cancer patients. The authors concluded that self-management education empowered individuals to become proactive in managing their symptoms such as utilising relaxation strategies to reduce distress levels (Loh et al., 2012). Deimling et al., (2006) reported that cancer-related health worries such as cancer recurrence were a significant predictor of anxiety and depression in survivors. In this current study, survivors discussed feeling isolated due to their symptoms, however, since attending OptiMal, the combination of education and support from fellow survivors validated their symptoms. Psychological distress is considered a determinant of health-related quality of life (Marengoni, Angleman, Melis, Mangialasche, Karp & Garmen et al., 2011). Therefore, self-management education and strategies provided in the OptiMal programme may have reduced anxiety levels, thus, improving the health-related quality of life of participants. The EQ-5D was chosen to measure quality of life in cancer survivors in this study. Although this measure did report statistically significant results, future research should consider the inclusion of additional quality of life measures specific to cancer patients such as the EORTC-QLQ-C30 and FACT-General.

5.7.6 Self-Efficacy

No statistically significant differences were observed in self-efficacy between the intervention and control group at three months follow-up compared to their baseline. However, the intervention group continued to improve over the three timepoints. Self-efficacy is considered an important component of self-management interventions as it increases cancer survivors' confidence to manage post-treatment symptoms thus improving their health and wellbeing (Foster & Fenlon, 2011; Foster et al., 2016). This in

turn increases the adaptation of behavioural changes as outlined by Bandura's Social Cognitive Theory (Bandura, 1977). Van den Berg et al., (2015) self-management intervention reported statistically significant improvements in general self-efficacy. However, no significant findings were reported in self-efficacy which may be reflective of the lack of statistical significance in the primary outcome measure used in this study. As discussed in section 5.7.2, the majority of participants were one year post-treatment. Perhaps, as survivors' participation in their daily activities increase so does their self-efficacy. Previous studies of self-management interventions have reported non-significant results in self-efficacy. For example, Foster et al., (2016) reported near-significant improvements in fatigue self-efficacy as a result of their self-management intervention.

Despite non-significant results, qualitative findings in our study suggest that participants reported increased confidence in managing their symptoms. For instance, participants developed a positive attitude towards their symptom management, describing it as a 'new normal'. This is a term frequently used by cancer survivors to describe life post-treatment (Shannonhouse. Myers, Barden, Clarke, Weimann & Forti et al., 2014). Participants reported that because of the self-management education and strategies, they were now aware of strategies to manage fatigue. Energy conservation techniques were implemented such as planning and pacing at home and in the workplace. This is reflective of Lorig and Holman's (2003) recommendations that individuals should be provided with information on how to interpret their symptoms which in turn increases their self-efficacy to manage their symptoms. Participants also utilised goal-setting to encourage behavioural changes such as increased exercise in their daily routine. The development of positive self-efficacy comes with repeated successes of implementing new behaviours over time, as reflected in Bandura's Social Cognitive Theory (Bandura, 1977). By using goal-setting, it appears that participants could implement self-management skills into their daily and weekly routine thus implementing positive changes in their behaviour. Additionally, Schjolberg et al., (2014) reported that increased understanding of symptoms and self-management skills can alleviate feelings of stress and guilt, easing the transition from treatment to survivorship, as reflected in this mixed-methods study.

5.7.7 Perceptions of OptiMal

Overall, participants' perception of the OptiMal programme was positive. Participants identified benefits of attending the programme including the presence of members of the multidisciplinary team, group support and goal-setting. The involvement of other health

professionals such as physiotherapy and dietetics was appreciated by participants. Exercise and diet are common concerns of cancer survivors post-treatment (Blacklock et al., 2010; Anderson et al., 2013; Buffart et al., 2014). The group format of OptiMal may have facilitated mechanisms that encouraged changes in health behaviours. Peer learning and validation of symptoms may have relieved feelings of anxiety among participants in the intervention. This key element of group support helps overcome social isolation by legitimising survivors' experiences (Weis, 2008; Harrison, Fullwood, Bower, Kennedy, Rogers & Reeves, 2011). In previous studies of OptiMal, the group-based structure was considered by participants to be a valued element of the programme (O'Toole et al., 2013; Garvey et al., 2015). Participants of OptiMal felt isolated and unsupported regarding the management of their symptoms. Group support allowed survivors to learn from each other and act as models for encouraging self-management behaviours. Participants in the OptiMal programme felt validated when other participants reported similar symptoms or viewed others in worse health than themselves or perceived others to be managing well despite their difficulties. This may have provided motivation for participants to learn to manage their own symptoms and needs thus promoting changes in health behaviours.

Group support can promote quality of life by encouraging the formation of health and wellbeing in cancer survivors through the adaption of positive behavioural changes (Hodges & Winstanley, 2012). Group interventions have been reported to alleviate feelings of anxiety in cancer patients. In a qualitative study of ovarian cancer patients, the authors found the exchange of informational and emotional support reduced feelings of anxiety and created a sense of connection between the group members (Ahlberg & Nordner, 2006). Both the quantitative and qualitative findings from the mixed-methods study support this. Group interventions can address cancer-related issues by allowing individuals to gain emotional support from others with similar experiences (Weis, 2008), as reflected in this current study. The provision of group supports post-treatment may lead to the development of better coping strategies thus improving the quality of life of survivors (Zucca, Boyes, Lecathelinais & Girgis, 2010). Interestingly, the option of using a web-based intervention was discussed with OptiMal participants however, the absence of group support was considered a disadvantage. Similarly, in Breau and Norman's (2003) study of prostate cancer patients, participants reported that group support provided better emotional support and coping skills than websites or books. Against the backdrop of improvements in technology to access information, group support may be a key mechanism in encouraging changes in health behaviours (Weis, 2008).

Participants who attended OptiMal discussed their difficulties communicating the impact of their persisting symptoms. This resulted in survivors feeling anxious and isolated which can affect quality of life (Michael et al., 2002; Piškur, 2013; Thraen-Borowski et al., 2013). Twenty-six people attended the OptiMal programme. The majority of participants attended all six sessions. No participants attended less than three sessions. Participants in the programme took unpaid or annual leave to attend the programme. Therefore, relatively good attendance rates in the OptiMal programme may be attributed to the need of cancer survivors for group support and education regarding self-management of post-treatment symptoms. For their web-based self-management intervention, Foster et al., (2016) also reported a high uptake for their study, with the authors suggesting that there is a demand from survivors for self-management resources. May et al., (2009) reported high attendance rates throughout their twelve-week self-management intervention for cancer survivors.

Along with group support, goal-setting was identified by participants of OptiMal as an important mechanism for positive self-management, as it increased survivors' motivation to incorporate self-management education and skills into their daily and weekly routines. Each session of the OptiMal programme included goal-setting, which is identified as a vital component of self-management interventions (Lorig & Holman, 2003). Goal-setting is considered an important element in encouraging individuals to incorporate self-management education received into their daily occupations thus promoting behavioural changes (Forrest, 2011). Goal-setting appears to be a consistent component in self-management interventions for cancer survivors, as reported in the systematic review published as part of this study (Boland et al., 2018). Lyons et al., (2006) reported that individuals with cancer can express their goals in occupation-based terms by describing their desire to return to certain activities that fulfil meaningful roles. In this study, participants were facilitated to set weekly occupation-focused goals which is reflective of the holistic perspective of occupational therapy practice (Crepeau et al., 2009).

Individuals with cancer can also gauge their quality of life through engagement in activities of importance to them (Lyons et al., 2006). Goal-setting provides control and choice which influences quality of life as it empowers individuals to engage in meaningful activities (Hammell, 2004). As a result, it is considered a core component of behavioural change (Harrison et al., 2011). The qualitative data from the mixed-methods study suggests that goal-setting facilitated engagement in behavioural changes. Goals set by participants in OptiMal included returning to work and college, incorporating exercise into their daily routine, making changes to their diet and returning to daily activities such as

maintaining their home environment. In this study, the engagement and achievement of occupation-based goals created a sense of accomplishment for participants of the OptiMal programme which could have resulted in the statistically significant improvements in their health-related quality of life. In previous research, cancer survivors have identified that returning to their daily routine can help maintain control and stability, develop a sense of self-worth and enhance self-development (Palmadottir, 2010). In previous studies of OptiMal, goal-setting was viewed as a source of motivation and an effective mechanism to enforce self-management strategies (O'Toole et al., 2013; Garvey et al., 2015). By empowering individuals through control and choice, this increases the likelihood of the adoption of positive behavioural changes thus promoting self-management. This is reflective of current cancer survivorship policies advocating self-management in survivorship such as the National Cancer Strategy 2017-2026, as outlined in section 2.4 (DOH, 2017).

5.8 Strengths and Limitations

This study is the first of its type in Ireland to explore the effectiveness of OptiMal, an occupation-based, self-management support intervention for cancer survivors of mixed diagnoses. There are some limitations to this study. The main limitation is the small sample size. The aim of an exploratory trial is to determine its feasibility and acceptability to cancer survivors. Power calculations, indicated that approximately 154 participants were required to ensure sufficient power to detect a significant effect change in the primary outcome measure (FAI). Despite the small sample size, statistically significant differences were reported in anxiety and quality of life outcome measures. However, future research is required to explore the effectiveness and sustainability of OptiMal programme with a larger number of mixed cancer survivors, provided earlier post-treatment.

Recruitment was slow and difficulties were encountered in the recruitment process. Medical teams were consistently reminded regarding the provision of the PIL at outpatient clinics by the researcher who also attended these clinics. However, survivors suitable for inclusion were not always provided with the PIL. Future studies should consider how best to increase the rate of recruitment. This may include attending multidisciplinary meetings or medical team meetings to remind staff of the study. Recruitment also took place in a cancer support service located nearby, however this commenced later in the recruitment stage. It may have been more beneficial to have liaised with this service at an earlier stage regarding recruitment in order to increase

sample size. Cancer survivors also declined to participate in the study and further reasons for this will be explored in the following chapter.

A key limitation of this study is that a pilot of the adapted OptiMal programme was not conducted; mainly because pilots of the original programme were carried out in 2013 and 2015 (O'Toole et al., 2013; Garvey et al., 2015). Both of the aforementioned studies demonstrated statistically significant improvements in areas such as activity participation, therefore it was deemed that a pilot was unnecessary. However, it is important to note these previous studies were conducted with individuals with multimorbidity. The aim of this current study was to determine the effectiveness and sustainability of OptiMal programme in a sample of adult cancer survivors and compare with a control group of adult cancer survivors who had all completed treatment within three months and up to two years. A mixed-methods study incorporating an exploratory RCT and focus groups was considered an appropriate method to achieving the aim of evaluating a complex intervention, as recommended by the MRC (2008). However, it may have been beneficial if a pilot had been conducted with the adapted OptiMal programme in an acute setting. Nevertheless, statistically significant improvements were reported in this mixed-methods study.

In addition to the systematic review, it may have been beneficial to conduct interviews with cancer survivors and healthcare professionals prior to conducting the mixed-methods study. This is recommended in the MRC framework (2008). This would have contributed to building a broader knowledge base regarding the suitability of the content of the OptiMal programme for cancer survivors. Nevertheless, survivors who attended OptiMal reported finding the content useful and beneficial.

With regards to the randomisation allocation procedure, a computer-generated randomisation sequence was used to randomise participants to the control and intervention groups. This was created when sufficient participants were recruited to run OptiMal and initial assessments completed. The researcher then informed participants of their allocation. There was a low risk of bias associated with the researcher's role in this process however it is a limitation to this study. If greater resources were available in the study, it may have been more appropriate for an independent person to generate the randomisation sequence and inform participants of their allocation in order to ensure complete transparency of the allocation process. Another limitation is that the researcher facilitated the OptiMal programme. However, a second facilitator was involved in delivering the programme in order to reduce the influence of the researcher.

Three months follow-up can be considered a relatively short period of time as a longer follow-up period time may provide greater insight into the sustainability of OptiMal. The focus groups were facilitated by an independent researcher post-intervention. However, at the three month follow-up, six participants were unable to attend the focus-group, therefore the researcher conducted the semi-structured interview, which may be considered a source of bias.

As discussed above, some of the measures used in the exploratory RCT were deemed unsuitable in particular the fatigue and cognitive outcome measures. Measures that were previously tested with cancer patients and survivors were chosen. However, following quantitative analysis and qualitative data obtained from participants of OptiMal, these measures may not have been sensitive enough to measure the exact impact of the OptiMal programme on these outcomes. This supports the benefit of utilising a mixed-methods study. The aim of an exploratory RCT and process evaluation is to identify weaknesses in the testing procedures, possible refinements and the acceptability of a complex intervention in preparation for the definitive trial (MRC, 2008). Alternative outcome measures have been proposed as described above. Further research is required to confirm their suitability with cancer survivors.

5.9 Conclusion

In this study, cancer survivors reported that persisting symptoms post-treatment impacted on their activity participation. Cancer survivors are encouraged to self-manage their health, however many are unaware of how to do this resulting in feelings of isolation and distress. As a result, cancer survivors reported a need for follow-up care after finishing treatment. OptiMal, an occupation-based, self-management intervention did not improve the activity participation of cancer survivors. However, it did reduce anxiety levels and improve the quality of life of cancer survivors who also considered it an acceptable intervention. The OptiMal programme appears to offer sustained benefits to participants through validating the presence of persisting symptoms and acquiring strategies to manage symptoms in daily activities. It empowered survivors with self-management knowledge and skills to assist with the transition from cancer treatment to survivorship.

As discussed previously, recruitment to the mixed method study was slow. Therefore, an additional study was conducted to explore reasons for cancer survivors to decline participation in the mixed-methods study.

6. Qualitative Evaluation of Non-Responders

6.1 Introduction

The purpose of this study was to explore reasons for declining to participate in the mixed-methods study in those who did not participate.

Self-management interventions have been associated with low uptake and high attrition rates in research and clinical practices (Boger, Ellis, Latter, Foster, Kennedy, Jones et al., 2015). Possible reasons include that self-management does not reflect the needs of all stakeholders and is not applicable to their everyday lives (Boger et al., 2015). In a systematic review by Coffey et al., (2016) cancer survivors reported not needing self-management interventions as they were receiving enough support from family and friends and were managing their condition successfully. The authors recommended that process evaluations of self-management interventions should explore reasons for non-participation in self-management interventions and explore barriers to engagement (Coffey et al., 2016). This in turn may assist healthcare professionals to tailor interventions to the needs of the individual (Trappenburg, Jonkman, Jaarsma, van Os-Medendorp, Kort, & de Wit, et al., 2013).

As part of this current study, qualitative data were gathered through semi-structured interviews. The aim of these interviews was to explore reasons for declining to participate in the mixed-methods study of a self-management intervention.

6.2 Methods

6.2.1 Study Design

A qualitative descriptive design as described by Sandelowski (2000), was chosen to address the aims of this study. Qualitative description aims to provide a rich, straight description of an experience or event, as described in detail in section 4.11.2, (Neergaard et al., 2009). Semi-structured interviews were conducted with participants to allow for an in-depth exploration of a topic and are considered a versatile method of data collection (Fylan, 2005).

6.2.2 Recruitment

Individuals who originally declined to participate in the randomised controlled trial were sent an invitation letter to participate in a semi-structured interview (See Appendix J) in

January 2017, approximately six months after being first approached about the mixed-methods study. A participation information leaflet (PIL) was also enclosed explaining the purpose of the interview (See Appendix J). The contact details of the supervisor and the researcher were included so potential participants could contact them directly. The researcher provided an overview of the research study and asked participants if they would like to be involved in the study or prefer time to consider their participation or decline participation. If a participant expressed an interest in participating in the study, the researcher organised a meeting with the participant. Written consent was obtained before the interview began (Appendix J). Ethical permission was obtained from Saint James' Hospital/Adelaide and Meath Hospital incorporating the National Children's Hospital (SJH/AMNCH) Research Ethics Committee in October 2016, see Appendix K.

6.2.3 Data Collection

Qualitative data were collected through semi-structured interviews with participants who declined to participate in the randomised controlled trial. All interviews were conducted by the researcher, were recorded and downloaded onto a password-protected encrypted computer. Interviews were conducted using a guide focusing on exploring post-treatment experiences and reasons for declining to participate in the randomised controlled trial, see Appendix L for details.

6.2.4 Data Analysis

Thematic analysis, as described in section 4.11.2, was employed to analyse the data. Semi-structured interviews were conducted with cancer survivors which were then transcribed by the researcher to ensure familiarity with the data (Braun & Clarke, 2006).

6.3 Findings

Forty cancer survivors were invited to participate in this current study. The majority of participants declined to take part due to work commitments. Twelve cancer survivors consented to participate in semi-structured interviews. Time constraints of the thesis influenced the limiting of recruitment at 12 participants. Table 6-1 presents the characteristics of the 12 participants. Breast and gynaecological cancer were the most commonly occurring cancer. Interviews were conducted between February and October 2017. Despite several attempts to conduct interviews face-to-face, eleven interviews were conducted via telephone and one interview was conducted face-to-face in an acute hospital. Reasons for non-availability to conduct face-to-face interviews included work and inability to travel to the site of the study (acute hospital) therefore phone interviews were considered more suitable. The semi-structured interviews lasted from 15-45

minutes. The average duration of interviews was 25 minutes. The mean age of participants were 45.8 years (SD: 10). All twelve participants were employed and were two years finished cancer treatment including surgery, chemotherapy and radiotherapy. The majority of participants received at least two types of treatment.

Table 6-1 Participant Characteristics of Study III

Mean Age (SD)	45.83 (10.2)
Gender Female Male	N= 11 1
Type of Cancer Breast Other (including lymphoma, lung, melanoma, gynaecological	6 6
Time since Treatment 2 years	12
Employment Status Full-time	12

Following data analysis, three main themes emerged from the data analysis; 1) Post-treatment Experience 2) Management of Symptoms 3) Reasons for Declining Participation. See Figure 6-1.

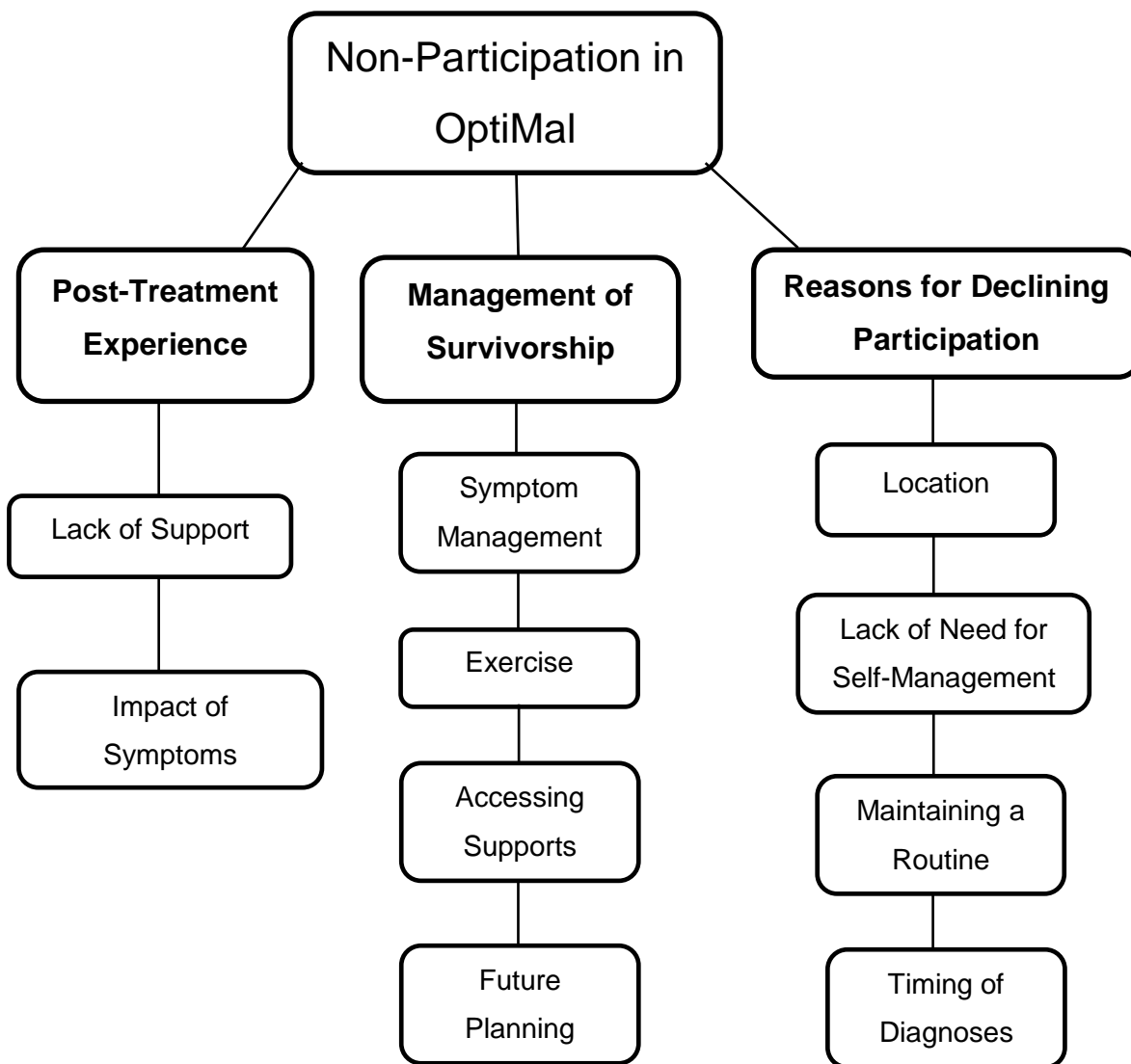


Figure 6-1. Visual Thematic Map of Data Analysis

1) Post-Treatment Experience

Similar to findings reported by survivors who attended OptiMal, participants also reported difficulties post-treatment including the absence of formal supports and the impact of continuing symptoms;

Lack of Support

One breast cancer survivor described a lack of formal support post-treatment and its subsequent impact;

'You come out of hospital and you're physically not feeling well and I was thinking "What do I do next? Where do I go to next?" ...there was really no one there for me at all' [P12]

Participants also reported how a lack of support left them feeling isolated and that their medical team were unsure regarding the next step;

‘It feels like there’s a lack of support, I do feel like they are not even sure where to send you next, you know? You really do feel like you’re out on your own’ [P9]

Impact of Symptoms

Similar to OptiMal attendees, participants also described the experience of symptoms post-treatment such as fatigue.

‘I would find myself probably more tired than I used to be. In the morning the energy levels are fine. Come the evening, three o’clock or four o’clock, I get very tired’ [P9]

‘I find that I have enough energy to walk for an hour but I couldn’t walk for another hour...there’s no kind of stamina or reserves there’ [P5]

Some participants also experienced cognitive difficulties post-treatment and its subsequent impact on daily activities;

‘It was very frustrating at times...I’d be talking to my husband about something I needed in the shop, and I couldn’t think of the name of it, “You know that thing that you put on the chips and it looks red?” ... instead of just saying tomato sauce. And then you have to keep asking the same question again because you forget the answer.... maybe it’s not even the memory, it’s the retention of the information’ [P2]

‘I used to know where everything was and now I’m kind of pulling things out looking for things’ [P4]

Participants also reported anxiety regarding the recurrence of their cancer. Survivors described feeling anxious particularly in advance of follow-up appointments;

‘If you get a slight pain or if you are going for the mammograms every year you are always really stressed out beforehand’ [P7]

‘I’m on my six month check-up now, it’s kind of in my head going “Oh God I’ve to go tomorrow, I hope everything’s okay” ... just little things like that’ [P10]

2) Management of Survivorship

Participants described managing symptoms using a variety of strategies including energy management, exercise and seeking out supports.

Symptom Management

Participants discussed how they developed their own strategies to manage post-treatment symptoms. Participants described implementing energy management strategies such as pacing and planning ahead to manage symptoms of fatigue:

'I get up and do a few things and kind of just say "I'll sit down for a few minutes" and then I'm back up again' [P4]

'I buy all my vegetables on a Wednesday. I go home, I parboil them, I put them all into freezer bags and into the freezer and my vegetables are there for the whole week' [P4]

One participant reported changing their employment routine to accommodate their energy levels:

'I did a little bit of work this morning and now that's it for the day' [P5]

Another participant benefitted from a phased return to work post-treatment:

'I went back part-time, I gradually built myself back into my job. I didn't want to jump into it and then have to come back out of work. I just did three days a week and then gradually four days and then I went to my five days' [P10]

Survivors discussed learning to manage symptoms of anxiety regarding the recurrence of their cancer:

'OK, could this be more than just a pain in my arm? Or a pain in my leg? I wouldn't be getting uptight about it, I wouldn't lose sleep about it, but that's just me, I know it doesn't work that way for everyone. I distract myself, it's always going to be there, the "Is it going to come back?" But I don't dwell on it...I don't give myself time to sit and think about it' [P2]

Another participant, two years post-treatment, described managing cognitive difficulties post-treatment and how this symptom began to resolve in recent months:

‘I didn’t really get frustrated with it, I just got more determined. For instance, if I was looking for somebody’s name, if I couldn’t think of it...it will come to me, I didn’t get stressed out about it...it might be three hours later that name would come. Eventually rather than waiting three hours, you were getting it straight off the bat and you weren’t getting as many episodes of not being able to remember something’ [P5]

Exercise

Several participants reported engaging in exercise post-treatment and how this helped manage symptoms such as fatigue;

‘After treatment, I started walking’ [P1]

‘What I found was the best way to beat the fatigue is to get up and walk and move’ [P2]

Participants remarked how their exercise tolerance improved post-treatment:

‘I got up and went walking. When I could only do two minutes, I did two minutes. If I could do 10 minutes, I did 10 minutes. Eventually I could do 20 minutes. It was only by doing it that you could increase it, so the sooner you get out and do it the better’ [P5]

Some participants made a conscious effort to incorporate exercise into their daily routine:

‘When I drop the kids to school, I walk the dog for a half an hour’ [P7]

‘I would walk and enjoy fitness classes. I would do stuff like that. I try and keep myself as occupied as possible’ [P9]

Accessing Supports

Many participants actively searched for further supports and attending other services including using the Internet to access information;

'I was Googling the side effects of Tamoxifen. And then, when I saw that people had memory loss, I was amazed, I was jumping around the kitchen, that day, because it wasn't just me [P2]

Some survivors attended the Daffodil Centre within the acute hospital to avail of information and found this beneficial;

'I just went along [to the Daffodil Centre] to see what they'd say but then I know other people wouldn't do that but the services are amazing' [P3]

One breast cancer survivor, when attending her general practitioner (GP) received information regarding a cancer support service;

'No, my own GP gave me the address for ARC' [P4]

Participants also reported how their family provided them with support:

'We've a good family, so it was easy, they were there for you, you could talk about it' [P11]

Participants remarked on receiving helpful information from meeting others while awaiting treatment:

'I talked an awful lot with other cancer patients, whether I'd be in a waiting room or in for radiation or chemo. I would get a lot of hints and tips from those people, and I didn't realise there was a thing called chemo-brain' [P5]

'You start meeting people and you're learning from other people sitting there, what she's going through, and I gave a few people tips of what I was doing' [P8]

Future Planning

Some participants spoke of refocusing their attention to the future since finishing treatment:

'I'm just looking to the future' [P1]

One participant offered to organise activities to provide support to individuals undergoing treatment:

‘I would love to...give sessions to ladies going through the same thing as well, and teach them a bit of crochet and how to manage the pain and anxiousness through it’ [P2]

The same participant also remarked on refocusing on activities of importance to them:

‘That’s another thing I would say as well, encourage people to do the things that they’ve been putting off for years. Like, meet that friend that you keep meaning to go for coffee with, or give that girl a ring that you keep saying...even write a list, say this is what you need to do’ [P2]

The idea of some future activities is still considered daunting as reported by one breast cancer survivor:

‘Well, the kids are on at me about going swimming. It’s just to get the confidence to put on the swimsuit and get in the pool. That would be one thing that I would love to get back to doing but I just feel at the moment I can’t’ [P7]

3) Reasons for Declining Participation

Participants identified several reasons for declining to participate in the mixed-methods study including location, lack of symptoms and lack of need to attend a self-management intervention.

Location

One participant, living on the outskirts of Dublin, reported that the expense of travelling to Dublin influenced her decision to participate in the mixed-methods study:

‘Well money always comes into it because it’s the cost of travelling over and back...like every time I go up to Dublin even for an appointment it costs me €50 to get up there and back between petrol and parking...you have to take all these things into consideration’ [P12]

Some participants identified a preference for programmes in their local area rather than in an acute hospital:

'It's always better to have a localised group going in the local area because there were a lot of time's I was too sick to travel' [P12]

'I wouldn't attend a group in the hospital, no. I kind of associate the hospital with my appointments and I like to be in and out as quick as possible. I'd like something close by, in the area' [P9]

Lack of Need for Self-Management

Many participants regarded cancer as no longer being part of their lives and therefore felt no need for a self-management intervention:

'In my head it's finished, I'm not thinking about cancer...I was sick and I'm fine now and that's it' [P1]

'No, no, I was very positive, I just considered myself cured. They took it [tumour] out, an illness that was treated and cured' [P6]

'If you let your positivity drop, you'll just drop with it. I think if you keep on top of that you're the better person and you're being positive through everything. It has an awful lot to do with attitude' [P8]

One participant remarked that upon reflection, they may have benefitted from meeting others in the programme upon finishing treatment:

'I think looking back now, had I met other women going through the same thing it would have been good for me but at the time [of recruitment] I didn't have an interest' [P7]

Maintaining a Routine

Many participants reported making slight adjustments to their daily routine throughout treatment to accommodate symptoms:

'I kept doing everything that I normally did. I still went to the gym, I still worked all the way through, wasn't doing my normal levels but I still continued. I kind of let it fit in with my life whereas I think other people would let it take over' [P3]

'It wasn't denial, it was just "OK, I have to go for this [treatment] on Monday but I will still go out on Friday night with my friends" [P6]

'I was feeling sorry for myself and I was like "Snap out of it" ... that's when I got up and I started doing things. I know I was tired but I still do little things I'd be doing around the house and that would keep my mind going' [P8]

Timing of Diagnoses

Participants considered that the timing of their diagnosis was crucial in determining the impact of continuing symptoms post-treatment. The majority of participants attributed their lack of symptoms to their early diagnosis and treatment;

'When they had done the surgery, they had taken everything and the radiation was just in case there were a few cells left that might have escaped, so because of that.... I didn't have a worry, mine was very easy, whereas for somebody, if the chemo's trying to shrink a tumour or something...I just think it's completely different' [P3]

'I was lucky enough to catch it really early, it was just keyhole surgery' [P11]

'I was just lucky to be caught on time. It was small in size the tumour itself and there were a lot of pre-cells' [P4]

'No, I just considered myself extremely lucky that it was discovered in the very early stages. I didn't have to go through the chemo and I felt extremely lucky that I just had to have the radiotherapy and the surgery. And that in itself made me very positive and I just felt very, very lucky' [P6]

6.4 Discussion

Participants of this current study reported experiencing continuing symptoms and difficulties managing these symptoms immediately post-treatment. Macmillan Cancer Support (2009) reported that the physical effects of cancer can occur at any time but particularly within the first year of finishing treatment. Previous studies advise the provision of self-management interventions within the first year of finishing treatment as it can assist with the transition from treatment to survivorship (McCorkle et al., 2011). Foster et al., (2016) evaluated a self-management intervention for survivors who have

finished treatment within five years. The authors concluded that providing the intervention closer to treatment completion would be of greater benefit to survivors. Findings from this current study suggest that cancer survivors experience continuing symptoms post-treatment and over time develop their own self-management strategies, in order to return to their daily activities. However, if self-management interventions such as OptiMal were provided earlier post-treatment, survivors could implement strategies to manage symptoms and thus buffer their impact on survivors' participation in daily activities.

Similar to those who participated in the mixed-methods study, most survivors in this qualitative study reported continuing symptoms post-treatment such as fatigue, anxiety and cognitive difficulties. These symptoms impacted upon daily activities and quality of life resulting in participants feeling isolated and frustrated. Participants discussed a lack of guidance in how to develop strategies including from their medical teams which is commonly reported by cancer survivors (Dilworth et al., 2014). As reported by Chou, Liu, Post and Hesse, (2011), survivors have previously accessed the Internet for information regarding post-treatment effects. However, this is not their preferred method of obtaining information which happens to be from their consultants. When this is unavailable, survivors then access the web (Chou et al., 2011). Researchers have highlighted that the quality of the information available online can vary and resources should be provided in face-to-face or written formats (Chou et al., 2011; Villarreal-Garza, Platas, Martinez-Cannon, Bargallo-Rocha, Aguiller-Gonzalez, Ortega-Leonard et al., 2017). OptiMal provides an opportunity for interaction with health professionals and fellow survivors while also providing reliable written information for survivors to refer to.

The majority of participants interviewed in this current study were two years post-treatment. Therefore, when invited to participate in the mixed-methods study, they had already developed their own strategies to manage post-treatment symptoms effectively. Coffey et al., (2016) reported in their qualitative meta-analysis of self-management interventions for cancer survivors, that individuals with chronic conditions often develop their own self-management strategies. In this current study, many participants reported devising their own self-management strategies and implementing these into their daily routine. Participants utilised energy management techniques such as pacing and planning ahead to manage symptoms such as fatigue. Participants also identified engaging in exercise which in turn improved fatigue levels. The impact of exercise on alleviating fatigue and other symptoms such as anxiety in cancer survivors is well-documented (Blacklock et al., 2010; Buffart, et al. 2014). These findings are reflected in

previous studies. Dunne, Mooney, Coffey, Sharp, Timmons and Desmond et al., (2017) interviewed head and neck cancer survivors, the majority of which were diagnosed within the last three years, to explore their self-management strategies. These survivors reported implementing strategies such as relaxation techniques to alleviate anxiety and fear of recurrence, implementing pacing techniques to manage fatigue and maintaining daily routines. Dunne et al., (2017) also referred to survivors' positive outlook or dispositional optimism regarding the management of post-treatment symptoms. Some participants accessed the Internet to gain information and support.

Coffey et al., (2016) contended that it should not be assumed that all survivors need to attend self-management support interventions. Previous studies have interviewed cancer patients who have declined to participate in self-management interventions. In this current study, some participants reported a lack of need for self-management as they considered their cancer to be 'over' or 'cured'. Many of these participants attributed their ability to manage due to the early diagnosis of their cancer and subsequent treatments. In their study, Chambers, Morris, Clutton, Foley, Giles and Schofield et al., (2015) interviewed lung cancer patients who did not participate in a cognitive-behavioural intervention. Participants reported not needing the intervention as they were managing their symptoms successfully and had good supports, such as family and friends, in place (Chambers et al. 2015).

Several factors may influence well-being in cancer survivorship including resilience, optimism, social support, coping responses, health locus of control which refers to an individuals' belief of being in control of their health and well-being and cancer worry (Hodges & Winstanley, 2012; Molina et al., 2014). In their study, Hodges and Winstanley (2012) reported that optimism, social support and fighting spirit had a significant influence on positive affect in cancer survivors. An internal health locus of control can also influence optimism in cancer survivorship (Hodges & Winstanley, 2012). Naus, Price and Peter, (2005) reported that an internal health locus of control was positively associated with low anxiety and wellbeing and predicted lower levels of depression in breast cancer survivors. In head and neck cancer survivors, high levels of optimism were associated with lower levels of distress six-eight months post-treatment (Llewellyn et al., 2008). Survivors who demonstrated high levels of optimism are more likely to actively seek or maintain social supports thereby maintaining a positive mood and protecting against negative psychological effects (Llewellyn et al., 2008; Mathews & Cook, 2009). In this current study, participants reported receiving adequate support from family and friends following treatment. Other participants reported actively seeking out supports. For

instance, some participants took the opportunity to discuss their symptoms with fellow cancer survivors while attending treatment or outpatient clinics. Participants found this helpful as they learned information regarding symptoms and strategies other survivors were implementing. Peer support is considered a key element of the OptiMal programme. Group-based, self-management interventions such as OptiMal, provide an opportunity for survivors to meet and learn from fellow survivors. Group support can alleviate feelings of social isolation which participants in this current study reported experiencing upon finishing treatment. Increasing post-treatment social supports can in turn result in cancer survivors adopting positive coping strategies (Zucca et al., 2010). Researchers suggest the importance of identifying people with low social supports and referring to relevant supportive care services (Zucca et al., 2010).

There is an increasing need to address the emotional impact of cancer post-treatment as physical issues are more widely discussed in survivorship than psychosocial issues (Foster et al., 2009; Boland et al., 2018). Interventions have been developed to improve optimism in cancer patients. Lee, Robin-Cohen, Edgar, Laizner, and Gagnon, (2006) evaluated an intervention which reported significant improvements in optimism in newly diagnosed breast and colorectal cancer patients. This intervention by Lee et al., (2006) consisted of four individualised sessions that helped guide participants to review their cancer experience in the context of other life events and to reflect on their own coping strategies. Interventions to improve optimism could be introduced during cancer treatment which may improve resilience in cancer survivors and assist with the transition to survivorship (Hodges & Winstanley, 2012; Molina, Yi, Martinez-Gutierraz, Reding, Yi-Frazier & Rosenberg, 2014). Research suggests that interventions to improve resilience in cancer patients should incorporate stress management techniques, coping skills, goal-setting and positive communication with health professionals, components that are present in the OptiMal programme (Molina et al., 2014; Garvey et al., 2015).

Contextual factors were also reasons for non-participation in the OptiMal programme including its location in an acute hospital and access issues including parking. This has been reported previously. Participants in the Risendal, Dwyer, Seidel, Lorig, Katzenmeyer and Coombs et al., (2013) study reported that the location including parking and commute time were important considerations for attending their self-management intervention. Hardcastle, Maxwell-Smith, Kamarova, Lamb, Millar and Cohen, (2018) reported similar issues regarding access and timing in their exploration of cancer survivors' non-participation in an exercise programme. In this current study, some participants reported preferring to attend programmes in their local area.

6.5 Strengths and Limitations

A strength of this study was to recruit twelve participants from a hard-to-reach population of cancer survivors who had already declined to participate in the mixed-methods study. Limitations have been identified in this study. Findings cannot be generalised from this study to cancer survivors who decline self-management support interventions based on twelve interviews. The majority of semi-structured interviews were conducted via telephone which can impede the development of rapport and interpretation of non-verbal responses which are considered a strength of face-to-face interviewing.

6.6 Conclusion

The aim of this current study was to explore reasons for cancer survivors declining to participate in a self-management intervention. Some survivors reported experiencing continuing symptoms post-treatment but developed their own self-management strategies such as fatigue management or actively seeking out supports to manage symptoms. Other survivors described symptoms as having a minimal impact on their daily activities which they attributed to their early diagnoses and treatments. Optimism, well-being and social support post-treatment may build survivors resilience post-treatment and ability to manage post-treatment symptoms. Further research is required to identify those in need of self-management support post-cancer treatment.

7. Discussion

7.1 Introduction

The overall aim of this research study was to evaluate the effectiveness and sustainability of OptiMal as a self-management intervention for cancer survivors. Three separate studies were undertaken as part of this research study. This chapter will provide an overall discussion of the results from the three studies. A systematic review of self-management interventions carried out with cancer survivors resulted in a variety of self-management interventions with differing content and modes of delivery. The mixed-methods study identified that OptiMal did not significantly change the primary outcome of activity participation but it did significantly reduce anxiety levels and improve the quality of life of cancer survivors. However, the cancer survivors who declined to participate in the mixed-methods study reported developing their own self-management strategies or that they did not require a self-management support intervention.

7.2 Persisting Symptoms

Cancer survivors who attended OptiMal and those who declined to participate both reported experiencing post-treatment symptoms including fatigue, pain, cognitive difficulties and anxiety. In both studies, participants described the impact of these symptoms on their activities including employment and family life and their subsequent quality of life. This is reflective of the literature (Silver & Gilchrist, 2011; Aaronson et al., 2014; Shneerson et al., 2015). Breast cancer survivors six months' post-treatment identified fatigue as the most important factor preventing their re-engagement in activities (Fleischer & Howell, 2017). In this current research study, the majority of survivors in the mixed-methods study were less than one year post-treatment while survivors who declined were mostly two years' post-treatment. This suggests that survivors are experiencing these symptoms up to at least two years after finishing treatment. According to previous research studies, survivors can experience continuing symptoms beyond two years. Foster et al., (2009) conducted a systematic review of studies evaluating the impact of treatment on survivors. In this review, all studies included individuals who were diagnosed greater than five years. Issues such as anxiety and depression were identified as having a negative effect on survivors' quality of life. Jones et al., (2016) found that one third of cancer survivors, who are up to six years' post-treatment, still experienced clinically significant levels of fatigue which impacted on their daily activities. In an Irish study of colorectal cancer survivors, Drury et al., (2017)

identified that out of 252 participants who completed treatment within the previous five years, two fifths of these individuals continued to experience chronic pain and this was associated with poor quality of life. This suggests that post-treatment symptoms can persist for years after finishing treatment. Participants who attended OptiMal and those who declined to participate in the study reported a lack of follow-up care on how to manage these symptoms. This gap in the cancer continuum has been recognised in recent national policies, particularly the National Cancer Strategy (2017-2026) (DOH, 2017). Therefore, self-management interventions have been proposed as a means of providing follow-up care by helping survivors manage continuing symptoms while adjusting to survivorship (McCorkle et al., 2011).

7.3 Self-Management Support for Cancer Survivors

One of the objectives of this research was to evaluate the current literature regarding the type and content of self-management interventions previously used with cancer survivors. This review resulted in a number of diverse interventions whose content varied considerably (Boland et al., 2018). Researchers have attributed this to the lack of a 'gold standard' definition for self-management (Barlow et al., 2002; Coffey et al., 2016; Howell et al., 2017). Perhaps, another explanation for the diversity of self-management interventions is that there are limited structures or pathways to support self-management education, particularly in cancer survivorship. It is only in recent years that cancer has been considered a chronic condition due to persisting symptoms and long-term follow-up (Lorig & Holman, 2003; Elliott et al., 2011). This lack of a pathway to support self-management education in cancer survivorship may be reflective of findings from survivors in the mixed-methods study and from those who declined to participate, on the lack of follow-up care following cancer treatment. It may also be attributed to the slow recruitment rate to the mixed-methods study. Medical teams may not have been aware of the potential role of self-management in survivorship and therefore needed frequent reminders to provide potential participants with the participant information leaflet for this study. Therefore, if self-management is considered an important element in improving quality of life in cancer survivors, a standardised definition of self-management is required to understand what components of self-managements are effective in doing so (Boland et al., 2018). Additionally, a pathway of supporting self-management in cancer survivorship is required to create a standardised, evidence-based approach to providing such interventions to cancer survivors (Dunne, Coffey, Sharp, Timmons, Desmond, Gooberman-Hill et al., 2018).

McCorkle et al., (2011) recommended the provision of self-management programmes as patients' transition from treatment to survivorship. The National Cancer Strategy (2017-2026) does not clearly outline when self-management or survivorship programmes should be provided post-treatment but acknowledges that physical and psychosocial symptoms not addressed within the first year of post-treatment can become chronic (DOH, 2017). This is reflective of the literature (McCorkle et al., 2011; Foster et al., 2016). Findings from the OptiMal programme indicate that survivors require self-management support within three to six months of the post-treatment period. This is a time when survivors are returning to their daily activities and can feel isolated as they are no longer in frequent contact with their medical team (CDC & LAF, 2004). The majority of participants who declined to participate in the mixed-methods study were two years' post-treatment and had developed their own self-management strategies at this point. Therefore, if self-management programmes, such as OptiMal, were provided closer to treatment completion, this could provide survivors with self-management education and strategies that would facilitate a quicker return to usual activities. This in turn may increase survivors' quality of life.

Participants in the OptiMal programme and those who declined to participate reported struggling to manage psychosocial symptoms such as anxiety and depression which in turn they believed impacted on their quality of life. In comparison, no significant differences were observed in activity participation in the mixed-methods study, suggesting that survivors appear to manage the physical impact of treatment compared to the psychosocial impact. Therefore, there is clearly a need to address the emotional impact of cancer (Boland et al., 2018). The OptiMal programme resulted in statistically significant improvements in quality of life and significant reduction in anxiety in cancer survivors. This highlights the need to address the psychosocial aspects of cancer survivorship early post-treatment.

7.5 Impact and Potential of OptiMal as a Self-Management Support

Intervention

There is an increasing focus in recent years on research and policies to address cancer survivorship care (Aaronson et al., 2014). In particular, the provision of psychosocial supports (Hewitt et al., 2005; DOH, 2013; DOH, 2017). Survivors can experience physical and psychosocial issues following treatment however physical issues are more widely discussed in the survivorship literature compared to psychosocial issues (Foster et al., 2009; Shneerson et al., 2015). Survivors who attended the OptiMal programme

and those who declined to participate in the mixed-methods study, reported experiencing psychosocial issues such as fatigue and anxiety post-treatment which impacted on daily activities including employment and social participation, subsequently affecting quality of life.

Participants also reported a lack of follow-up care post-treatment to manage continuing symptoms in particular how to manage psychosocial issues and is reflective of previous research (Dilworth et al., 2014). Survivors reported difficulty communicating with others and feeling isolated. Survivors were relying on follow-up medical appointments for information, however medical appointments may decrease over the years (Chou et al., 2011). Philip et al., (2013) argues that the majority of literature focuses on the emotional impact of cancer during the diagnosis and treatment stage while less is known about the cancer survivorship stage. The National Cancer Strategy (2017-2026) acknowledged this gap in service in Ireland regarding the lack of psychosocial support services and its subsequent impact on survivors' activity participation (DOH, 2017).

The struggle to manage psychosocial symptoms can affect survivors' abilities to develop effective coping strategies (McGinty et al., 2012; Philip et al., 2013). Therefore, addressing the psychosocial impact of cancer may improve wellbeing and confidence in transitioning to cancer survivorship which in turn improves quality of life (Hodges & Winstanley, 2012; Molina et al., 2014; DOH, 2017). Few interventions have addressed psychosocial issues such as anxiety or fear of recurrence (Economou & Reb, 2017). However, self-management interventions that have addressed psychosocial issues with cancer survivors have reported significant results (Mishel et al., 2005; van den Berg et al., 2015). Mishel et al., (2005) provided a workbook intervention while van den Berg et al., (2015) provided a web-based intervention, a reflection of the diversity of interventions currently provided to cancer survivors. Neither studies explored participants' perceptions of their respective programmes to understand what contributed to their statistically significant results as per MRC guidelines (MRC, 2008). In the mixed-methods study, focus groups were held with participants of OptiMal to ascertain their perspectives and acceptability of the programme. As a result, participants reported benefit from increased understanding of symptom management following the education and strategies provided during OptiMal. This in turn facilitated participants to implement positive behavioural changes such as increased exercise and return to work and education. This may have contributed to the statistically significant improvements in anxiety and quality of life compared to the control group. Increased understanding of symptoms and acquiring self-management skills, core components of self-management interventions, can alleviate

feelings of stress and guilt, easing the transition from treatment to survivorship, as reflected in this current research study (Lorig & Holman, 2003; Schjolberg et al., 2014). Previous studies have reported the benefits of self-management education in reducing anxiety and depression in cancer survivors (Loh et al., 2013; Howell et al., 2017). Survivors who declined to participate in the mixed-methods study reported that they utilised their own self-management strategies to manage continuing symptoms such as energy management and social supports reported a greater sense of wellbeing. Researchers and policy makers suggest that self-management interventions may be a suitable intervention to address the psychosocial impact of survivorship (McCorkle et al., 2011; DOH, 2017).

A significant number of cancer survivors approached during the recruitment process, declined to participate. This suggests that there may be a cohort of cancer survivors who perceive a lack of need for self-management programmes post-cancer treatment. Survivors who declined participation in the mixed-methods study attributed the impact of post-treatment symptoms to the timing of their diagnosis. Some survivors believed that their lack or the minimal impact of symptoms were a result of early diagnosis and subsequent treatments. Therefore, a key challenge remains in how to identify those who are in need of self-management. Zucca et al., (2010) suggested identifying cancer survivors with low social supports and referring them to appropriate post-treatment services. It may be that the timing of the provision of self-management interventions may also be crucial in identifying this cohort.

7.6 Suggestions for Future Research

Future research is required to define the concept of self-management. A standardised definition would offer some insight into what core components of self-management interventions influence outcomes such as activity participation, quality of life, self-efficacy, anxiety and depression. Additionally, further research is required to create an evidence-based pathway for cancer survivors as they transition from treatment to survivorship, in particular to address psychosocial issues. Research suggests that medical teams are unsure how to manage the psychosocial needs of cancer survivors (Economou & Reb, 2017). An evidence-based pathway can assist medical teams to direct survivors towards follow-up care on how to manage post-treatment issues, in particular psychosocial issues, which can affect survivors' quality of life.

Due to smaller numbers than originally powered for, no statistically significant changes were observed in the primary outcome measure, namely the FAI. Despite this, statistically significant improvements were observed in some secondary outcome measures including quality of life and anxiety. Therefore, results cannot be generalised to the cancer survivorship population. The exploratory RCT and process evaluation from the mixed-methods study indicated that the OptiMal programme may be an acceptable intervention for cancer survivors as it helped to significantly improve quality of life and reduce anxiety in cancer survivors. Survivors attributed this to their increased knowledge and confidence in managing post-treatment symptoms. However, a definitive RCT with a larger cohort of mixed cancer survivors may be required to detect if statistically significant differences can be observed in the primary outcome measure, the FAI and if improvements quality of life and anxiety can be maintained. However further consideration is needed to explore potential challenges to this. For instance, some of the outcome measures were deemed unsuitable and alternatives were suggested as per section 5.7. There is also a need to explore more suitable outcome measures to statistically measure the impact of self-management knowledge and skills on individuals' confidence levels and whether this can influence outcome measures such as the frequency of activity participation.

The number of cancer survivors are continuing to increase in Ireland (NCRI, 2014). Cancer survivors can experience physical and psychosocial symptoms within the first year of finishing treatment (Shneerson et al., 2015). Future research should investigate effective recruitment strategies to target this population, in particular male cancer survivors. Potentially, targeting male-dominated cancers such as prostate cancer may increase male participation in self-management support interventions. Further research should also evaluate the OptiMal programme with cancer survivors earlier post-treatment, ideally less than or within one-year post-treatment.

The follow-up period for the OptiMal programme was three months, which could be considered a relatively short period of time, nevertheless significant findings were reported at this time point. In contrast, a key finding of the systematic review was the lack of sustainability of self-management interventions. Future research should evaluate if these results are sustainable at six and twelve months follow-up or whether survivors need reiteration of self-management support interventions (Boland et al., 2018).

Cancer survivors appear to have different needs related to self-management support. Therefore, there is an onus to identify individuals who would benefit from self-

management following cancer treatment. Further research is required to identify survivors who are at an increased risk of a lack of psychosocial support post-treatment and to explore the impact of providing such supports on cancer survivors' coping abilities.

7.7 Implications for Policy and Practice

Cancer survivors experience continuing symptoms post-treatment such as pain, fatigue, anxiety and cognitive difficulties which can impact upon survivors' ability to participate in activities of importance to them thus affecting quality of life (Silver & Gilchrist, 2011). In this study, some cancer survivors reported difficulty managing these symptoms and a need for follow-up care post-treatment. Occupational therapists are proficient in providing self-management education and strategies and utilising goal-setting to ensure individuals create meaningful goals of importance to them (Baxter et al., 2017). Unique skills in activity analysis and occupational performance problems presented by chronic conditions, allow occupational therapists to create interventions that encourage individuals to return to their daily activities (Hand et al., 2011; Baxter et al., 2017). The OptiMal programme facilitated by occupational therapists resulted in some cancer survivors returning to activities such as education and employment. Cancer is now considered a chronic condition therefore occupational therapists are positioned to provide effective self-management interventions to the cancer survivorship population (Elliott et al., 2011). Greater awareness of the potential role of occupational therapy in cancer survivorship is required through the facilitation of occupation-based, self-management interventions and the publication of subsequent research.

In Ireland, there is a greater emphasis on national policy to provide survivorship programmes to encourage survivors to return to employment or daily activities (DOH, 2017). Self-management has also been highlighted as an appropriate element of survivorship programmes (DOH, 2017). The results of this research study support the need for survivorship programmes that incorporate a self-management and group-based approach. By providing self-management education and strategies, survivors can manage post-treatment symptoms and return to their daily activities. Survivorship programmes can also raise awareness to the general public of the existence of continuing symptoms post-cancer treatment. In this study, survivors reported feeling isolated and unable to explain their symptoms to others. Additionally, by addressing the needs of cancer survivors' post-treatment, this ensures cancer services provide an all-round, high quality of care, another key area of development in the National Cancer Strategy (DOH, 2017). In this study, OptiMal, an occupation-based, self-management

support intervention, was considered an acceptable intervention by cancer survivors, therefore further research regarding its effectiveness and sustainability is warranted.

Perhaps, before commencing treatment, survivors could be provided with information regarding persistent symptoms and how to access services to manage symptoms post-treatment. This would help prepare survivors for the potential impact and subsequent management of post-treatment symptoms. This could form part of cancer survivorship policy currently being implemented in Ireland as a result of the National Cancer Strategy 2017-2026 (DOH, 2017). In this study, many survivors were unaware of continuing symptoms and valued meeting others in similar situations. Survivors also reported the need for self-management interventions earlier post-treatment. The provision of information regarding these interventions to survivors prior to treatment could help address these needs.

Survivors need to have access to members of the multidisciplinary team post-treatment as part of their follow-up care. The OptiMal programme, facilitated by occupational therapists, incorporated a multidisciplinary approach. Participants of OptiMal reported benefit from meeting health professionals including physiotherapists and dieticians who helped alleviate post-treatment concerns regarding exercise and nutrition, which is reflective of the literature (Blacklock et al., 2010; Anderson et al., 2013). This research study supports the recommendations outlined in the National Cancer Strategy (2017-2026) of the need to expand the workforce of cancer services in Ireland (DOH, 2017). The incidences of cancer are increasing in Ireland as is cancer survival rates (NCRI, 2014). At some point, occupational therapists and other members of the multidisciplinary team will work with individuals with a primary or secondary diagnosis of cancer. Therefore, professionals need to be aware of the impact of post-treatment symptoms particularly on survivors' quality of life and the role of self-management in supporting survivors to make the transition from treatment to survivorship (Buckland & Mackenzie, 2017).

7.8 Conclusion

The aim of this research was to evaluate the effectiveness and sustainability OptiMal as a self-management intervention for cancer survivors. Self-management interventions previously conducted with cancer survivors appear to lack sustainability. A mixed-methods study comparing adult cancer survivors who attended OptiMal compared to adult cancer survivors who received usual care, did not report significant changes in the

primary outcome measure of frequency of activity participation. However, it did result in significant improvements in health-related quality of life and anxiety in the intervention group compared to the control group at three months follow-up. Cancer survivors report a need for follow-up support post-treatment to manage persisting symptoms particularly psychosocial symptoms. The content and design of OptiMal, particularly the group support and goal-setting, were appreciated by cancer survivors. Future research is required to evaluate the effectiveness and sustainability of OptiMal with larger number of cancer survivors, earlier post-treatment. However, there are cancer survivors who report a lack of perceived need for self-management post-treatment. Further research is required to identify those in need of self-management following cancer treatment.

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APPENDIX A

PUBLISHED SYSTEMATIC REVIEW



Self-management interventions for cancer survivors: a systematic review

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Abstract

Purpose Many cancer survivors experience problems with persisting symptoms such as pain, fatigue, anxiety and depression post-treatment. Self-management interventions are recommended for cancer patients as they can help individuals identify and manage these continuing symptoms. This systematic review examines the type, content and impact of self-management interventions for cancer survivors on health outcomes such as activity participation, self-efficacy, quality of life and symptom management.

Methods This was a systematic review of the English language scientific literature searched for randomised controlled trials (RCT), systematic reviews and meta-analyses of self-management programmes conducted with cancer survivors. Six databases were systematically searched.

Results Initial searches yielded 2633 citations. Following screening and a risk of bias assessment, six studies were included in the final review. Heterogeneity of the interventions precluded meta-analysis. Three studies reported significant differences between groups in a number of areas including fatigue, physical functioning, distress and self-efficacy at their first follow-up assessment. These studies included two psychosocial interventions and one exercise and diet intervention. Not all findings were sustained across studies at follow-up assessment.

Conclusion It is not possible to draw definitive conclusions as to the impact the different types of self-management programme had on cancer survivors. The sustainability of the interventions reviewed was poor, suggesting that cancer survivors require interventions that can be applied into their daily activities.

Keywords Self-management · Cancer survivors · Systematic review

Introduction

The National Cancer Registry of Ireland (NCRI) reported that by the end of 2014, the number of cancer survivors in Ireland was 139,526 [1]. In Ireland, the 5-year survival rate for all invasive cancers in females rose from 52% during the 5-year

period of 1994 to 1999 to 61.5% in 2004 to 2009 [2]. In the male population, greater improvements were seen with survival rates rising from 42% between 1994 and 1999 to 60% from 2004 to 2009. Preventative screening, early diagnosis and widespread treatments have contributed to these increases [2].

As survival rates are increasing, cancer is now regarded as a chronic rather than a fatal condition commonly with persistent symptoms following treatment [3, 4]. Cancer survivors experience symptoms such as fatigue, pain, anxiety and depression post-treatment [5]. Cancer survivors returning to usual roles and routine can experience continuation of these symptoms resulting in social isolation, decreased participation and financial and familial strain [6]. With economic and time constraints affecting the provision of services, it can be difficult for hospital-based services to meet the needs of cancer survivors [7]. Due to these pressures, there is a move towards self-management, although many cancer survivors are unaware of how to manage their continuing symptoms [5].

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Self-management in chronic conditions

Effective self-management provides individuals with the ability to ‘monitor one’s condition and to effect the cognitive, behavioural and emotional responses needed to maintain a satisfactory quality of life’ [8]. It provides knowledge and skills to manage both the physical and psychosocial aspects of chronic illness. Self-management is considered key in bridging the gap between cancer survivors’ needs and the ability of health services to meet those needs [9].

Self-management typically incorporates five core skills of problem-solving, decision-making, resource utilisation, communication with healthcare professionals and action planning or goal setting [10]. It distinguishes itself from traditional health education by its emphasis on the application of these five core self-management skills to one’s own situation [10]. Self-management interventions are considered to be an integral part of cancer treatment as they increase the patient’s knowledge of issues arising post-treatment such as lingering symptoms of fatigue or recurrence anxiety. These interventions enable individuals to implement self-management strategies, thereby reducing levels of distress and encouraging empowerment [11–13]. This shifts the focus on survivors from passive recipient to active participant in managing cancer as a chronic illness [8]. Self-management interventions are often facilitated by health professionals. It is believed that this approach increases adherence due to participants’ confidence in health professionals’ knowledge and the encouragement provided to participants [14].

Despite recommendations to provide cancer survivors with self-management strategies, limited evidence is available regarding self-management interventions with no definitive conclusions of their effectiveness and further research is recommended [15, 16]. The purpose of this research was to systematically review self-management interventions in cancer survivors in relation to the type, content and impact of these interventions compared to usual care on at least one outcome of activity participation, self-efficacy, quality of life and symptom management and on at least one occasion during follow-up.

Methods

The methods are presented according to the PRISMA guidelines [17].

Eligibility criteria

A Population, Interventions, Comparators and Outcomes (PICO) table was created to form inclusion criteria and screen papers based on their title and abstract. Articles were suitable for inclusion if they met the following criteria:

Inclusion criteria

- (i) Randomised controlled trials (RCT) or systematic review/meta-analysis of RCTs
- (ii) Cancer survivors who were aged 18 years or over when diagnosed and completed primary treatments (surgery, chemotherapy and/or radiation therapy)
- (iii) Group, individual and/or online self-management interventions
- (iv) Viable comparison groups including participants randomised to usual care or waiting list control (WLC)
- (v) At least one of the following reported outcomes were measured: activity participation, quality of life, self-efficacy or symptom management

Exclusion criteria

- (i) Non-RCTs or systematic reviews/meta-analysis of non-RCTs
- (ii) Cancer survivors who were diagnosed during childhood or participants who were recently diagnosed or undergoing primary treatments
- (iii) Interventions conducted at the diagnosis or treatment stage or focused on one component e.g. exercise, return to work
- (iv) Studies written in languages other than English

There is no ‘gold standard’ definition for self-management; however, Barlow et al. define it as the ‘individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent with living with a chronic condition’ [8]. For this review, studies were included if they contained multi-component interventions aimed at facilitating at least one of five core self-management skills (problem-solving, decision-making, resource utilisation, communication with healthcare professionals and action planning or goal setting).

Search methods:

Search terms were developed in consultation with a medical librarian and applied to the following databases: EMBASE, Scopus, PubMed, CINAHL, PsycINFO and Cochrane. Search terms included ‘self-management’ and ‘self-efficacy’ combined with Boolean terms (and/or) for ‘cancer survivor’. Limitations were employed specific to each database ensuring that only RCTs published in English were included. Appendix A contains examples of two full electronic search strategies for the two databases used.

Study selection

Each study that resulted from the searches was screened for suitability based on their title and abstract by one author (LB). Studies were excluded when it was clear from their title and abstract that the article did not relate to the inclusion criteria. Where there was a lack of clarity from the title and abstract, the full text was obtained to determine its suitability.

Data collection process

A data extraction tool based on the Cochrane Handbook for Systematic Review of Interventions [18] was used by two of the authors (LB, KB) to independently extract data from the included studies with the following information:

- Author, year of publication
- Study design, randomisation, allocation concealment, blinding of participants, outcome assessment, attrition bias, reporting bias and other biases
- Participant numbers, cancer types, country and setting, inclusion and exclusion criteria
- Type of intervention: web-based, group, individual (i.e. face-to-face), content, duration, health professionals as intervention facilitators
- Outcomes—primary and secondary outcomes, follow-up time period

Discrepancies were resolved by discussion between the two reviewers, and a third reviewer was available if they were unresolved.

Risk of bias in individual studies

Two reviewers (LB, KB) assessed risk of bias of each study based on the Cochrane Handbook [18]. This tool assesses bias on random sequence generation, allocation concealment, blinding, incomplete outcome data, selective reporting and other sources of bias. In these studies, the risk of bias for each of these domains was determined to be low, high or unclear. Low indicates the domain was performed adequately, high if inadequately performed and unclear if insufficient information was provided to make a judgement. Disagreements were resolved by discussion between the two reviewers, and a third reviewer was available if they were unresolved.

Results

Study selection

The electronic searches identified 2633 studies (Fig. 1). Upon the removal of duplicates, 2042 citations were screened and

29 citations were retained. Full texts of these articles were obtained. Nine were immediately excluded including seven citations which were conference abstracts, one article was a literature review and one was a systematic review. The remaining 20 articles were assessed for bias. As a result, six articles were eligible for inclusion in the final analysis.

Study characteristics

See Table 1 for an outline of study characteristics of the six studies including location, details of the intervention, participant details (including cancer type), duration and facilitators of the intervention.

Risk of bias in individual studies

A summary of the risk of bias assessment for each study is shown in Fig. 2. Initially, 20 articles were assessed for bias using the RevMan 5.1 Risk of Bias tool. As a result, 14 studies were excluded from the final review for a variety of reasons (Appendix B). The results of the risk of bias of the remaining six articles are displayed as follows in Fig. 2.

Synthesis of results

A meta-analysis of primary and secondary outcomes was planned if sufficient information was available. However, they were differences across the studies in terms of diversity of populations studied, interventions examined, the range of outcomes measures used and follow-up periods. This precluded a statistical synthesis of the included studies' results. Therefore, a narrative summary of the data was carried out. This focused on the nature of the intervention (web-based, group, individual) including content, duration, follow-up, facilitators and the findings from these interventions (Tables 1 and 2).

Content

Table 1 contains detailed information regarding the content of the six interventions. Three out of six studies focused on increasing physical activity [20–22]. Two studies [21, 22] described their exercise interventions which included aerobic and resistance exercise.

Two studies [20, 21] addressed diet. Lee et al. [21] used an online personalised diet programme which involved participants planning their daily caloric requirements in accordance with BMI values, body weight and daily level of activity. Foster et al. [20] did not provide any detailed information regarding the diet content.

Three studies focused on psychosocial adjustment of transition to survivorship [19, 23, 24]. Two studies used workbooks [19, 23] and one used web-based intervention [24].

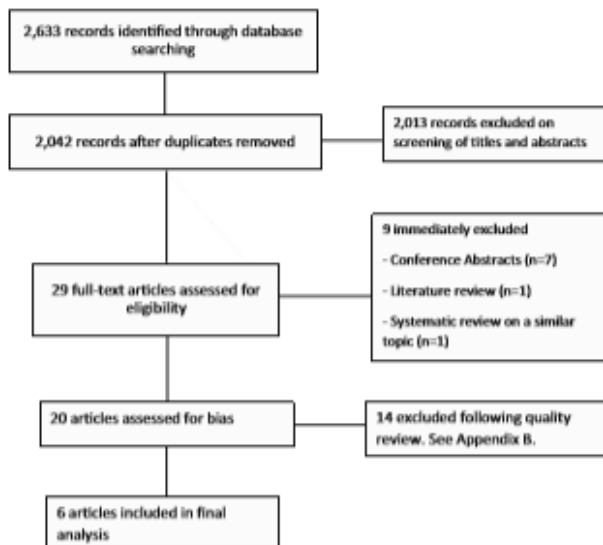


Fig. 1 PRISMA flow chart of the results of the study selection process

Mishel et al. [23] focused on managing recurrence anxiety in long-term breast cancer survivors while Beatty et al. [19] and van den Berg et al. [24] focused on the transition to survivorship for individuals who finished treatment within a year. Both Mishel et al. [23] and Beatty et al. [19] provided participants with relaxation tapes and education on long-term physical and psychosocial issues (see Table 1).

Foster et al. [20] provided self-management skills to long-term cancer survivors to help manage cancer-related fatigue and was the only study that allowed participants to choose the topics to cover over the 6-week intervention.

All six interventions incorporated goal setting i.e. encouraging participants to incorporate the information obtained into achieving personal goals and behavioural changes through the use of assignments or ‘homework’ (see Table 1).

Impact of interventions

Out of the six studies, three [21, 23, 24] demonstrated statistically significant differences between the control and intervention groups at their first follow-up assessment (Table 2). Outcome measures varied between the three interventions as did their results with significant improvements noted in several areas including cognitive reframing, cancer knowledge, social support satisfaction [23] dietary quality, fatigue severity, appetite loss [21] distress, fear of cancer recurrence and self-efficacy [24] (Table 2). Two of these three interventions contained some form of involvement from health professionals [21, 23]. The workbook-based intervention by Mishel et al. [23] involved four weekly phone calls by nurses to guide participants through the intervention. The

involvement of health professionals by Lee et al. [21] was minimal in that a nutritionist contacted participants to ensure food records were being maintained properly, but it is unclear how often this was done. The two web-based interventions lasted 12 weeks [21] and 16 weeks [24] respectively in comparison to the 4-week duration of the workbook-based intervention by Mishel et al. [23].

Of the three studies with significant differences between the control and intervention groups, only one study reported significant differences at longitudinal follow-up. Van den Berg et al. [24] conducted longitudinal follow-up at 6 and 10 months post-intervention. Fear of cancer recurrence was the only significant improvement sustained in the intervention group at the 6-month follow-up. This significant improvement was not sustained at the 10-month follow-up, and no other significant differences between groups were found. Mishel et al. [23] assessed the sustainability of their intervention with a 10-month longitudinal follow-up. This was to allow participants time to identify and experience triggers of cancer recurrence and use the strategies provided. Several significant differences were noted in the intervention group compared to the control group in areas such as cognitive reframing, cancer knowledge and social support satisfaction (Table 2). Lee et al. [21] did not conduct longitudinal follow-up limiting the ability to assess the sustainability of their intervention.

Two studies with no statistically significant between-group differences reported significant within-group differences post-intervention. In their small study, Beatty et al. [19] reported significant improvements from baseline for both the control and intervention groups in venting emotions and cognitive functioning post-intervention. May et al. [22] reported significant improvements in physical activity and quality of life within the physical therapy group and the physical therapy and cognitive behavioural therapy group post-intervention. Both studies lasted 12 weeks. Beatty et al. [19] included only breast cancer survivors while May et al. [22] included mixed cancer diagnoses.

Both studies conducted longitudinal follow-up assessments. Beatty et al. [19] conducted follow-up at 6 months post-intervention. The improvements within both groups in venting emotions and cognitive functioning were no longer significant, and no other significant results were reported. In comparison, May et al. [22] reported sustained significant post-intervention improvements in physical activity and quality of life at 3- and 9-month follow-up within both groups.

The only study to report non-significant differences within or between groups was Foster et al. [20]. This study reported non-significant improvements following the 6-week intervention and at the 12-week follow-up.

Table 1 Characteristics of included studies

Study name and country	Participants	Sample size, gender, intervention vs control	Intervention, length	Intervention facilitators	Format	Programme details
Beatty et al. (2010) [19], Australia	Breast, women who had completed treatment within the past 3 months Mean age 53.05 SD 11.44	n = 40 Female 40 Intervention: n = 20, Control: n = 20	Self-guided workbook, 12 weeks	No health professional involvement	Workbook sent to participants.	Focused on facilitating breast cancer survivors' transition from treatment to survivorship Based on 3 major components: education on common medical and psychosocial issues, suggestions and worksheets to address these issues, survivor stories Relaxation and meditation tape provided to all programme participants RESTORE, a fatigue management web-based programme; 5 educational topics accessible over a 6-week period First 2 sessions introduce cancer-related fatigue (CRF) and goal setting. Participants could choose to complete all 3 remaining topics or focus on one of those topics for the remaining 3 weeks These topics included (i) diet, exercise, sleep, home and work life; (ii) thoughts and feelings; and (iii) talking to others Topics incorporated CBT and self-management skills. Goal setting implemented throughout Participants encouraged to plan their exercise and dietary behaviours in line with current guidelines Educational sessions included considerations when planning exercise and diet and barriers to sustainability of same Participants kept a web-based diary throughout recording daily exercise and number of units of each food group consumed. This information provided daily feedback to participants on their goal achievements.
Foster et al. (2016) [20], England	Mixed cancers, survivors 5 years or less post-diagnosis with self-reported moderate to severe levels of fatigue Mean age 57.8 SD 9.95	n = 159 Male 37 Female 122 Intervention: n = 83 Control: n = 76	Self-guided web-based intervention, 6 weeks	No health professional involvement	5 topics in total, each session delivered weekly online	
Lee et al. (2014) [21], South Korea	Breast, women who completed primary treatment within 12 months prior to the study Mean age 42.35 SD 5.7	n = 59 Female = 59 Intervention: n = 30 Control: n = 29	Self-guided web-based intervention, 12 weeks	Nutritionist contacted participants in intervention group to ensure food diaries were recorded correctly—unclear how often participants contacted	Group members encouraged to use the programme weekly through automated messaging	
May et al. (2009) [22], Netherlands	Mixed cancers, last curative treatment completed 3 months before study entry Mean age 48.8 SD 10.9	n = 147 Male 24 Female 123 PT and CBT: n = 76 PT: n = 71	Face-to-face, individual and group-based; physical training (PT) and cognitive behavioural training (CBT), 12 weeks	PT guided by 2 physiotherapists, CBT facilitated by a psychologist and a social worker	PT group—12 weeks, twice weekly, 2-h group sessions PT and CBT = same PT programme but CBT was weekly, 2-h group sessions	PT group: personalised exercise programme including aerobic bicycle and muscle strength training followed by group sports (badminton, soccer, swimming or balancing games) CBT group: educational sessions on a number of topics including stress, fatigue, exercise and relaxation CBT group assignments provided to facilitate application of self-management skills in

Table 1 (continued)

Study name and country	Participants	Sample size, gender, intervention vs control	Intervention, length	Intervention facilitators	Format	Programme details
Mishel et al. (2005) [23], USA	Breast, women who were 5–9 years post-treatment, stages I–III Mean age 64 SD 8.9	n = 509 Women = 509 Intervention: n = 244 Control: n = 265	Workbook sent to participants, 4 weeks	Nurses	Intervention nurses conducted weekly phone calls for 4 weeks	everyday life using goal setting and problem-solving Workbook addressed recurrence anxiety of cancer survivors. Nurses trained in the intervention guided participants through the workbook for 4 weeks Workbook contained behavioural strategies to develop self-management skills and information on long-term treatment side effects. Audiotape provided to teach coping responses such as relaxation and visual imagery to triggers of cancer recurrence
van den Berg et al. (2015) [24], Netherlands	Breast, survivors who had finished treatment 2 to 4 months pre-baseline Mean age 50.81 SDL 8.7	n = 150 Female 150 Intervention: n = 70 Control: n = 80	Self-guided web-based intervention, 16 weeks	No health professional involvement	New material released weekly followed by e-mail reminders	BREATH, web-based programme guided by CBT Aim was to enable breast cancer survivors to take control of and adjust to survivorship Content based on 4 phases of adjustment to breast cancer: looking back, emotional processing, strengthening and looking ahead. Participants required to complete assignments, assessments and videos

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Beatty 2010	+	+	+	+	+	+	?
Foster 2015	+	+	+	+	?	+	?
Lee 2014	+	+	+	+	+	+	+
May 2009	+	?	+	+	+	+	+
Mishel 2005	+	?	+	+	+	+	+
Van den Berg 2015	+	?	+	+	+	+	+

Fig. 2 Risk of bias summary: authors' judgements about each risk of bias item for the six included studies

Discussion

The findings highlight the diversity of self-management interventions for cancer survivors, both in format and content, currently available in the published literature. Therefore, it was difficult to provide a conclusive summary of what constitutes a self-management intervention. In addition, the findings of the review highlight the lack of sustainability of self-management interventions.

The content of the six included interventions varied considerably. This may reflect the uncertainty in relation to the most important components and what constitutes a self-management intervention [8]. For example, the impact of exercise on improving fatigue and anxiety in cancer survivors is well documented [25, 26]. However, only three of the six studies [20–22] addressed physical activity. Both Lee et al. [21] and May et al. [22] reported significant improvements in physical activity in their respective studies indicating that this may be one aspect of a self-management programme that participants follow through on.

In relation to content of self-management interventions, diet is considered an important factor to help reduce recurrence [27]. However, only two of the six studies [20, 21] included diet in their intervention. In their study, Lee et al. [21] reported a significant improvement in dietary quality in the intervention group post-intervention. Evidence suggests that interventions targeting specific outcomes generally result

in significant benefits [28]. All six studies targeted specific outcomes including exercise, diet, anxiety, depression, coping and quality of life, and significant results were reported post-intervention in five of these six studies. One study reported non-significant effects in their targeted outcomes [20]. However, in this study, participants in the intervention group were given the choice of whether to cover diet and exercise topics which may have affected their outcomes.

Of the three interventions that produced significant between-group differences at their first follow-up assessment, two addressed psychosocial issues [23, 24] including anxiety and depression. This is reflective of the findings of Howell et al. [28] who in their systematic review reported that self-management education may be beneficial for relieving symptoms of anxiety and depression. A significant amount of literature on the emotional impact of cancer is focused on the diagnosis and treatment stage, while less is known about the survivorship stage [29]. Additionally, in the survivorship stage, physical issues are more widely discussed than psychosocial issues [30]. The findings from our study indicate that there is a clear need to address the emotional impact of cancer post-treatment and self-management may play a key role, thus improving quality of life.

Goal setting was one element of self-management interventions evident across all the six studies. Participants were provided with 'homework' or assignments to facilitate goal setting. This allowed participants to incorporate the information received into their daily routine, thus promoting behavioural changes and encouraged adherence to the interventions [31]. This appears to be a consistent inclusion in self-management interventions.

Two studies that produced significant post-intervention results were both web-based interventions of long duration [21, 24]. This reflects the change of focus in recent years to utilising technology to provide health interventions. The remaining web-based intervention by Foster et al. [20] which lasted 6 weeks was affected by a high attrition rate and did not report any significant differences for any outcomes. This suggests that longer-duration web-based interventions may result in participants embedding self-management knowledge and skills into their daily activities. It is important to note that Lee et al. [21] and van den Berg et al. [24] conducted many statistical tests which may have increased the chance of a type 1 error i.e. identifying a false positive. This may have led to misleading conclusions whereby some of the significant effects of the intervention on outcomes were not true effects but chance findings [32]. Multiple testing increases the chances of detecting effects of interventions just by chance [33].

Although only 4 weeks in duration, a workbook-based intervention delivered by nurses [23] reported statistically significant improvements in the intervention group compared to the control group. In comparison, the other workbook-based intervention by Beatty et al. [19] was 12 weeks in duration,

Table 2 Reported outcomes of included studies, post-intervention and follow-up

Study name	Type of study, length	Outcome measures	Immediate post-intervention results	Longitudinal follow-up	Follow-up results
Beatty et al. (2010) [19]	2-arm RCT: workbook intervention vs usual care, 12 weeks	Coping Operations Preference Enquiry (COPE), EORTC-QLQ-C30	No significant time-by-group interactions; significant improvements within group in venting emotions ($p = 0.034$) and cognitive functioning ($p = 0.042$)	6 months	No significant time-by-group interactions; significant improvements within group in venting emotions and cognitive functioning not maintained
Foster et al. (2016) [20]	2-arm RCT: web-based intervention vs leaflet, 6 weeks	Perceived self-efficacy for fatigue self-management, cancer survivors' self-efficacy scale, Functional Assessment of Cancer Therapy (FACT-G), Personal Wellbeing Index, Patient Health Questionnaire, Brief Fatigue Inventory (BFI)	No significant differences between groups noted; near-significant improvement between groups in fatigue self-efficacy ($p = 0.09$)	12 weeks	No significant differences between groups noted; between-group difference in fatigue self-efficacy decreased becoming negligible
Lee et al. (2014) [21]	2-arm RCT: web-based intervention vs 50-page educational booklet, 12 weeks	Exercise and intake of fruit and veg, Dietary Quality Index, EORTC-QLQ-C30, HADS, Brief Fatigue Inventory (BFI), Stage of Change, Perceived Self-Efficacy	Significant increases for the intervention group compared to control in moderate aerobic exercise ($p < 0.0001$), eating five servings of fruit and vegetables per day ($p = 0.0001$), dietary quality ($p = 0.001$), self-efficacy for exercise management ($p = 0.024$) and in self-efficacy to increase fruit and vegetable intake ($p = 0.023$); significant improvements reported for the intervention group compared to control in fatigue severity ($p = 0.032$), physical functioning ($p = 0.023$) and appetite loss ($p = 0.034$)	No longitudinal assessment carried out	N/A
May et al. (2009) [22]	2-arm RCT: physical therapy vs physical therapy and cognitive behavioural therapy (CBT), 12 weeks	EORTC-QLQ-C30, Physical Activity Scale for the Elderly (PASE)	No statistically significant difference between the two groups; statistically significant improvements in quality of life (QOL) ($p < 0.001$) and physical activity ($p < 0.05$) was found within both groups	3, 9 months	No statistically significant differences between groups; statistically significant improvements in QOL ($p < 0.001$) physical activity ($p < 0.05$) within both groups sustained at 3 and 9 months
Mishel et al. (2005) [23]	2-arm RCT: workbook intervention vs usual care, 4 weeks	Cancer Survivor Knowledge Scale, 5-item Patient/Provider Communication Scale, Social Support Questionnaire, Cognitive Reframing Subscale of the Self-control Schedule, Cognitive Coping Strategies Questionnaire, Total Information Received and Helpfulness of the Information 25-item measure, Profile of Mood States-Short Form	No immediate post-intervention assessment carried out	10 months	Significant increases for the intervention group compared to control in cognitive reframing ($p = 0.01$), cancer knowledge ($p = 0.001$), social support satisfaction ($p = 0.029$), information received ($p = 0.001$) and helpfulness of information ($p = 0.001$)

Table 2 (continued)

Study name	Type of study, length	Outcome measures	Immediate post-intervention results	Longitudinal follow-up	Follow-up results
van den Berg et al. (2015) [24]	2-arm RCT: web-based intervention vs usual care, 16 weeks	Symptoms Checklist-90 (SCL-90), Cancer Empowerment Questionnaire, HADS, EORTC-QLQ-C30, Breast Cancer Module (QOL), Distress Thermometer, Illness Cognitions Questionnaire, Remoralization Scale, Master scale, Positive Adjustment Questionnaire (PAQ), Impact of Event Scale, Self-efficacy Scale, Cancer Worry Scale (CWS), Cancer Acceptance Scale (CAS), Checklist Individual Strength - Fatigue, Openness to Discuss Hereditary Cancer in the Family Scale Big Five Inventory, Trimbos/MTA questionnaire	Significant differences between groups observed; intervention group reported significantly less distress ($p < 0.05$) than the control group. Intervention group reported significant improvements in 8 of the secondary measures compared to control; general distress ($p < 0.05$), fatigue ($p < 0.05$), fear of recurrence ($p < 0.001$, $p < 0.05$), cancer-specific distress ($p < 0.01$), general self-efficacy ($p < 0.05$), general remoralisation ($p < 0.01$) and cancer-specific new ways of living ($p < 0.05$)	6, 10 months	Only one significant time-by-group interaction at 6 months reported in the intervention group in fear of cancer recurrence ($p = 0.005$) No significant differences between groups reported in any study measures at 10 months

with no health professional involvement. Beatty et al. [19] did not report any significant differences between groups immediately post-intervention or at longer-term follow-up. However, the findings in Beatty et al. [19] were limited by a small sample size ($n = 40$).

On reviewing the impact of health professional involvement in self-management interventions, no clear conclusions can be made based on the studies from this review. Of the six studies, three interventions had some involvement by health professionals [21–23] which varied from full facilitation of the intervention [22] to minimum telephone contact with participants [21, 23]. Two of these studies reported significant differences between the intervention and control groups [21, 23]; however, both studies used different delivery methods. Of the three remaining studies with no health professional involvement [19, 20, 24], one of these studies using a web-based intervention [24] reported significant differences between the intervention and control groups. Based on these six studies, it is therefore not possible to conclude whether the involvement of health professionals contributes to any improvement in adherence to self-management strategies. To establish this, studies are required comparing the outcomes of a self-management intervention with two groups, one of which is facilitated by a health professional.

The lack of consensus on the format and content of self-management interventions made it difficult to review and provide definitive recommendations on preferred self-management interventions for cancer survivors. This has been reported in previous systematic reviews. Coffey et al. [34] conducted a meta-synthesis of qualitative studies exploring cancer survivors' experiences of self-management interventions. The authors reported difficulties in selecting studies for inclusion due to the lack of a 'gold-standard' definition. Similarly, Howell et al. [28] were unable to conduct a meta-analysis to identify the essential components of self-management education due to the variety of interventions and outcome measures used in their included studies.

Conducting longitudinal follow-up is important to determine if interventions can sustain their effectiveness [35]. Mishel et al. [23] and van den Berg et al. [24] conducted longitudinal follow-ups to assess sustainability of their interventions. Mishel et al. [23] conducted their first follow-up assessment 10 months post-intervention, but not at earlier time points when the impact of the intervention may have been more evident. Van den Berg et al. [24] conducted follow-up assessments at 6 months with one significant improvement in fear of cancer recurrence sustained in the intervention group. However, this was not sustained at the 10-month follow-up and no other significant improvements were noted. It appears that the authors were unable to demonstrate sustainability of the self-management interventions over a long period of time. Self-management is considered a lifelong task; therefore, it may be unrealistic to expect a self-management programme

for cancer survivors to sustain these benefits on a long-term basis [10]. Additionally, the mean age of participants ranged from 42 to 64 years [21, 23] which could be a time when other chronic diseases are developing either due to cancer treatments or for other reasons [27]. Therefore, life demands are changing which can result in participants needing different self-management strategies to manage these changes. Reiteration of these interventions may be required to provide participants with the skills to self-manage their chronic diseases in addition to post-cancer issues.

Limitations

Due to the heterogeneity in the study populations and types of interventions included in the six studies, it was not possible to conduct a meta-analysis which may have provided a statistical measure of the impact of self-management interventions with cancer survivors.

Further limitations of this review are the inclusion of RCTs in English only as part of the search strategy which reduces the opportunity to evaluate studies not reported in English. A small number of studies were included in the final review, so these findings should be interpreted with caution. The lack of a ‘gold standard’ definition of self-management and the differing viewpoints on what constitutes a self-management intervention made the initial study screening process difficult [8]. This was overcome, in part, by keeping self-management terms broad in the literature search.

Conclusion

Due to the diversity in the focus of the interventions, their delivery methods, the period of interventions and the presence or absence of facilitators of the interventions, limited recommendations can be made from this systematic review regarding optimal self-management interventions for cancer survivors. Lack of sustainability of the effectiveness of the six included self-management interventions is an issue raising questions on the long-term impact and cost-effectiveness of self-management interventions. A standardised definition of self-management is also needed which may help to ascertain which core components of self-management interventions are effective for improving health outcomes such as activity participation, self-efficacy, quality of life and symptom management in cancer survivors. Finally, further research is needed to determine if self-management interventions facilitated by health professionals result in more significant and sustainable outcomes than interventions with no health professional involvement.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human participants performed by any of the authors.

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APPENDIX B

SCREENING AND SELECTION TOOL

Review Question + Inclusion Criteria = Screening/Selection tool

Review Question:

What types of self-management interventions have been carried out with cancer survivors?

Inclusion Criteria: (PICOS)

Population: Adult Ca survivors (18 years onwards), cancer diagnosed in adulthood

Intervention: Groups, individual, online

Comparator: Groups, individual, online

Outcomes: (At least 1 of these) Activity participation, Quality of Life, Self-efficacy, Changes re. symptom management

Study Design: RCT

Screening & Selection Tool

Title of Study:

Author Name:

	Include	Exclude
Study Design	RCT, systematic review/meta-analysis	Not an RCT or systematic review/meta-analysis
Population	Adult cancer survivors with good prognosis Post treatment In transition stage/remission	Children with cancer Cancer obtained in childhood Adult cancer at diagnosis or treatment stage
Interventions	Group, Individual, Online self-management interventions,	Psychosocial only interventions Physical only interventions Psycho-oncology interventions Interventions at diagnosis & treatment
Comparators	Group, Individual, Online self-management interventions,	Psychosocial only interventions Physical only interventions Psycho-oncology interventions Interventions at diagnosis & treatment
Outcomes	(At least 1 of these) Activity participation, Quality of Life, Self-efficacy Changes re. symptom management	

APPENDIX C

SYSTEMATIC REVIEW SEARCH TERMS

Searched 10/8/15

EMBASE

LIMITS: Young Adult, Adult, Middle Aged, Aged, Very Elderly

- 1 ((cancer OR tumor* OR tumour*) NEAR/3 surviv*):ab,ti **W/O L = 70,095 W/L = 25,806**
- 2 (self NEAR/3 (care OR manage* OR help OR efficacy)):ab,ti **W/O L = 56,331 W/L = 27,078**
- 3 1 AND 2 **W/O L = 625 W/L = 300**
- 4 'self care'/exp OR 'self help'/exp **W/O L = 56,126 W/L = 21,196**
- 5 'cancer survivor'/exp OR 'neoplasm'/exp OR 'oncology'/exp **W/O L = 3,691,197 W/L = 1,167,034**
- 6 4 AND 5 **W/O L = 3,292 W/L = 1,252**

Scopus: searched 10/8/15

LIMITS: English papers only

- 1 TITLE-ABS (self W/3 management) **W/O L = 18,466 W/L = 17,033**
- 2 TITLE-ABS (self W/3 care) **W/O L = 19,186 W/L = 16,936**
- 3 #1 OR # 2 **W/O L = 35,454 W/L = 31,879**
- 4 TITLE-ABS (cancer W/3 surviv*) **W/O L = 45,394 W/L = 41,944**
- 5 TITLE-ABS (tumor* W/3 surviv*) **W/O L = 28,736 W/L = 25,767**
- 6 TITLE-ABS (tumour* W/3 surviv*) **W/O L = 28,736 W/L = 25,767**
- 7 TITLE-ABS (neoplasm* W/3 surviv*) **W/O L = 512 W/L = 434**
- 8 #4 OR #5 OR #6 OR #7 **W/O L = 72,057 W/L = 65,742**
- 9 #3 AND #8 **W/O L = 223 W/L = 217**

PubMed

Limits: English papers only, Adult 19+, Young Adult 19-24, Adult 19-44, Middle Aged + Aged: 45+, Middle Aged: 45-64, Aged 65+, 80 and over: 80+

- 1 surviv*[tiab] AND (cancer[tiab] OR tumor*[tiab] OR tumour*[tiab] OR neoplasm*[tiab]) **W/O L = 307,690 W/L = 135,963**

- 2 self care[tiab] OR self manage*[tiab] OR self help[tiab] OR OR self efficacy[tiab]
W/O L = 41,437 W/L = 20,242
- 3 1 AND 2 **W/O L = 521 W/L = 286**
- 4 "Neoplasms"[Mesh] **W/O L = 2,719,927 W/L = 912,778**
- 5 "Self Efficacy"[Mesh] OR "Self Care"[Mesh] OR "Self-Help Groups"[Mesh] OR
"Social Support"[Mesh] **W/O L = 112,554 W/L = 55,655**
- 6 "Survivors"[Mesh] OR "Survival Analysis"[Mesh] OR "Survival Rate"[Mesh] **W/O
L = 329,980 W/L = 214,585**
- 7 4 AND 5 AND 6 **W/O L = 993 W/L = 716**

CINHAL

Limits: English, All adult, middle aged 45-64 years, adult 19-44, aged 65+, aged 80 & over

- 1 TI ((cancer OR tumor* OR tumour*) N3 surviv*) OR AB ((cancer OR tumor*
OR tumour*) N3 surviv* **W/O L = 9,022 W/L = 4,185**
- 2 TI (self N3 (care OR manage* OR help OR efficacy)) OR AB (self N3 (care
OR manage* OR help OR efficacy)) **W/O L = 25,642 W/L = 11,942**
- 3 1 AND 2 **W/O L = 248 W/L = 156**
- 4 MH "Cancer Survivors" **W/O L = 5,818 W/L = 2,089**
- 5 MH "Self Care" **W/O L = 20,821 W/L = 7,494**
- 6 3 OR 5 **W/O L = 21,013 W/L = 7,613 3 AND 5 W/O L = 56 W/L = 37**

PsycINFO

Limits: English, adulthood (18 & older), young adulthood 18-29, thirties 30-39, middle aged 40-64, aged 65 & older, very old 85 & older.

- 1 TI ((cancer OR tumor* OR tumour*) N3 surviv*) OR AB ((cancer OR tumor*
OR tumour*) N3 surviv* **W/O L = 4,918 W/L = 3,270**
- 2 TI (self N3 (care OR manage* OR help OR efficacy)) OR AB (self N3 (care
OR manage* OR help OR efficacy)) **W/O L = 53,722 W/L = 32,703**
- 3 1 AND 2 **W/O L = 252 W/L = 195**
- 4 ((DE "Self Management" OR DE "Self Instructional Training") AND (DE
"Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE
"Endocrine Neoplasms" OR DE "Leukemias" OR DE "Nervous System

Neoplasms" OR DE "Terminal Cancer")) AND (DE "Survivors") **W/O L = 17**
W/L = 11

COCHRANE

- 1 (cancer or tumor* or tumour*) near/3 surviv*:ti,ab,kw **W/O L = 6,683**
- 2 self NEAR/3 (care OR manage* OR help OR efficacy):ti,ab,kw **W/O L = 11,148**
- 3 #1 AND #2 **W/O L = 153**
- 4 [mh"Self-Help Groups"] OR [mh"Self Care"] OR [mh"Self Efficacy"] OR [mh"Social Support"] **W/O L = 7,873**
- 5 [mh"Survivors"] OR [mh"Survival Analysis"] OR [mh"Survival Rate"] **W/O L = 23,485**
- 6 [mh"Neoplasms"] **W/O L = 54,566**
- 7 #4 AND #5 AND #6 **W/O L = 101**
- 8 #3 OR #7 **W/O L = 202** #3 AND #7 **W/O L = 52**

Total No of studies: 2633

No of Duplicates: 591

Total Studies: 2042

Included: 29

Excluded: 2,013

APPENDIX D

CHARACTERISTICS OF EXCLUDED STUDIES

Name	Reasons for Exclusion
Chambers 2011	Participants currently have cancer
Cimprich 2005	Process evaluation study - high levels of bias identified throughout
Given 2010	Participants undergoing chemotherapy
Korstjens 2008	Same study as May 2009 – already included
Korstjens 2011	Same study as May 2009- already included
Meraviglia 2013	Feasibility study
Miyashita 2005	High levels of bias identified in all sections
Osei 2013	High risks of bias identified regarding methodology
Pergolotti 2015	Some participants are undergoing treatment
Stuhldreher 2008	Study protocol
Turner 2014	Study protocol
van den Berg 2013	Same study as van den Berg, 2015 – already included
Watson, 2014	Study protocol
Zhang, 2014	Unclear bias identified throughout - incomplete data

APPENDIX E

PARTICIPATION INFORMATION LEAFLET AND INFORMED CONSENT FORM – MIXED-METHODS STUDY

Participation Information Leaflet

The effectiveness of OPTIMAL a self-management programme for cancer survivors

Principal Investigator: Dr. Deirdre Connolly, Head of Discipline Occupational Therapy, Trinity Centre for Health Sciences, St James' Hospital, James' Street, Dublin 8

Co-Investigators: Dr. Sinead Cuffe, Consultant Oncologist, St James' Hospital
Lauren Boland, Occupational Therapist BSc. (Hons), PhD student, Trinity Centre for Health Sciences, St James' Hospital
Aoife O'Gorman, Occupational Therapy Manager, Occupational Therapy Department, St James' Hospital

You are being invited to participate in a research project to assess the effectiveness of OPTIMAL a self-management programme for cancer survivors. However before you decide whether to give permission to participate in the study you should understand what the study will involve. Please read this leaflet carefully and discuss it with others before you decide if you want to take part.

Background and need

The National Cancer Registry Ireland (2014) has projected that cancer diagnoses will double by 2040. The risk of dying from cancer has decreased by 1% leading cancer survival rates to increase (NCRI, 2013). This infers that the number of cancer survivors in Ireland will increase. Interventions regarding self-management skills are a growth area with only limited evidence available at present (Shneerson, et. al. 2014). It is believed that self-management programmes can be most effective to cancer survivors as they transition from the end of treatment to survivorship (McCorkle, et. al., 2011). Many cancer survivors experience problems such as pain, fatigue, anxiety and depression following treatment (Shneerson, et. al., 2014). Self-management programmes increase the individual's knowledge of problems arising post-treatment thereby reducing levels of distress and encouraging empowerment (Schjolberg, et al., 2014; Shneerson, et. al., 2014).

OPTIMAL Programme

A self-management programme, OPTIMAL (O'Toole, Connolly, Smith, 2013), will be offered to those who have completed their cancer treatments. OPTIMAL is a six-week programme designed for people with multimorbidity to develop self-management knowledge and skills. OPTIMAL aims to improve participants' understanding of self-management principles and the need to effectively manage their own health. Each week includes an educational component. Topics covered include fatigue management, pain management, anxiety and stress management, exercise and activity, cognitive strategies, and effective communication with health professionals. These topics reflect the main issues identified by cancer survivors (Shneerson, et. al., 2014). OPTIMAL also includes a weekly goal setting component where participants are facilitated to set goals to apply the education components of the programme into their daily routines. This promotes the behavioural changes required to sustain self-management knowledge and skills (Lorig, 2003).

Invitation

Therefore you are invited to participate in this research study to examine the effectiveness of OPTIMAL a six-week self-management intervention for cancer survivors. First you will be asked to complete questionnaires to understand how you are managing your everyday activities. You will then be randomly assigned to a control or an intervention group. The control group will receive standard care as per usual. The intervention group will receive the six-week OPTIMAL programme in a group format. Following the conclusion, you will be asked to complete the same questionnaires as before to gauge whether there has been an improvement in your self-management skills and quality of life and again at three months. You will also be invited to participate in a focus group to provide feedback on the OPTIMAL programme and interviews at three months' time.

Is this research likely to benefit anyone?

The OPTIMAL programme has proven to be beneficial to people with chronic conditions. This program is designed to provide you with self-management skills such as energy conservation, relaxation, cognitive strategies, nutrition and exercise techniques that will help you with performing your everyday activities.

Will there be any risks?

There are no anticipated risks associated with taking part in this study.

Will there be any cost?

All we ask is that you are able to travel to St. James' Hospital to take part in the OPTIMAL group programme. There are no costs involved for you to participate in this study.

Confidentiality?

Your identity will remain confidential at all times. Your name will not be published and will not be disclosed to anyone. All data collected will be stored securely and confidentially for five years and then destroyed.

Is this project covered by insurance?

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

When will the questionnaires be distributed?

If you are interested in participating in this study please contact the researchers using the details listed at the end of this page. They will arrange to meet with you. Before the meeting they will send you the questionnaires and consent form to allow you time to read over them and form any questions which will be answered upon meeting with the researchers.

What will happen to the information from the questionnaires?

Information will be used solely for the purposes of this study, all information will be kept strictly confidential and used for no other purposes. The information gathered will be kept in a locked filing cabinet on a password protected computer.

Do I have to take part?

You are under no obligation to take part in this study and may withdraw at any time. This will not affect your current or future care in St. James Hospital. However if you decide to participate you understand that the investigators may withdraw your participation in the study at any time without your consent.

Does this project have permission to be carried out?

This project has Research Ethics approval from St James' Hospital research ethics committee.

Who should you talk to if you have any questions or concerns?

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from the principal researcher Dr Deirdre Connolly or the co-investigator Lauren Boland, by telephone **(01) 8963216/ 018963222** or email at **connoldm@tcd.ie** or **laboland@tcd.ie**. If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

Thank you for considering participation in this study,

Dr Deirdre Connolly,
Head of Discipline of Occupational Therapy,
Trinity Centre for Health Sciences,
St James' Hospital,
James' Street,
Dublin 8

Contact Details to Participate in the Study:

connoldm@tcd.ie/ 01 896 3216

laboland@tcd.ie/ 01 896 3222

Informed Consent Form: Examine the effectiveness of OPTIMAL a six-week self-management intervention for cancer survivors

Research Team: Dr. Deirdre Connolly, Dr. Sinéad Cuffe, Ms. Lauren Boland, Ms. Aoife O’Gorman

Declaration: I have read and understood the information leaflet and I consent to taking part in this research study. I understand that agreeing to take part means that I am willing to:

- Complete self-report questionnaires at three time points including the Frenchay Activities Index, the Canadian Occupational Performance Measure, Hospital Anxiety and Depression Scale, EQ5D quality of life scale, Cognitive Failures Questionnaire, the FACIT-Fatigue scale questionnaire and Stanford Chronic Disease Self-Efficacy Scale.
- Participate in OPTIMAL, a six-week self-management programme.
- Participate in a focus group following the immediate conclusion of the programme and a follow-up interview at a three month interval.

I understand the purpose of this research and agree to participate voluntarily in the OPTIMAL self-management programme. I understand that I can withdraw from the research at any time without affecting my care in St. James’ Hospital. I understand that my identity will remain confidential at all times. I give permission for information gathered throughout the programme to be used by the researchers in their study.

I understand that by participating in the focus group or interview my voice will be audio-taped as part of the process. I understand that I will receive a copy of the main themes identified by the researchers and that I can request any changes to be made if I am unhappy with the content.

Name (Block Capitals): _____

Address: _____

Tel and email: _____

Signature: _____

Date: _____

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE.....

Date:.....

APPENDIX F

ETHICAL APPROVAL – MIXED-METHODS STUDY

THIS NOTEPAPER MUST NOT BE USED FOR
PRESCRIPTIONS OR INVOICING PURPOSES

SJH/AMNCH Research Ethics Committee Secretariat

Claire Hartin Ph: 4142199

email: claire.hartin@amnch.ie



**THE ADELAIDE & MEATH
HOSPITAL, DUBLIN**

**INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL**

TALLAGHT, DUBLIN 24, IRELAND

TELEPHONE +353 1 4142000

Lauren Boland
Occupational Therapy
Trinity College Dublin
Discipline of Occupational Therapy
Trinity Centre for Health Sciences
St. James's Hospital
James's Street
Dublin 8

14th December 2014

**RE: Examine the effectiveness of a OPTIMAL a six-week self-management
intervention for cancer survivors**

**REC Reference : 2014-12 Chairman's Action (12) (please quote references and title on all
correspondence)**

Dear Ms. Boland,

Thank you for your correspondence in which you requested ethical approval of the above
referenced research project.

The Chairman, on behalf of the SJH/AMNCH Research Ethics Committee has reviewed your
submission and has given ethical approval.

Yours sincerely,

**Claire Hartin
Secretary**

SJH/AMNCH Research Ethics Committee

APPENDIX G

OUTCOME MEASURES

Please indicate your answer by placing a ✓ in the relevant box.

1. Age	_____
2. Gender	Male <input type="checkbox"/> ₁ Female <input type="checkbox"/> ₂
3. Marital Status	Single <input type="checkbox"/> ₁ Married <input type="checkbox"/> ₂ In a Relationship <input type="checkbox"/> ₃ Separated/divorced <input type="checkbox"/> ₄ Widowed <input type="checkbox"/> ₅
4. Living Situation	Living alone <input type="checkbox"/> ₁ Living with family <input type="checkbox"/> ₂ Living with others than family <input type="checkbox"/> ₃
5. Diagnosis/Type of Cancer	
6. Type of treatment <i>Please tick all that apply</i>	Surgery <input type="checkbox"/> ₁ Chemotherapy <input type="checkbox"/> ₂ Radiation therapy <input type="checkbox"/> ₃ Other: please state _____
7. When did you finish your treatment?	3 months ago <input type="checkbox"/> ₁ 6 months ago <input type="checkbox"/> ₂ 1 year ago <input type="checkbox"/> ₃ 2 years ago <input type="checkbox"/> ₄ Other please state: _____
8. Highest level of education	Primary <input type="checkbox"/> ₁ Secondary to inter cert/junior cert level <input type="checkbox"/> ₂ Secondary to leaving cert level <input type="checkbox"/> ₃ College/University <input type="checkbox"/> ₄
9. Employment status prior to diagnosis	Full-time <input type="checkbox"/> ₁ Part-time <input type="checkbox"/> ₂ Unemployed <input type="checkbox"/> ₃ Retired <input type="checkbox"/> ₄ Full-time housewife <input type="checkbox"/> ₅
10. Current employment status (If this has not changed from Q9 please go straight to Q11)	Full-time <input type="checkbox"/> ₁ Part-time <input type="checkbox"/> ₂ Unemployed <input type="checkbox"/> ₃ Retired <input type="checkbox"/> ₄ Full-time housewife <input type="checkbox"/> ₅ Not working currently due to diagnosis/treatment <input type="checkbox"/> ₆
11. Please tick what best describes your current or most recent employment	Non-manual (e.g. administrative, managerial, supervisory, office and other professional e.g. teacher) <input type="checkbox"/> ₁ Mixed, non-manual and manual (e.g. sales and service occupations such as waitress, personal care attendant, patient care nurse, nurse's aide, driver) <input type="checkbox"/> ₂ Manual with no supervisory duties (e.g. carpenter, roofer, loader) <input type="checkbox"/> ₃

<p>12. Do you have any long-term chronic health problems/illnesses as diagnosed by a doctor?</p>	<p>Yes <input type="checkbox"/>₁ No <input type="checkbox"/>₂</p> <p>If Yes please answer Question 13</p> <p>If No please go straight to Question 14</p>
<p>13. Please tick all that apply to you and whether you are being treated for at this moment</p>	<p>High Blood Pressure <input type="checkbox"/>₁ -> I am being treated for this now <input type="checkbox"/>₂</p> <p>Diabetes <input type="checkbox"/>₃ -> I am being treated for this now <input type="checkbox"/>₄</p> <p>Arthritis or rheumatism <input type="checkbox"/>₅ -> I am being treated for this now <input type="checkbox"/>₆</p> <p>Asthma <input type="checkbox"/>₇ -> I am being treated for this now <input type="checkbox"/>₈</p> <p>Osteoporosis <input type="checkbox"/>₉ -> I am being treated for this now <input type="checkbox"/>₁₀</p> <p>Other please state:</p>
<p>14. Why do you want to participate in this program? <i>Please tick all that apply. Please rate in order of priority with 1 being the most important</i></p>	<p>Want to learn to manage my different symptoms e.g. fatigue, anxiety, pain <input type="checkbox"/>₁</p> <p>Want to meet people <input type="checkbox"/>₂ Want to learn about diet and exercise <input type="checkbox"/>₃</p> <p>Want to improve my activity levels <input type="checkbox"/>₄</p> <p>Other please state:</p>

The Frenchay Activities Index

Below are statements about how frequently you engage in different activities. Please circle the answer which most closely applies to you.

In the last **three months** how often have you:

Prepared meals	Most days	1 – 2 times a week	Less than once a week	Never
Done the washing up	Most days	1 – 2 times a week	Less than once a week	Never

In the last **three months** how often have you:

Washed clothes	At least weekly	between once a week to once a month	1-2 times in past 3 months (less than once a month)	Never
Light housework (dusting, polishing, ironing)	At least weekly	between once a week to once a month	1-2 times in past 3 months (less than once a month)	Never
Heavy housework (hoovering, changing beds, cleaning windows, etc)	At least weekly	between once a week to once a month	1-2 times in past 3 months (less than once a month)	Never
Local shopping	At least weekly	between once a week to once a month	1-2 times in past 3 months (less than once a month)	Never
Social outings (clubs, cinema, meeting friends etc)	At least weekly	between once a week to once a month	1-2 times in past 3 months (less than once a month)	Never
Walked outside for more than 15 minutes (approx 1 mile)	At least weekly	between once a week to once a month	1-2 times in past 3 months (less than once a month)	Never
Actively pursued a hobby	At least weekly	between once a week to once a month	1-2 times in past 3 months (less than once a month)	Never
Driven a car/gone in a bus	At least weekly	between once a week to once a month	1-2 times in past 3 months (less than once a month)	Never

In the last **six months** how often have you undertaken:

Travel, outings/car rides	At least weekly	3-12 in past six months	1-2 times in past six months	Never
Gardening	Heavy/All necessary	Moderate	Light	Never
Household DIY/car maintenance	Heavy/All necessary	Moderate	Light	Never
Read books (not paper/magazines)	More than one a fortnight	One a fortnight	One in six months	Never

Gainful work (paid work only)	Over 30 hours/week	10-30 hours/week	Up to 10 hours/week	None
--------------------------------------	--------------------	------------------	---------------------	------

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

Self-Care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

Usual Activities (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

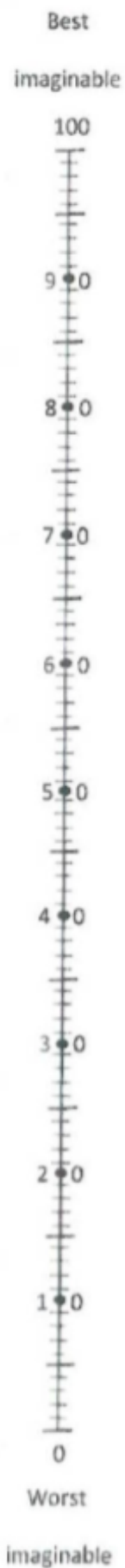
Pain/Discomfort

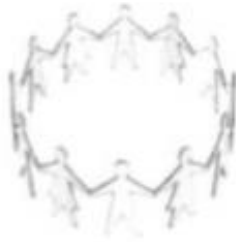
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

Anxiety/Depression

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.





STANFORD PATIENT EDUCATION RESEARCH CENTER

Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

	D	A		D	A		
			I feel tense or 'wound up':				I feel as if I am slowed down:
	3	Most of the time		3	Nearly all the time		
	2	A lot of the time		2	Very often		
	1	From time to time, occasionally		1	Sometimes		
	0	Not at all		0	Not at all		
			I still enjoy the things I used to enjoy:				I get a sort of frightened feeling like 'butterflies' in the stomach:
	0	Definitely as much		0	Not at all		
	1	Not quite so much		1	Occasionally		
	2	Only a little		2	Quite Often		
	3	Hardly at all		3	Very Often		
			I get a sort of frightened feeling as if something awful is about to happen:				I have lost interest in my appearance:
	3	Very definitely and quite badly		3	Definitely		
	2	Yes, but not too badly		2	I don't take as much care as I should		
	1	A little, but it doesn't worry me		1	I may not take quite as much care		
	0	Not at all		0	i take just as much care as ever		
			I can laugh and see the funny side of things:				I feel restless as I have to be on the move:
	0	As much as I always could		3	Very much indeed		
	1	Not quite so much now		2	Quite a lot		
	2	Definitely not so much now		1	Not very much		
	3	Not at all		0	Not at all		
			Worrying thoughts go through my mind:				I look forward with enjoyment to things:
	3	A great deal of the time		0	As much as I ever did		
	2	A lot of the time		1	Rather less than I used to		
	1	From time to time, but not too often		2	Definitely less than I used to		
	0	Only occasionally		3	Hardly at all		
			I feel cheerful:				I get sudden feelings of panic:
	3	Not at all		3	Very often indeed		
	2	Not often		2	Quite often		
	1	Sometimes		1	Not very often		
	0	Most of the time		0	Not at all		
			I can sit at ease and feel relaxed:				I can enjoy a good book or radio or TV program:
	0	Definitely		0	Often		
	1	Usually		1	Sometimes		
	2	Not Often		2	Not often		
	3	Not at all		3	Very seldom		

Please check you have answered all the questions

The Cognitive Failures Questionnaire (Broadbent, Cooper, FitzGerald & Parkes, 1982)

The following questions are about minor mistakes which everyone makes from time to time, but some of which happen more often than others. We want to know how often these things have happened to you in the past 6 months. Please circle the appropriate number.

	Very often	Quite often	Occasionally	Very rarely	Never
1. Do you read something and find you haven't been thinking about it and must read it again?	4	3	2	1	0
2. Do you find you forget why you went from one part of the house to the other?	4	3	2	1	0
3. Do you fail to notice signposts on the road?	4	3	2	1	0
4. Do you find you confuse right and left when giving directions?	4	3	2	1	0
5. Do you bump into people?	4	3	2	1	0
6. Do you find you forget whether you've turned off a light or a fire or locked the door?	4	3	2	1	0
7. Do you fail to listen to people's names when you are meeting them?	4	3	2	1	0
8. Do you say something and realize afterwards that it might be taken as insulting?	4	3	2	1	0
9. Do you fail to hear people speaking to you when you are doing something else?	4	3	2	1	0
10. Do you lose your temper and regret it?	4	3	2	1	0
11. Do you leave important letters unanswered for days?	4	3	2	1	0
12. Do you find you forget which way to turn on a road you know well but rarely use?	4	3	2	1	0
13. Do you fail to see what you want in a supermarket (although it's there)?	4	3	2	1	0
14. Do you find yourself suddenly wondering whether you've used a word correctly?	4	3	2	1	0

		Very often	Quite often	Occasionally	Very rarely	Never
15.	Do you have trouble making up your mind?	4	3	2	1	0
16.	Do you find you forget appointments?	4	3	2	1	0
17.	Do you forget where you put something like a newspaper or a book?	4	3	2	1	0
18.	Do you find you accidentally throw away the thing you want and keep what you meant to throw away – as in the example of throwing away the matchbox and putting the used match in your pocket?	4	3	2	1	0
19.	Do you daydream when you ought to be listening to something?	4	3	2	1	0
20.	Do you find you forget people's names?	4	3	2	1	0
21.	Do you start doing one thing at home and get distracted into doing something else (unintentionally)?	4	3	2	1	0
22.	Do you find you can't quite remember something although it's "on the tip of your tongue"?	4	3	2	1	0
23.	Do you find you forget what you came to the shops to buy?	4	3	2	1	0
24.	Do you drop things?	4	3	2	1	0
25.	Do you find you can't think of anything to say?	4	3	2	1	0

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References

- Broadbent, D.E., Cooper, P.F., FitzGerald, P., & Parkes, K.R. (1982). The Cognitive Failures Questionnaire (CFQ) and its correlates. *British Journal of Clinical Psychology*, 21, 1-16.

FACIT Fatigue Scale (Version 4)

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Not at all	A little bit	Some- what	Quite a bit	Very much
HE7	I feel fatigued	0	1	2	3	4
HE12	I feel weak all over	0	1	2	3	4
An1	I feel listless ("washed out")	0	1	2	3	4
An2	I feel tired.....	0	1	2	3	4
An3	I have trouble <u>starting</u> things because I am tired.....	0	1	2	3	4
An4	I have trouble <u>finishing</u> things because I am tired	0	1	2	3	4
An5	I have energy	0	1	2	3	4
An7	I am able to do my usual activities.....	0	1	2	3	4
An8	I need to sleep during the day	0	1	2	3	4
An12	I am too tired to eat.....	0	1	2	3	4
An14	I need help doing my usual activities	0	1	2	3	4
An15	I am frustrated by being too tired to do the things I want to do.....	0	1	2	3	4
An16	I have to limit my social activity because I am tired.....	0	1	2	3	4

**STEP 1:
IDENTIFICATION OF OCCUPATIONAL PERFORMANCE ISSUES**

To identify occupational performance problems, concerns and issues, interview the client, asking about daily activities in self-care, productivity and leisure. Ask clients to identify daily activities which they want to do, need to do or are expected to do by encouraging them to think about a typical day. Then ask the client to identify which of these activities are difficult for them to do now to their satisfaction. Record these activity problems in Steps 1A, 1B, or 1C.

**STEP 2:
RATING
IMPORTANCE**

Using the scoring card provided, ask the client to rate, on a scale of 1 to 10, the importance of each activity. Place the ratings in the corresponding boxes in Steps 1A, 1B, or 1C.

STEP 1A: Self-care

Personal Care
(e.g., dressing, bathing,
feeding, hygiene)

Functional Mobility
(e.g., transfers,
indoor, outdoor)

Community Management
(e.g., transportation,
shopping, finances)

IMPORTANCE

STEP 1B: Productivity

Paid/Unpaid Work
(e.g., finding/keeping
a job, volunteering)

Household Management
(e.g., cleaning,
laundry, cooking)

Play/School
(e.g., play skills,
homework)

STEP 1C: Leisure

Quiet Recreation
(e.g., hobbies, crafts, reading)

Active Recreation
(e.g., sports, outings, travel)

Socialization
(e.g., visiting, phone calls, parties, correspondence)

IMPORTANCE

STEPS 3 & 4: SCORING - INITIAL ASSESSMENT and REASSESSMENT

Confirm with the client the 5 most important problems and record them below. Using the scoring cards, ask the client to rate each problem on performance and satisfaction, then calculate the total scores. Total scores are calculated by adding together the performance or satisfaction scores for all problems and dividing by the number of problems. At reassessment, the client scores each problem again for performance and satisfaction. Calculate the new scores and the change score.

Initial Assessment:

OCCUPATIONAL PERFORMANCE PROBLEMS:

1. _____

2. _____

3. _____

4. _____

5. _____

PERFORMANCE 1

SATISFACTION 1

Reassessment:

PERFORMANCE 2

SATISFACTION 2

SCORING:

Total score = $\frac{\text{Total performance or satisfaction scores}}{\text{\# of problems}}$

PERFORMANCE SCORE 1

SATISFACTION SCORE 1

PERFORMANCE SCORE 2

SATISFACTION SCORE 2

$\frac{\quad}{\quad} = \boxed{\quad}$

$\frac{\quad}{\quad} = \boxed{\quad}$

$\frac{\quad}{\quad} = \boxed{\quad}$

$\frac{\quad}{\quad} = \boxed{\quad}$

CHANGE IN PERFORMANCE = Performance Score 2 - Performance Score 1 =

CHANGE IN SATISFACTION = Satisfaction Score 2 - Satisfaction Score 1 =

APPENDIX H

FOCUS GROUP INTERVIEW GUIDE

Participant Focus Group Questions

Purpose

You have been asked to participate in this focus group interview because of your participation in the group over the last six weeks. I am interested in your opinions about the group design and content and what impact if any the group had on you and on your quality of life.

This is just a conversation. We are interested in all your ideas, comments and suggestions. There is no right and wrong answers. We want both positive and negative feedback.

Procedure

If at anytime you want to stop please let me know. This discussion should take approximately **30-40 minutes**. Although we will audiotape the interview, your identity will never be revealed, or connected in any way to your comments. While we may report quotes collected during this interview, at no time will we connect those comments with any individual. No one except the researcher will listen to the tape. Let me know if you would like to skip a question because you don't know how to respond to it.

Let's discuss how the group affected you if at all over the last few weeks

Impact of the group

What did you learn about managing your symptoms in the group? Did it help you manage your symptoms on a daily basis?

Have you made any specific changes to your routine? If so how have they impacted on your quality of life/confidence? If not, why not?

Which elements of the programme initiated these changes i.e. the fatigue management, exercise, nutrition?

What was the most important thing that you did or learnt during the group?

In what overall ways, if any, **have you benefited** from the group?

- What were your main difficulties before attending this group? [Probe: fatigue, cognition, pain, diet, exercise]

- What kind of impact did the group have on your health and these symptoms?

- What impact did the group have on your activities i.e. are you performing more or less activities?
- Did the group have any effect on your quality of life/confidence?

Do you feel these impacts or effects that the group has had will last now that the group is ending?

Now let's consider the design and structure of the group

Group Design

What did you think of the number of sessions? Was it too much or too little?

What did you think of the length of each session? Was 2 hours too long? Could it have been longer? Was the time of day suitable - the afternoon?

What are your opinions of the topics that were covered in the group? Did you feel there were any topics that should have been included or left out?

What session did you find the most helpful or beneficial?

What was the least helpful session?

If you could change anything about the group what would it be?

Imagine it is your job to design a group to help people who have finished cancer treatment manage symptoms such as fatigue, pain, stress, exercise, nutrition etc.

How do you think you could get people to come to a group like this? What would be the best way to inform/contact people about the group?

Do you think the group would have been better if there had been an even number of men and women in the group?

Do you think a programme like this should be ran after finishing treatment – when would be a suitable time – 6 weeks/3months following treatment?

Let's think about the goal setting that was covered every week

Goal Setting

Did you find filling out the goal setting sheets helpful?

Did you look at the goal setting sheet during the week?

Did setting goals make you do things you wouldn't have done otherwise?

Do you think the group was enough to help achieve your goals/ difficulties you identified that you set when you first met Lauren?

Why/ why not? What else or what other supports if any would you have liked?

We will discuss the group booklet and other resources (e.g. other health professionals)

Group Booklet

How often, if at all, did you look at the booklet and information provided [*Probe: Which sections did you use? What made you decide to look at these sections?*]

To what extent was the booklet helpful? [*Probe: what makes you think this?*]

Is there anything else that would be useful to help you manage your health that you feel should have been included?

Did you find the other health professionals (physiotherapist, nutritionist) helpful?

Finally, what was your overall impression or opinion of the group as a whole?

Good or Bad?

Thank you very much for your time and participation!

APPENDIX I

ETHICAL APPROVAL – CANCER SUPPORT SERVICE

THIS NOTEPAPER MUST NOT BE USED FOR
PRESCRIPTIONS OR INVOICING PURPOSES



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SJH/AMNCH Research Ethics Committee Secretariat
Claire Hartin Ph: 4142199
email: claire.hartin@amnch.ie

Ms. Lauren Boland
Discipline of Occupational Therapy
Trinity Centre for Health Sciences
St. James's Hospital
James's Street
Dublin 8

14th July 2016

Re: To examine the effectiveness of OPTIMAL a six week self-management intervention for cancer survivors

REC Reference: 2016-07 List 25 (17)
(Please quote reference on all correspondence)

Dear Ms. Boland,

Thank you for your recent correspondence to SJH/AMNCH Research Ethics Committee in which you requested an amendment in relation to the above referenced study

The Chairman, Dr. Peter Lavin, on behalf of the Research Ethics Committee, has reviewed this request and grants permission for this amendment, on the condition that the patients call the researchers of their own free will.

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee

The SJH/AMNCH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

APPENDIX J

PARTICIPATION INFORMATION LEAFLET, COVER LETTER AND INFORMED CONSENT FORM STUDY III

Self-Management for Cancer Survivors

26/09/2016

Dear

My name is Lauren Boland. I am a PhD student with the Discipline of Occupational Therapy, Trinity College Dublin and the oncology services in St James' Hospital. You were recently invited to take part in my study which is investigating the effectiveness of a six-week, group-based programme for cancer survivors. This programme, called OPTIMAL, is aimed at providing individuals with skills to manage difficulties in areas such as fatigue and anxiety management, exercise, cognition and nutrition.

Although the programme was offered to a large number of people, many of those invited to participate chose not to do so. We are therefore interested in exploring some of the reasons people chose not to participate in the programme in order to identify alternative methods of providing this information.

You were one of the people who was approached and chose not to participate in the study. Therefore we would like to invite you to take part in a short interview to explore reasons why you chose not to participate and to find out if you would have preferred this post-cancer treatment information delivered in a different way. Please read the enclosed participant information leaflet to help you decide if you wish to take part in the interview. If you have any questions about the research, you can contact me on my details below or you can contact my supervisor, Dr. Deirdre Connolly on the details below.

As a follow up to this letter, I will telephone you in a few days to ask if you wish to participate in the study. Alternatively, if you are interested in taking part, you can contact me on the information provided below and we will arrange a time of your convenience to conduct the interview.

Thank you for taking the time to read the enclosed information.

Yours faithfully

Lauren Boland, Occupational Therapist, PhD Candidate,
Discipline of Occupational Therapy,
Trinity Centre for Health Sciences,
St. James' Hospital, Dublin 8

Tel: 01-8963222/0879284951, laboland@tcd.ie

Supervisor: Dr. Deirdre Connolly, Associate Professor, Discipline of Occupational Therapy, connoldm@tcd.ie Tel: 01-8963216

Exploring formats for self-management information for people post-cancer treatment/s.

The Discipline of Occupational Therapy, Trinity College, Dublin, designed a group-based programme, OPTIMAL, for cancer survivors from St James oncology services to manage their health post-cancer treatment. OPTIMAL is a six-week programme aimed at providing participants' with knowledge and skills to effectively manage their own health after they have completed all their treatment/s. Topics covered include fatigue, pain, anxiety and stress management, exercise and activity, cognitive strategies and effective communication with health professionals, families and employers

The programme has been running over the past 18 months, however, uptake for the programme has been lower than expected. We are therefore carrying out a study to explore reasons why people chose not to participate in the programme and to find out if another format is needed to provide information to people who have finished their cancer treatment/s. The study involves interviewing those who were eligible for the programme but declined it. This information will contribute to identifying alternative methods to meeting the needs of cancer survivors post-treatment.

Who is eligible for this study?

- Any person who was invited to participate in the OPTIMAL programme but chose not to

What does the study involve?

The study involves taking part in a short interview with the researchers listed below. The interview will be audio recorded and the interview transcript will be sent to you to ensure you are happy with the information you provided.

What happens next?

You will be contacted by one the researchers listed below in the coming few days to ask if you wish to participate in the study and/or to answer any questions you may have about the study. Alternatively, if you are interested in taking part, you can contact the

researchers at the details provided below to arrange a time of your convenience to conduct the interview.

If you would like more information on this study you can contact: Lauren Boland, 01 8963222 or laboland@tcd.ie, and Dr. Deirdre Connolly on 01 8963216 or connoldm@tcd.ie.

Exploring different formats for providing self-management health-related information for people post-cancer treatment/s.

Informed Consent Form:

Research Team: Dr. Sinéad Cuffe, Dr. Cliona Grant, Prof. John Kennedy, Dr. Noreen Gleeson, Ms. Aoife O’Gorman, Ms. Lauren Boland and Dr. Deirdre Connolly

Declaration: I have read and understood the information leaflet and I consent to taking part in this research study. I understand that agreeing to take part means that I am willing to:

- Participate in an interview to explore reasons for not participating in the OPTIMAL programme.

I understand the purpose of this research and agree to participate voluntarily in an interview. I understand that I can withdraw from the research at any time without affecting my care in St. James’ Hospital. I understand that my identity will remain confidential at all times. I give permission for information gathered throughout this interview to be used only by the researchers in this study.

I understand that by participating in the interview my voice will be audio-taped as part of the process. I understand that I will receive a copy of the main themes identified by the researchers and that I can request any changes to be made if I am unhappy with the content.

Name (Block Capitals): _____

Address: _____

Tel and email: _____

Signature: _____

Date: _____

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE

Date:.....

APPENDIX K

ETHICAL APPROVAL – STUDY III

THIS NOTE/PAPER MUST NOT BE USED FOR
PRESCRIPTIONS OR INVOICING PURPOSES



**THE ADELAIDE & MEATH
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Ms. Lauren Boland
Discipline of Occupational Therapy
Trinity Centre for Health Sciences
St. James's Hospital
James's Street
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28th October 2016

**RE: Examine the effectiveness of a OPTIMAL a six-week self-management
intervention for cancer survivors**

REC Reference: 2014-12 Chairman's Action (12): 2016-List 37 (10)
(Please quote reference on all correspondence)

Dear Ms. Boland,

The REC is in receipt of your recent letter to SJH/AMNCH Research Ethics Committee in which you requested an amendment to the above named study.

The Chairman, Dr. Peter Lavin, on behalf of the Research Ethics Committee, has reviewed your letter and has granted ethical approval for amendment.

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee

The SJH/AMNCH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

APPENDIX L

INTERVIEW GUIDE – STUDY III

Participant Interview Questions

Purpose

You have agreed to participate in this interview for the purposes of this research study. I am interested in your opinions/thoughts around your own needs following cancer treatment and your reasons for declining to participate in the OPTIMAL programme.

This is just a conversation. We are interested in all your ideas, comments and suggestions. There is no right and wrong answers. We want both positive and negative feedback.

Procedure

If at anytime you want to stop please let me know. Although we will audiotape the interview, your identity will never be revealed, or connected in any way to your comments. While we may report quotes collected during this interview, at no time will we connect those comments with any individual. No one except the researcher will listen to the tape. Let me know if you would like to skip a question because you don't know how to respond to it.

Can you tell me about your cancer

- how did you get on with your treatments,
- How did you find the time period (of three months) from finishing treatment to your first outpatient appointment?
- What are you doing now,
- Are you back at work, full time house-wife, etc,
- Are you back doing your usual activities (self-care, work/productivity, leisure)

Did you experience any difficulties after finish treatment? [*Probe: fatigue, cognition, pain, diet, exercise*]

What impact did the symptoms have on your activities i.e. were you performing less activities, slowed down?

What strategies or techniques did you use to help manage these difficulties or the transition from finishing treatment to returning to your usual routine? [*Probe: attend support groups, classes, obtain information via the internet, exercise or diet changes*]

Where did you access information around these strategies? [*Probe: common knowledge, internet, friends, family, through other cancer survivors*]

Was there any kind of information you would have liked to have received after finishing treatment? (*Probe: managing certain symptoms, returning to work*)

How would you have liked to receive this information? [*Probe: information booklets, group meetings, health professionals*]

Do you think cancer survivors should receive some form of support (individual or group), after finishing treatment? Why/why not?

Finally, when is the best time period to receive this support/information? Towards the end of treatment, 6 weeks, 3 months, six months post treatment.

[You were invited to participate in a self-management programme but declined, can you tell me the reasons for declining to participate in the programme? (*Probe: managing well already, work commitments, elements of the programme – time commitment*)]

If answer is regarding elements of the programme;

What elements of the programme did not appeal to you? (*Probe: topics covered, length of programme, group aspect, location*)

If the programme was available in your local community or at the weekend, to avoid clashes with work commitments, do you think you would attend the programme then?

Would you have preferred individual sessions, or a group of people with the same cancer type?

Do you think cancer survivors should receive some form of support (individual or group), after finishing treatment? Why/why not?

Was there any kind of information you would have liked to receive after finishing treatment? (*Probe: managing certain symptoms, returning to work*)

- Did you experience any difficulties after finish treatment? [*Probe: fatigue, cognition, pain, diet, exercise*]
- What impact did the symptoms have on your activities i.e. were you performing less activities, slowed down?
- Do you feel these impacts or effects still play a part in your everyday life?

How would you have liked to receive this information? i.e. information booklets, group meetings, health professionals.

Finally, when is the best time period to receive this information? Towards the end of treatment, 6 weeks, 3 months post treatment.

Thank you very much for your time and participation!