An exploration of the referral
patterns of members of a
community palliative care team to
specialist palliative care outpatient
physiotherapy for community
based individuals with advanced
cancer

by

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Declaration

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Summary

This study explored referral patterns of members of a community palliative care (CPC) team to a specialist palliative care (SPC) outpatient physiotherapy service for community based individuals with advanced cancer. SPC services are concerned with improving the quality of life of individuals with a life limiting illness through the expert management of symptoms including physical, psychosocial and spiritual. It is recommended that SPC services comprise of a multidisciplinary team including physiotherapists.

Individuals with advanced cancer remain the highest proportion of people accessing SPC services in Ireland. They can experience a wide variety of symptoms including pain, fatigue, breathlessness, decreased mobility and a lower quality of life. Physiotherapy interventions have been shown to be effective in managing many of these symptoms. Physiotherapy led exercise programmes have demonstrated improvements in fatigue, mobility and quality of life. Individuals with advanced cancer who have engaged in SPC physiotherapy reported many benefits including a sense of achievement. Despite evidence to support the role of physiotherapy in SPC, the referral rate to physiotherapy ranges from 24 – 32%. The purpose of this study therefore was to explore referral patterns of a CPC team to a SPC physiotherapy service for community based individuals with advanced cancer.

This study used a mixed methods approach. The quantitative phase of the study compared the profiles of those referred to SPC physiotherapy with those not in terms of demographic details, diagnosis, burden of disease, symptoms experiences and the severity of these. This was achieved through a retrospective medical chart audit, using a data extraction tool designed to answer the research questions. Thirty-eight charts of those referred to SPC physiotherapy and 102 charts of those not were reviewed. Descriptive and comparative statistics were used to present the results. The qualitative phase consisted of focus groups to explore the CPC teams understanding of the role of SPC physiotherapy and what factors are considered prior to referring to physiotherapy. Focus groups were audio recorded and transcribed verbatim. They were analysed using a thematic content framework approach.

There were a number of variables from the medical chart audit that achieved a significant difference. Those who were referred to SPC physiotherapy were younger than those who were not, they had a higher score on the palliative performance score indicating a better functional ability, they were under the care of the CPC services for longer, had received more cancer related treatment prior to their referral to SPC services, and were continuing to undergo more cancer related treatment at the time of their initial assessment with SPC services. On examining for differences in the proportion of individuals referred with different cancer types, the only significant difference was in

prostate cancer. A significantly higher proportion of individuals with prostate cancer were referred to physiotherapy than not referred. There was also no difference between the groups regarding the burden of metastatic disease, the symptoms experienced or the severity of these.

The main themes identified from the focus groups were referrals to physiotherapy, the knowledge and expertise of physiotherapy practice in SPC services and the development of SCP physiotherapy services. The participants discussed referrals to physiotherapy in relation to the management of symptoms, mainly decreased mobility and breathlessness. They discussed the psychological benefit to individuals who attend physiotherapy. As well as identifying those who they refer to physiotherapy, they also identified a cohort that they did not refer. Reasons for this included not being aware of the role of physiotherapy in the management of symptoms such as pain or fatigue, a concern that individuals may not be able to engage in physiotherapy or that there may not be an achievable benefit. They also identified potential areas in which they would like the physiotherapy service to develop.

The difference in the performance status of those referred to SPC physiotherapy compared to those not referred may reflect the assumption that individuals with a lower performance status may not be able to participate in physiotherapy or achieve a meaningful benefit. Similarly, the difference in age may be due to a belief that reduced functional ability is expected in older individuals and as such these individuals may not benefit from rehabilitation. The predominance of referrals for decreased mobility and breathlessness management, coupled with the participants not considering a referral to SPC physiotherapy for pain or fatigue management, highlights the need for education regarding the role of physiotherapy in the management of these symptoms. Limitations in the resources available in the physiotherapy department within the study site may also have influenced the results of this study.

One of the primary recommendations from this study is the need for education regarding the breadth of the role of SPC physiotherapy. Education also needs to address the benefit of physiotherapy for individuals from both a physical and psychological and social perspective, especially older individuals and those with a lower performance status. Another recommendation is the development a referral pathway to SPC physiotherapy to prompt referrals in response to disease progression, symptoms experienced and psychological distress. The results of this study highlight the importance of clear communication between SPC physiotherapy services and those who are referring. Further research is needed to explore reasons why individuals are not referred to SPC physiotherapy, particularly older individuals and those with a lower performance status.

Glossary

6MWT	6 Minute Walk Test
ADL's	Activities of Daily living
ADT	Androgen Deprivation Therapy
BPI	Brief Pain Inventory
CI	Confidence Interval
CIS-Fatigue	Checklist Individual Strength - Fatigue severity subscale
CPC	Community Palliative Care
EAPC	European Association of Palliative Care
EORTC-C30	European Organisation for Research and Treatment of Cancer - Core Questionnaire
ESAS	Edmonton Symptom Assessment Scale
ESMO	European Society for Medical Oncology
FACT-F	Functional Assessment of Cancer Treatment - Fatigue subscale
FACT-L	Functional Assessment of Cancer Treatment - Lung Cancer
GI	Gastro-Intestinal
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HR-QOL	Health Related Quality of Life
HSE	Health Service Executive
IHF	Irish Hospice Foundation
KPS	Karnofsky Performance Scale
MDM	Multidisciplinary Meeting
MDT	Multi-Disciplinary Team
MND	Motor Neuron Disease
MQOL	McGill Quality of Life Instrument
NCCP	National Comprehensive Cancer Pathway
NICE	National Institute for Health and Care Excellence
OPD	Outpatient Department
OT	Occupational Therapist / Therapy
PAS	Patient Administration System
PCPSS	Palliative Care Problem Severity Score
PHN	Public Health Nurse
PMedHx	Past Medical History
PPS	Palliative Performance Scale
PV	Prolonged Vaginal

QOL	Quality of Life
RCT	Randomised Control Trial
SD	Standard Deviation
SFHD	St. Francis Hospice Dublin
SPC	Specialist Palliative Care
TENS	Transcutaneous Electrical Nerve Stimulation
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation
WTE	Whole Time Equivalent

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1. Introduction

1.1. Background and Need

Individuals with advanced cancer are the highest proportion of specialist palliative care (SPC) service uses in Ireland (Health Service Executive & Irish Hospice Foundation, 2008). The role of SPC services is to support individuals with a life limiting illness through expert symptom management; physical, psychosocial or spiritual (World Health Organisation, 2002). SPC services are provided in acute hospitals, community services and inpatient hospices. SPC services are tailored to the individuals need based on their symptoms and are delivered in collaboration with primary healthcare services such as general practitioners and hospital consultants.

Individuals with advanced cancer may experience many distressing symptoms including pain, breathlessness, fatigue, decreased mobility and a lower quality of life. The proportion of individuals who experience these symptoms is difficult to quantify due to the variety of different measures available to assess this. This can lead to a different interpretation of symptoms and also lead to symptoms not being recorded unless the symptom is assessed as moderate or severe (Kirkova et al., 2011, Van den Beuken-van Everdingen et al., 2007, Van den Beuken-van Everdingen et al., 2009).

In the literature reviewed for this study, the published rates of the number of individuals with advanced cancer who experienced pain ranged from 58 – 84% (Van den Beuken-van Everdingen et al., 2007, Walsh et al., 2000). The numbers of individuals with advanced cancer who reported breathlessness as a symptom ranged from 46 – 58% (Van den Beuken-van Everdingen et al., 2009, Kirkova et al., 2011). However, this increased to 90% for individuals with advanced lung cancer (Farquhar et al., 2014). Fatigue was reported in a number of different ways in the literature examined in this study. Kirkova et al. (2011) reported that 69% of individuals with advanced cancer experienced fatigue. Van den Beuken-van Everdingen et al. (2009) reported that 45 – 69% of individuals with advanced cancer reported ‘feeling tired’. The presence of these symptoms can negatively affect individuals’ quality of life (QOL) (Van den Beuken-van Everdingen et al., 2009, Cramarossa et al., 2013).

Physiotherapy is recognised as a core discipline within specialist palliative care (SPC) services (Department of Health and Children, 2001). The National Institute for Health and Care Excellence (NICE) guideline 'Improving supportive and palliative care for adults with cancer' recommended that physiotherapists be included as part of the specialist palliative care team, with a specific emphasis on the role of rehabilitation for these patients (NICE, 2004). SPC physiotherapy interventions have demonstrated improvements in the symptoms experienced by individuals with advanced cancer. In randomised control trials, Farquhar et al. (2014) and Higginson et al. (2014) both reported improvements in breathlessness experienced by individuals with advanced cancer following an interdisciplinary SPC intervention that included physiotherapy. Chasen et al. (2013) reported improvements in fatigue following an eight week interdisciplinary intervention which included twice weekly physiotherapy led exercise classes. Improvements in fatigue scores were also reported following physiotherapy led exercise interventions by Van den Dungen et al. (2014) and McGrillen and McCorry (2014). Physiotherapy led exercise interventions have also demonstrated improvements in mobility, and quality of life (Oldervoll et al., 2011, Van den Dungen et al., 2014, Chasen et al., 2013). There have also been a number of studies who have positively described the experiences of those who had engaged in SPC physiotherapy (Gulde et al., 2011, Turner et al., 2016).

The majority of research that investigated the benefit of physiotherapy for individuals with advanced cancer recruited community based individuals. Despite this, the referral rate for community based individuals ranges from 24 – 32% compared with 65 – 100% of individuals in inpatient services. Jensen et al. (2014) reported that all individuals admitted to an inpatient SPC service were offered physiotherapy with 92% of them engaging in at least one intervention. Cobbe and Kennedy (2012) reported that 65% of individuals in an inpatient SPC service were referred to physiotherapy and 58% engaged physiotherapy. However, Cobbe et al. (2013) reported a referral rate of 24% and Mueller and Decker (2011) reported a referral rate of 32% of community based individuals under the care of SPC services to physiotherapy. A potential reason for the lower rate of referral for community based individuals to physiotherapy may be the reliance on other healthcare professionals identifying a need for physiotherapy.

Anecdotally, it had been noted within the physiotherapy service of the research site, that there appeared to be a cohort of individuals that may have benefitted from outpatient SPC physiotherapy prior to an admission to the hospice. This variation in the referral patterns, in conjunction with the published low referral rates to SPC physiotherapy for community based individuals prompted the research question.

This study aims to explore the referral patterns to SPC physiotherapy for community based individuals. Identifying the profile of individuals who are referred to SPC physiotherapy and comparing them to those who are not will help to identify any patterns in terms of demographics, disease profile and symptoms experienced. While a number of studies have described the profile of individuals who have been referred to and engaged in SPC physiotherapy, this is the first study, to our knowledge to compare in detail the profiles of individuals who are referred to SPC physiotherapy service and those who are not. The second part of this study will explore the community palliative care (CPC) teams understanding of the role of physiotherapy in SPC and identify the factors that they consider prior to referring individuals to physiotherapy.

1.2. Research Context:

St. Francis Hospice Dublin (SFHD) provides SPC services to north Dublin city and county encompassing a population of approximately 621,000 individuals. There are four clinical strands of the services provided across two sites.

- ❖ Community services; Members of the CPC team provide care in the individual's home. The team included doctors, nurses, medical social workers and chaplains.
- ❖ Outpatient services; Community based individuals are referred for a specific discipline (physiotherapy, complementary therapy or lymphoedema) and attended for their scheduled appointment.
- ❖ Day care service; Community based individuals attend for 5 hours, are reviewed by a specialist nurse, medical social worker and complementary therapist as required and they may engage in other activities such as art as they choose.
- ❖ Inpatient services; Individuals are admitted for symptom control or end of life care. They are reviewed by members of the multi-disciplinary team (doctors, nurses, physiotherapists, occupational therapists, complementary therapists and medical social workers) as appropriate.

At the time of this study, physiotherapy services were provided to inpatients and to community based individuals through the outpatient service.

1.3. Research aims and objectives

The overall aim of this research was to understand the referral patterns of the CPC team to specialist palliative care SPC physiotherapy for community based individuals with advanced cancer.

The research questions were

1. Are there significant differences in the profile of individuals in a community palliative care service who are referred to SPC physiotherapy from those who were not referred to physiotherapy?
2. What is the CPC teams' understanding of the role of physiotherapy in SPC and what factors initiate a referral to the service?

The specific objectives were:

1. To describe the profile of individuals under the care of the community palliative care (CPC) team who are referred to SPC physiotherapy and those who are not.
2. To compare the profiles of those who are referred to SPC physiotherapy and those who are not, in terms of demographic details, disease profile and symptoms experienced.
3. To explore the CPC teams' understanding of the role of physiotherapy in a SPC service.
4. To identify what factors members of the CPC team consider when referring individuals who they believe may benefit from SPC physiotherapy.

1.4. Methodology Used

This was a mixed methods research study using a sequential exploratory design (Creswell, 2011). Quantitative data were collected through a medical chart audit in order to describe the profile of individuals referred to SPC physiotherapy and compare them to those who were not referred. A data extraction tool was developed to record demographic details, social supports, disease information, previous and ongoing treatment, phase of illness, palliative care performance status, symptoms experienced, pain severity and severity of other symptoms. Descriptive analysis was completed in order to describe the profile of individuals. The continuous data were described as mean (standard deviation) or median (interquartile range). The categorical data were presented as count (percentage). Comparative analysis was completed to compare the profiles of individuals who were referred to SPC physiotherapy to those who were not. This included independent t-tests, Wilcoxon Sign rank test and Chi-squared tests as appropriate to the data type and normality of distribution.

To contextualise the data collected from the medical chart audit, focus groups were also carried out to examine the CPC team's understanding of the role of physiotherapy in SPC and how they identify individuals who they feel would benefit from SPC physiotherapy. All members of the CPC team were invited to participate in the focus groups. A focus group arranged at each clinical site and those who consented to participate in the research attended. The focus groups were facilitated by the research supervisor who has experience in qualitative interviewing but not affiliated with the research site. This reduced the risk of bias. The focus groups were audio recorded and these were transcribed verbatim. The transcripts were analysed using a thematic analysis framework.

1.5. Definition of terms

1.5.1. Palliative care

Palliative care is defined as an approach that improves the quality of life of individuals with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation, 2002). Palliative care needs are assessed through four domains; physical wellbeing, social and occupational wellbeing, psychosocial wellbeing and spiritual wellbeing (National Clinical Programme for Palliative Care, 2014).

1.5.2. Specialist Palliative Care

Specialist Palliative Care is defined by (Ryan et al., 2014) as services whose core activity is limited to the provision of palliative care. These services are involved in the care of individuals with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources.

1.5.3. Community Palliative Care

Community palliative care refers to the provision of specialist palliative care to the individuals in their own homes. Members of the community palliative care team work in collaboration with the individuals primary care team and provide an advisory support in relation to complex symptom management (Department of Health and Children, 2001).

1.5.4. Specialist Palliative Care Physiotherapist

The specialist palliative care physiotherapist works solely in the provision of palliative care. They have advanced knowledge and understanding of the full spectrum of trajectories of life-limiting conditions when responding to complex and multidimensional care needs. They act as an expert resource to physiotherapy colleagues who work outside SPC services (Ryan et al., 2014).

1.5.5. Primary Care Physiotherapist

The primary care physiotherapist is a member of the primary care team which includes general practitioners, community nursing, occupational therapist, medical social workers and healthcare assistants. A primary care team is a team of health professionals who work closely together to meet the needs of the people living in the community. They provide a single point of contact to the health system for the person. The role of the primary care team is to provide a range of services that are focused on improving the health and social well-being of community based individuals. They also help to co-ordinate individuals care across a variety of health and social care services (Health Service Executive et al., 2011).

1.6. Conclusion

This study intends to explore the referral patterns of the CPC team to SPC physiotherapy for community based individuals with advanced cancer. It aims to accurately describe the profile of individuals who are referred to SPC physiotherapy and compare them to those who are not. This study hopes to contribute to the body of knowledge regarding the understanding of other healthcare professionals in relation to the role of physiotherapy in SPC. As referrals to SPC physiotherapy are often dependent on other healthcare professionals recognising the need, it is important to understand their perception of the role of physiotherapy in SPC.

The observations of this study can be used to inform SPC physiotherapy departments develop their service, in order to meet the needs of those who are referred. Examining the profile of those who were not referred and the reasons discussed within the focus groups that some individuals were not considered for SPC physiotherapy may also influence service development.

The study will provide recommendations for education for other healthcare professionals regarding the role of SPC physiotherapy. To this end, it is anticipated that it will facilitate the design of future educational programmes, particularly addressing the concerns regarding individuals' ability to participate in SPC physiotherapy and the benefit of SPC physiotherapy in the management of symptoms other than decreased mobility and breathlessness.

The findings from this study will also inform the development of a referral pathway to SPC physiotherapy. Considerations for a referral pathway should include the timing of a referral and prompts to refer in response to symptom need.

2. Literature Review

2.1. Introduction

This chapter will provide an overview of specialist palliative care (SPC). SPC is a person centred approach that is concerned with quality of life. It will also describe the role of physiotherapy in SPC and how it supports the needs of the individual. The literature regarding physiotherapy in the management of common symptoms experienced by individuals with advanced cancer will be discussed. The experience of people who engaged with SPC physiotherapy will be presented. The referral practices of healthcare professionals to SPC physiotherapy will also be discussed.

2.1.1. Literature Retrieval

The focus of this literature review is on how physiotherapy in SPC services can support the needs of those with advanced cancer. A narrative overview of the literature to support the role of physiotherapy in SPC is presented.

In order to identify the pertinent literature, electronic searches were carried out using PubMed, CINAHL complete and MEDLINE. Keywords used in the search included 'physiotherapy', 'pain', 'fatigue', 'breathlessness', 'dyspnoea', 'rehabilitation', 'exercise', 'symptoms in palliative care', 'benefit of SPC', 'understanding of physiotherapy', 'referrals', and 'physiotherapy' or 'specialist palliative care' or 'advanced cancer'. To further augment the literature retrieval process, manual searches of the reference list of relevant research were also carried out.

External publications from the Health Service Executive (HSE), Irish Hospice Foundation (IHF), Hospice UK and the National Institute for Health and Care Excellence (NICE) were also used to support the literature review.

The literature will be reviewed and discussed in the following categories; specialist palliative care, physiotherapy in the management of symptoms experienced by those with advanced cancer, physiotherapy service provision in SPC and the beliefs and attitudes of healthcare professionals towards physiotherapy in SPC.

2.2. Definition of Palliative Care

Palliative care is a relatively new speciality of modern medicine. In the 1980s a number of notable events occurred to develop and formalise the role of palliative care worldwide within health care. Firstly, a collaboration between cancer pain management experts and 'terminal care experts' developed cancer pain relief clinical guidelines in 1986 which were then adopted by the World Health Organisation (WHO). Then in 1987, the UK became the first European country to formalise their medical training scheme to include palliative care as a speciality. Finally in 1989, the first palliative care definition was endorsed by the WHO following a committee meeting of experts in palliative care (Clark, 2011).

Currently the WHO defines palliative care as "an approach that aims to improve the quality of life of patients and their families who are facing problems associated with life-threatening illnesses. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" (World Health Organisation, 2002). While there may be an assumption that palliative care is primarily focused on pain management at end of life, the WHO include physical, psychosocial and spiritual principles within the remit of palliative care. They include providing relief from pain and other distressing symptoms, offering a support system to help individuals to live as actively as possible until their death, offering a team approach to address both their needs and their family's' needs, and integrating a psychological and spiritual aspects in the delivery of care. Palliative care should affirm life and accept dying as a normal process while neither hastening nor postponing death (World Health Organisation, 2002). The WHO (2017) advises that palliative care should be applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and include investigations as required to better understand and manage distressing clinical complications. The overarching aim of palliative care is to enhance the quality of life (QOL) of people faced with a life limiting illness.

2.3. Specialist Palliative Care

In Ireland, the Department of Health has defined three hierarchical levels of palliative care provision (Department of Health and Children (2001). Level one, known as a palliative care approach, is described as adopting the principles of palliative care by all healthcare professionals and promoting physical and psychosocial wellbeing throughout a person's illness. Level two, generalist palliative care, is provided by healthcare professionals who have some additional training in palliative care. Level three, specialist palliative care (SPC), refers to services or healthcare professionals whose core activity is the provision of palliative care. The Health Service Executive (HSE) and Irish Hospice Foundation (IHF) recommend that SPC services are provided by an inter-disciplinary team, under the direction of a palliative medicine consultant (Health Service Executive & Irish Hospice Foundation, 2008). The inter-disciplinary team should include doctors, nurses, medical social workers, chaplains, pharmacists, physiotherapists, occupational therapists, speech and language therapists and dieticians. Specialist palliative care services are involved in the care of individuals with more complex and demanding care needs, and consequently, require a greater degree of training and staffing levels (Health Service Executive & Irish Hospice Foundation, 2008).

In Ireland, the National Clinical Programme for Palliative Care (2014) developed a needs assessment guidance to help identify individuals who would benefit from SPC involvement. The eligibility criteria for referral to SPC services include having a life-limiting illness, and current or anticipated complexities relating to symptom control requiring end of life care planning, or presenting with other physical, psychosocial or spiritual care needs that cannot reasonably be met by the current care providers i.e. general practitioner and primary care teams. SPC teams do not replace primary care teams but work collaboratively with them.

SPC community services support individuals at home through expert symptom management and aim to reduce the number of potentially avoidable hospital admissions or emergency department visits at end of life (Seow et al., 2010, Noble et al., 2015). It has been estimated that approximately 90% of individuals in their last year of life will spend some time in hospital (Gott et al., 2011). In a Canadian study examining the use of community based SPC services among 9018 individuals with palliative care needs, those who were referred to SPC services 6 months before death had a 35% lower

probability of being admitted to hospital compared with those referred 3 – 4 weeks prior to death (Seow et al., 2010). A United Kingdom (UK) based study conducted by Noble et al. (2015) found that those referred to SPC community services prior to a hospitalisation spent less time in hospital (mean 3.3 days) compared with those who were not referred (mean 10.9 days). These findings suggest that early involvement of SPC community services can enable people to stay at home for longer.

In the Irish context, SPC services are available in acute hospitals via the palliative care team, community palliative care teams, SPC day hospices, SPC outpatients and inpatient hospice care services (Health Service Executive, 2009). The provision of specialist palliative care services across all domains varies widely despite standard minimal staffing recommendations for each discipline as outlined by the National Advisory Committee on Palliative Care (2001). For example, in the community setting, one palliative medicine consultant per 160,000 population, one SPC nurse per 25,000 population and a medical social worker, a physiotherapist and an occupational therapist per 125,000 population is recommended.

In 2017, the HSE published the Palliative Care three year development framework which reviewed the existing SPC services in Ireland during 2016 (Health Service Executive, 2017). Staffing deficits are described across a range of professions. For example, in community palliative care nursing, there is a deficit of 23.1 whole time equivalent (WTE) (12%) posts. Crucially however, staffing deficits are more pronounced among allied health professions. In Ireland, 37.8 (WTE) SPC community based physiotherapist are recommended however with just 5 WTE physiotherapists in post across all SPC services within Ireland, there is a deficit of 32.8 WTE (87%). Occupational therapy with the same recommended staffing level, also have a significant deficit of 29.8 WTE (79%). The consequence of staffing deficits of SPC physiotherapists within the community setting is that the physiotherapy needs of these individuals requiring SPC support are being addressed by level one or level two palliative care practitioners, who would not be expected to have the same level of competence with this cohort (Ryan et al., 2014).

The competences underpinning the palliative care approach, generalist palliative care and specialist palliative care practitioners in physiotherapy are outlined in detail in the Palliative Care Competence Framework (Ryan et al., 2014). SPC physiotherapists are expected to have an advanced knowledge of life limiting illnesses while responding to complex and multidimensional needs. The advanced competences of the SPC physiotherapist include but are not limited to; advanced symptom management, palliative rehabilitation, timely and focused interventions based on the needs and goals of the individual, close collaboration with other members of the multi-disciplinary team (MDT), excellent communication with the individual and their family and managing the psychological impact of a life limiting illness on function and other symptoms. Physiotherapy is a recognised core profession within SPC and as such should have specialist physiotherapists providing an expert service to patients (Ryan et al., 2014).

2.4. Management of common symptoms in advanced cancer

People with advanced cancer are the most frequently referred individuals to SPC services in Ireland (Health Service Executive & Irish Hospice Foundation, 2008). These individuals can experience a wide range of symptoms including pain, fatigue, breathlessness, reduced function/mobility, poor QOL, and anxiety and depression. Early identification and assessment of symptoms, in conjunction with appropriate evidence based treatment should be available to everyone with advanced cancer to maximise their wellbeing (World Health Organisation, 2002). The essence of palliative care is a holistic patient centred approach which incorporates both pharmacological and non-pharmacological interventions that address both physical and psychosocial symptoms. As the primary focus of this thesis examines the role of physiotherapy in SPC services, the literature discussed in this section will focus on those symptoms for which there is evidence to support the role of physiotherapeutic interventions.

2.4.1. Pain

Pain experienced by people with advanced cancer is very complex in nature (Smith and Saiki, 2015). Physical pain may occur at the site of the primary tumour or at the sites of metastatic disease. Cancer treatments can also cause pain, for example pain associated with chemotherapy induced peripheral neuropathy and pain around surgical sites. Individuals can also experience pain due to an underlying comorbidity such as arthritic conditions (Patel et al., 2013).

Pain is the most common symptom experienced by people with advanced cancer as identified by several studies, with estimates ranging from 58-84% depending on the measure used and the focus of the pain assessment. Both Walsh et al. (2000) and Kirkova et al. (2011) reported a similar number of individuals with advanced cancer reporting pain (84% of 1000 patients and 83% of 796 patients) using the same clinical 38 item symptom checklist. In a large population based study in the Netherlands, Van den Beuken-van Everdingen et al. (2007) reported that 58% of people undergoing palliative treatment (n=571) and 75% of individuals for whom treatment was no longer appropriate (n=90) experienced moderate or severe pain as captured using the European Organisation for Research and Treatment of Cancer Core Questionnaire (EORTC-C30) and the Brief Pain Inventory (BPI). A meta-analysis of symptom prevalence in older adults (>65) with advanced cancer reported a pooled incidence of pain of 66.3% (Van Lancker et al., 2014). It is evident from these studies that many people with advanced cancer experience pain which can impact on their overall wellbeing.

Cancer pain can be considered to be nociceptive, visceral, neuropathic, incidental or mixed in nature (Smith and Saiki, 2015). The European Society for Medical Oncology (ESMO) published comprehensive guidelines for the management of cancer pain in 2012 which focus primarily on the medical approach including the use of opioids and other adjunctive analgesia such as simple analgesia, non-steroidal anti-inflammatory drugs, neuropathic analgesia and the use of nerve blocks. It also advised the use of radiotherapy and bisphosphonates in the management of metastatic bone pain (Ripamonti et al., 2012). The National Institute for Health and Care Excellence (NICE) guidelines 'Palliative care for Adults: strong opioids for cancer pain' and the National Clinical Guideline No. 9: Pharmacological management of cancer pain in adults also

provide comprehensive information with regards to the use and titration of opioid medication in the management of cancer pain including incidental pain (NICE, 2012, Department of Health, 2015). Non-pharmacological approaches to the treatment of pain are recommended by a number of expert groups such as the British Pain Society and the American agency for health and care policy and research (British-Pain-Society, 2010, Jacox et al., 1994).

The presence of pain cannot be considered in isolation, as the impact of pain can affect other aspects of the individuals' wellbeing. Pain can impact on their functional ability. A large population based study of older adults in the United States (n=8,245) found that those who experienced pain had a higher prevalence of functional difficulties which increased with the number of reported pain sites (Patel et al., 2013). For individuals with four or more sites of pain they reported an odds ratio of 2.05 (95% Confidence Interval (CI) 1.83 – 2.3) of being unable to walk approximately a quarter of a mile and an odds ratio of 2.9 (2.07 – 4.07) for being unable to grasp small objects.

There are many physiotherapy interventions for pain management. These include exercise, manual therapies including joint mobilisation and massage, hot and cold therapy, transcutaneous electrical nerve stimulation (TENS) and the provision of supports and splints (Jacox et al., 1994, Van den Broek et al., 2013). While these treatments are routine physiotherapy interventions, the skill of the SPC physiotherapist lies in the ability to modify treatment in response to the underlying pathology and other symptoms experienced by the individual (Van den Broek et al., 2013). Of note, however, to date there have been no studies that have examined the direct effects of physiotherapeutic techniques on pain scores in people with advanced cancer, highlighting that current practice is largely guided by clinical expertise.

Cognitive approaches to cancer pain management have been shown to be effective in people with advanced cancer (Syrjala et al., 2014). These approaches include cognitive behavioural therapy, coping skills, education regarding pain mechanisms and relaxation with imagery. Although these techniques are not physiotherapy specific, they are approaches that physiotherapists can use in conjunction with their interventions. Similarly promoting independence and self-efficacy are a routine component of physiotherapy interventions. A conceptual model proposed by Boveldt et al. (2014)

suggests that patient empowerment could potentially positively influence pain in individuals with cancer. Self-efficacy and shared decision making between the clinician and the patient form the basis of this model.

Successful pain management in SPC involves a combination of pharmacological and non-pharmacological approaches which takes into account the mechanism of pain, the impact of pain and other external influences on the individuals' experience of pain. SPC physiotherapists working collaboratively with other members of the SPC team can positively contribute towards the management of pain in advanced cancer.

2.4.2. Breathlessness

Breathlessness in advanced disease, including cancer, is a complex symptom that may arise due to respiratory, cardiovascular, musculoskeletal, systemic causes or psychological triggers (Chin and Booth, 2016). Breathlessness can cause significant distress and anxiety to individuals which can have a negative effect on their quality of life (Chin and Booth, 2016). Breathlessness can also impact on their functional ability and independence in completing activities of daily living (ADL's), thus increasing reliance on carer support (Hately et al., 2003).

Two studies measuring symptom burden in advanced cancer, using the same 38-item symptom checklist, reported similar rates of breathlessness (Walsh et al., 2000, Kirkova et al., 2011). Walsh et al. (2000) reported that 50% of 1000 individuals with advanced cancer complained of breathlessness. Similarly Kirkova et al. (2011) found that 58% of 796 people reported breathlessness. Van den Beuken-van Everdingen et al. (2009) reported that 22% of individuals undergoing palliative treatment (n=571) and 46% of those for whom treatment was no longer feasible (n = 90) reported moderate to severe breathlessness. A higher percentage of individuals reporting breathlessness is reported in those with advanced lung cancer which range from 75% (Johnson and Currow, 2016) to 90% (Farquhar et al., 2014). These studies suggest that breathlessness is a common symptom for people with advanced cancer, especially those with lung cancer.

As there are many non-pharmacological approaches to breathlessness management, the literature tends to focus on evaluating the effectiveness of multimodal clinically based services rather than on a single non-pharmacological intervention. These interventions include breathing techniques, postural and positioning advice, fan therapy, physical exercise, pacing advice and relaxation and anxiety management and are individualised to the person based on clinical judgement (Farquhar et al., 2014, Chin and Booth, 2016). Non-pharmacological interventions for breathlessness management are primarily delivered by physiotherapists and occupational therapists.

Farquhar et al. (2014) examined the level of distress caused by breathlessness as the primary outcome to measure of effectiveness of a UK SPC interdisciplinary breathlessness service in a small scale randomised control trial (RCT). The participants (n=23) were reviewed by a palliative medicine consultant, a clinical specialist occupational therapist and a clinical specialist physiotherapist who provided clinically indicated pharmacological and non-pharmacological interventions. They found a significantly greater reduction in distress in the intervention arm following the intervention compared with the control group (n=24) as measured by an 11-point numerical rating scale (adjusted difference -1.29 (95% CI -2.57 to -0.005, p=0.049)).

Higginson et al. (2014), in a slightly larger RCT, also reported improvements in people's ability to manage their breathlessness following a similar interdisciplinary based breathlessness management service. The intervention included a medical review by both respiratory and palliative care consultants with a follow up review from both a SPC physiotherapist and occupational therapist. Significant improvements were seen in participants' ability to manage their breathlessness as measured by the mastery subsection of the chronic respiratory questionnaire (0.58 (95% CI 0.01 to 1.15, p=0.048)) when comparing the intervention arm (n=42) to the control group (n=40) upon completion of the breathlessness programme. The services described in these RCTs are reflective of clinical practice where people avail of both medical and non-pharmacological management of breathlessness.

A Cochrane review published in 2011 also supported the use of non-pharmacological interventions for the management of breathlessness in palliative care patients. The review concluded that there was high strength evidence for the use of neuromuscular stimulation and chest wall vibrations and moderate strength evidence for the use of walking aids and breathing exercises in breathlessness management (Bausewein et al., 2011).

These studies indicate that non-pharmacological interventions for the management of breathlessness can improve patient outcomes. Significant improvements were observed when individuals participated in multimodal interventions that incorporated both a medical and therapeutic approaches. The therapeutic interventions were most commonly provided by physiotherapy and occupational therapy.

2.4.3. Fatigue

Fatigue is a multifaceted symptom, the aetiology of which is not yet fully understood. Solid tumours and anti-cancer treatments can affect patients' metabolism through a variety of pathophysiological processes such as the production of inflammatory cytokines from the tumour or cancer related treatments (Yennurajalingam and Bruera, 2011). Concurrently psychological issues, deconditioning, uncontrolled symptoms, anaemia, infections and hypoxia may also be contributing to fatigue experienced by patients (Yennurajalingam and Bruera, 2011). The European Association for Palliative Care (EAPC) currently defines fatigue as 'a subjective feeling of tiredness, weakness or lack of energy' (Radbruch et al., 2008). However, the identification of fatigue as a symptom varies depending on what assessment tool is used. The EORTC-C30 has 3 questions that together are referred to as the 'fatigue construct'. These include 'Were you tired', 'Have you felt weak' and 'Did you need to rest' (Radbruch et al., 2008). The Edmonton Symptom Assessment Scale (ESAS) records fatigue as a singular item scored out of 10. It is worth noting that the discrepancy with regards to terminology used for fatigue makes comparison between studies challenging. Also, when interpreting these scales, it is important to be cognisant of the different dimensions of fatigue that are being measured. For example, the ESAS rates the severity of fatigue but does not measure the impact of fatigue on individuals' ability to complete ADLs.

In the self-developed symptom checklist by Walsh et al. (2000), the descriptive terms of 'easy fatigue' and 'weakness' are used to identify fatigue, however the authors did not define these terms. They reported that 'easy fatigue' was experienced by 69% of individuals and 'weakness' was experienced by 66% of 1000 individuals with advanced cancer. Similarly, Kirkova et al. (2011) reported that 69% of individuals with advanced cancer (total n=796) experienced fatigue using the same checklist. Van den Beuken-van Everdingen et al. (2009) reported that the fatigue construct of the EORTC-C30 was the most common moderate to severe, non-pain symptom identified by individuals under the care of SPC services. The percentage of people 'feeling weak', 'feeling tired' and 'need to rest' was recorded as 31%, 45% and 43% respectively for those undergoing palliative treatment and 65%, 69% and 74% respectively for those for whom treatment was no longer feasible. A meta-analysis of symptom prevalence experienced by older adults with advanced cancer also reported a high incidence of 'fatigue' and 'weakness' with a pooled prevalence rate of 77.8% and 66.3% (Van Lancker et al., 2014). From these studies it appears that fatigue is reported by many individuals with advanced cancer.

The EAPC published a comprehensive review of fatigue in palliative care patients in 2008 (Radbruch et al., 2008). They reported that fatigue can impact on both physical and mental abilities and is often associated with low mood. This expert group recommend a multidisciplinary approach to fatigue management. They also concluded that there was strong evidence that physical exercise training reduced cancer related fatigue. The National Comprehensive Cancer Network (NCCN) Clinical Practice guidelines in Oncology for the management of cancer related fatigue also recommend both pharmacological and non-pharmacological approaches (Berger et al., 2015). They concluded that there is category one evidence to support physical activities, physical based therapies and psychosocial interventions. A study of the physiotherapy management of cancer related fatigue in the UK, found that 78% of physiotherapists recommended and / or used exercise as part of their treatment and 74% taught other strategies including activity pacing (Donnelly et al., 2010).

Physiotherapy-led exercise training, as part of an interdisciplinary approach to fatigue management may have a role in the overall management of cancer related fatigue. An interdisciplinary palliative rehabilitation programme used the multidimensional fatigue inventory to measure fatigue. It measures fatigue across three domains: general fatigue, physical fatigue and decreased physical activity. Participants reported a significant

reduction in fatigue scores, when comparing pre-intervention assessment to post-intervention assessment across all domains; general (15.53(3.3) v's 13.35(3.49) $p < 0.001$), physical (15.9(3.27) v's 14.09(3.42) $p < 0.001$) and decrease activity (15.38(3.62) v's 13.69(3.97) $p = 0.001$) (Chasen et al., 2013). The interventions in this eight-week single arm intervention study included twice weekly physiotherapy led exercise classes and interventions from medical, nursing, occupational therapy, dietetics and social work as required. This study is an example of an effective interdisciplinary approach to fatigue management which is suggested within the literature.

A small RCT evaluated the effects of an eight-week home exercise programme on fatigue for individuals with stage 4 lung or colorectal cancer (Cheville et al., 2013). Participants randomised to the intervention ($n=26$) received a 90 minute instructional session with a physiotherapist who educated them on a resistance based exercise programme and a pedometer based walking programme. Fatigue was measured using the Functional Assessment of Cancer Therapy – Fatigue subscale (FACT-F) at the time of recruitment and at eight weeks for both intervention and control participants ($n=30$). Following the intervention, the mean change in fatigue scores (4.46 (95% CI 0.81-8.11)) was significantly greater in the intervention group compared to the control group (-0.79 (95% CI -4.26-2.67, $p=0.03$)).

Two small single arm physiotherapy led exercise intervention studies, have also reported improvements in fatigue scores (Van den Dungen et al., 2014, McGrillen and McCorry, 2014). Participants in a six week exercise programme experienced a significant reduction in the Checklist Individual Strength Fatigue severity subscale (CIS-fatigue) (pre-intervention 30.4(13.7) v's post-intervention 26.0(14.1) $p=0.01$) following the intervention (Van den Dungen et al., 2014). Similarly McGrillen and McCorry (2014) reported improvements in fatigue scores using the FACT-F for participants following ten physiotherapy led exercise sessions (pre-intervention 22.3(11.6) v's post-intervention 29.3(8.9) $p=0.005$).

2.4.4. Decreased Functional Ability

Functional ability can be defined as the actual or potential capacity of an individual to perform the activities and tasks that can be normally expected (Encyclopaedia of Public Health (2008). The term 'functional ability' can be used to describe a wide range of tasks including mobility, self-care (toileting, washing, dressing, eating) and social interactions. Physical functional ability is one of the most important determinates of quality of life (QOL) for individuals under palliative care services (Oldervoll et al., 2006). Decreased functional ability is also linked to higher care needs which can be a predictor of hospitalisation at end of life (O'Brien and Jack, 2010).

Decreasing functional ability, while an inevitable consequence of progressive cancer, can also be an initial symptom of cancer, or can arise as a result of anti-cancer treatment and associated deconditioning (Cobbe, 2013). Cancer cachexia also contributes to a deterioration in physical function due to the loss of skeletal muscle mass (Solheim et al., 2018). Despite this, functional ability is not often reported in the evaluation of symptom burden in SPC (Walsh et al., 2000, Kirkova et al., 2011, Van den Beuken-van Everdingen et al., 2009, Van Lancker et al., 2014). However, when examining patient priorities, Strömberg et al. (2006) found that 39% of individuals prioritised reduced physical function in their top five symptoms they considered most 'troublesome'. This Danish study included 175 people with advanced cancer who identified symptoms through combination of the EORTC-C30 and the ESAS. Similarly, LeBlanc et al. (2015) also found that functional symptoms were the most commonly reported patient identified symptom amongst 97 individuals with advanced non-small cell lung cancer. This study used an 80 item system review survey; each assessed using an 11-point severity scale. Fifteen functional symptoms were identified which ranged from being able to sit up to being able to do hard work or run.

Physical functional ability may be affected by motor deficits, sensory deficits, cerebellar dysfunction, cognitive impairment, deconditioning or a combination of these (Franklin and Cheville, 2011). The management of these can include teaching compensatory strategies, using supportive devices such as walking aids and splints and appropriately prescribed exercise (Franklin and Cheville, 2011).

An emerging theme in recent literature is the implementation and evaluation of exercise programmes for people with advanced cancer aiming to improve or maintain physical functioning. In SPC clinical settings, exercise interventions are delivered by a SPC physiotherapist who has the expertise and advanced knowledge of the complexity of factors that impact on physical function and can modify exercise in response to changes that may occur due to their condition (Ryan et al., 2014).

One large RCT evaluated the effects of a six week aerobic and strengthening exercise programme for a heterogeneous sample of individuals with advanced cancer (Oldervoll et al., 2011). Following the intervention both hand grip strength (2Kg (95% CI 0.4-3.5Kg, $p=0.01$)) and the six minute walk test (6MWT) (60m (95% CI 16-103.4m, $p=0.008$)) were significantly higher in the intervention arm ($n=78$) compared to the control arm ($n=85$). Hand grip strength is a valid measure of overall muscle strength and therefore can be considered an important component of functional ability (Taekema et al., 2010). It has also been found to be a valid predictor of survival in patients with advanced cancer and as such, is often used as an outcome measure in exercise trials (Kilgour et al., 2013).

In an RCT which examined exercise for men with prostate cancer with bone metastases, Galvão et al. (2017) reported a significant difference in self-reported functioning between the exercise group ($n=22$) compared to the control group ($n=26$) following the intervention as measured by the physical functioning subscale of the SF-36 (mean difference 3.2 (95% CI 0.4-6.0, $p=0.028$)). Examples of items on this scale include washing and dressing, being able to walk several hundred meters, climb stairs and engagement in moderate or vigorous activities. Participants in the intervention group completed a twelve-week exercise programme which included aerobic and resistance exercises. The exercises prescribed were adjusted based on the sites of bone metastases to avoid excessive loading. Significant differences were also observed in knee extension strength between the groups following the intervention (mean difference 6.6Kg (95% CI 0.6–12.7KG, $p=0.033$)), however due to the location of metastases, only 9 exercise participants and 12 from the control group were able to complete this measure.

Two small single arm intervention studies have also reported improvements in physical ability and strength following completion of an exercise programme for individuals with advanced cancer (Oldervoll et al., 2006, Van den Dungen et al., 2014). These two interventions consisted of both aerobic and resistance exercises which participants completed twice weekly for six weeks. Seventeen individuals who completed the intervention experienced a significant improvement in 6MWT distance (435m (135.2m) v's 480m (137m), $p < 0.01$) and hand grip strength (36.1Kg (12.6Kg) v's 39.7Kg (13.2Kg) $p < 0.01$) when comparing pre-intervention assessment to post-intervention assessment (Van den Dungen et al., 2014). Oldervoll et al. (2006) similarly reported significant improvements in the 6MWT distance (481m (144m) v's 510m (156m) $p = 0.007$) and timed sit to stand test (5.1sec (2.3sec) v's 4.1sec (1.4sec) $p = 0.001$) based on data collected from 34 participants before and after the exercise intervention.

Within clinically based SPC services, the effect of physiotherapy-led exercise interventions that included both an aerobic and strengthening component which are individualised to the person have also been evaluated (McGrillen and McCorry, 2014, Talbot Rice et al., 2014). McGrillen and McCorry (2014) reported improvements in the 6MWT (335.8m (145.7m) v's 400.5m (159.1m) $p < 0.001$) and 1 minute repeated sit to stand (16.9 (7.96) v's 23.5 (8.2) $p = 0.001$) in fourteen participants following ten supervised exercise sessions. Twenty eight people completed a similar nine week exercise programme in a study published by Talbot Rice et al. (2014). They reported that participants experienced a mean improvement in both gait speed (0.23m/s (95% CI 0.03 – 0.44m/s, $p = 0.03$)) and five times sit to stand (-5.44 sec (95% CI -10.43 – -0.46sec, $p = 0.03$)) following the intervention.

Functional ability was assessed as one aspect of an eight-week interdisciplinary palliative rehabilitation programme (Chasen et al., 2013). The physiotherapy component of this programme involved twice weekly exercise groups. Sixty-eight people completed the programme and significant improvements were observed when comparing pre-intervention data to post-intervention data. These included improvements in the 6MWT distance (367.38m(123.23m) v's 422.68m(127.6m), $p < 0.001$), timed up and go (11.39sec(6.49sec) v's 9.07sec(3.92sec), $p < 0.001$) and functional reach test (32.69cm(8.03cm) v's 36.01cm(8cm), $p = 0.001$).

Currently, there is a lack of evidence to support the role for exercise in ameliorating cancer cachexia (Grande et al.). However, Solheim et al. (2018) proposed a multimodal approach to the treatment of cancer cachexia that address the inflammatory mechanism, nutritional deficits and exercise training. This approach is based on a successful feasibility study in which 23 individuals with advanced lung or pancreatic cancer completed the intervention, which consisted of daily anti-inflammatory medication, twice daily nutritional supplements, twice weekly 30 minute aerobic exercise and three times per week resistance exercises. Secondary end point of change in weight, strength and walking distance were not adequately powered to conclude effectiveness of the intervention although those in the intervention arm maintained their weight compared to the control group (n=18) (Solheim et al., 2017).

The exercise interventions in the above studies, with the exception of Galvão et al. (2017) took place in SPC physiotherapy settings. All programmes included a strengthening and aerobic component, with some also including balance exercises. The programmes utilised routine equipment in a physiotherapy setting, such as resistance bands, free weights, stationary bikes and balance equipment. Participants attended in small groups and as such, these programmes are easily reproducible in the clinical setting.

Exercise interventions in the palliative care setting have been shown to improve the physical ability as demonstrated by improvements in a number of different outcome measures. Exercise prescription in SPC needs to be modified in relation to disease location and the individual's ability to participate. In the clinical setting, SPC physiotherapists have the knowledge and skills to provide safe and effective exercise interventions. This includes knowledge of the interplay of symptoms on how the individual may present and the potential complications of advanced cancer such as pathological fractures and spinal cord compression. It also includes an awareness of the psychological and spiritual distress that people with advanced cancer may experience (Ryan et al., 2014).

2.4.5. Quality of Life and Non-Physical Symptoms

Palliative care is concerned with both physical and psychosocial wellbeing as reflected in many symptom assessment tools including the physical symptoms discussed above and psychological items such as anxiety, depression and insomnia. People with advanced cancer are also known to have a poorer health related QOL which can be attributed to a combination of physical and non-physical symptoms as a result of the disease or its treatment, therefore QOL is considered to be an important outcome in determining effectiveness of SPC interventions (Kassianos et al., 2018).

With regards to psychological symptoms, Walsh et al. (2000) reported that in a cohort of 1000 individuals with advanced cancer 41% of them experienced depression, 24% reported anxiety and 49% reported sleep difficulties', as captured using a 38 item symptom checklist. Kirkova et al. (2011) published similar results using the same 38 item symptom checklist based on 796 individuals with advanced cancer. They found that 40% of people reported depression, 24% reported anxiety and 48% reported difficulties sleeping. Van den Beuken-van Everdingen et al. (2009) reported that 19% of 571 individuals undergoing palliative cancer treatment experienced severe anxiety and severe depression as measured by a score ≥ 11 in the Hospital Anxiety and Depression Scale (HADS). In the same study, the percentage of individuals who reported moderate or severe symptoms of 'trouble sleeping' was 30%, 'feeling tense' was 24%, 'feeling worried' was 38% and 'feeling irritable' was 22% as identified using the EORTC-C30. A meta-analysis completed by Van Lancker et al. (2014) reported that 50% of older adults with advanced cancer experienced anxiety, 48% experienced low mood and 30% experienced difficulties sleeping. Strömberg et al. (2006) found that of 175 people with advanced cancer, 19% identified depression as one of their top five prioritised symptom. These studies indicate that many individuals with advanced cancer experience some level of psychological distress although the cause of this distress is not examined in these studies.

The QOL of individuals with advanced cancer can be directly affected by the presence of both physical and psychological symptoms as evident from studies carried out by Van den Beuken-van Everdingen et al. (2009) and Cramarossa et al. (2013). Van den Beuken-van Everdingen et al. (2009) completed linear regression analysis and found that fatigue ($p < 0.001$), pain ($p < 0.001$), loss of appetite ($p < 0.001$) and constipation ($p < 0.001$) had a significant negative effect on QOL. Cramarossa et al. (2013) completed multivariate analysis also found that pain ($p < 0.0001$), loss of appetite ($p < 0.0001$) and emotional functioning ($p < 0.0001$) were all associated with a lower QOL. QOL can also be affected by reduced physical functioning either as a result of the disease or disease modifying treatment (Kassianos et al., 2018).

The overall aim of SPC services is to improve the QOL of individuals under their care. A meta-analysis and systematic review of the impact of SPC services on health-related quality of life (HR-QOL) for individuals with advanced cancer concluded that they may experience improvements in several domains of HR-QOL including pain, nausea, fatigue, physical and psychological functioning with the involvement of SPC services (Kassianos et al., 2018).

To date there has been a number of interdisciplinary studies which include a physiotherapy component which have shown improvements in psychological symptoms and QOL. Ferrell et al. (2015) reported a significant improvement in QOL as measured by the Functional Assessment of Cancer Therapy – Lung (FACT-L). They found that individuals with lung cancer who participated in an interdisciplinary palliative care programme had higher scores compared with those receiving standard care (110.5(16.8) v's 99.2(21.1), $p < 0.001$). The intervention, which was conducted in the United States of America (USA) included the management of both physical and non-physical symptoms by an interdisciplinary team consisting of doctors, nurses, dieticians, chaplains, social workers and physiotherapists.

In Canada, Chasen et al. (2013) developed an eight week palliative rehabilitation programme which included twice weekly physiotherapy led exercise groups and interventions from medical, nursing, occupational therapy and medical social worker as required. Anxiety and depression were measured using the Edmonton Symptom Assessment Scale (ESAS) which is an eleven-point numerical rating scale. Following completion of this single arm intervention, significant improvements in anxiety (3.24(2.98) v's 2.35(2.48), $p = 0.004$) and depression (2.97(2.63) v's 1.89(2.22) $p = 0.005$) were observed when comparing baseline data to post-intervention data for the sixty-eight participants.

Physiotherapy led exercise intervention studies in palliative care have also reported improvements in QOL scores. Van den Dungen et al. (2014) reported improvements in QOL scores as measured by the EORTC-C30 in seventeen participants who completed a six week exercise intervention (pre-intervention 63.5(23.3) v's post-intervention 69.9(20.5) $p = 0.02$). McGrillen and McCorry (2014) also reported improvements in QOL scores using the McGill Quality of Life Instrument (MQOL) in participants who had completed ten supervised physiotherapy led exercise interventions (pre-intervention 6.1(1.7) v's post-intervention 7.2(1.4), $p = 0.005$).

The literature presented demonstrates that individuals with advanced cancer may experience many symptoms including pain, fatigue, breathlessness, decreased mobility, anxiety, depression and a lower QOL. There are a variety of physiotherapeutic interventions that have been shown to be effective in the management of these symptoms both in isolation and as part of an interdisciplinary approach.

2.5. Physiotherapy Practice in SPC

Physiotherapy is a recognised core discipline within SPC services. Physiotherapists working directly in SPC services have a wide range of clinical skills, an understanding of disease related complications and impact of psychosocial distress on symptoms and the individuals' ability to engage with physiotherapy services (Jennings, 2013). The NICE guideline 'Improving supportive and palliative care for adults with cancer' recommended that physiotherapists be included as part of the specialist palliative care team, with a specific emphasis on the role of rehabilitation for these patients (NICE, 2004).

2.5.1. Rehabilitation in Specialist Palliative Care

Rehabilitative palliative care is an interdisciplinary approach in which all members of the team, including nurses, doctors, psychosocial practitioners and allied health professionals, work collaboratively with the individual, their relatives and carers to support them to achieve their personal goals and priorities (Tiberini and Richardson, 2015). The goal of rehabilitative palliative care is to improve QOL by enabling people to be as active and productive as possible with minimum dependency on others regardless of life expectancy (Tiberini and Richardson, 2015).

Rehabilitation in palliative care is often described as preventative, restorative, supportive or palliative. These terms have been adopted from the Dietz four track cancer rehabilitation model first proposed during the 1960s (Franklin and Cheville, 2011). Preventative rehabilitation focuses on preventing avoidable functional deterioration as a consequence of the disease or its treatment. Restorative rehabilitation aims to improve function and independence to previous levels. The aim of supportive rehabilitation is to maximise function and independence despite disability. Palliative rehabilitation is supporting patients to adapt to irreversible changes in function and associated loss of independence (Tiberini and Richardson, 2015). SPC physiotherapists are skilled in their ability to recognise and tailor the rehabilitative approach to the individual's needs, regardless of the stage of illness (Ryan et al., 2014, Franklin and Cheville, 2011).

2.5.2. Participant's experience of SPC Physiotherapy

Overall, analysis of the experience of those who have engaged with SPC physiotherapy services, including physiotherapy led group exercise classes have been positive (Dahlin and Heiwe, 2009, Turner et al., 2016, Gulde et al., 2011, Malcolm et al., 2016). These studies explored participants' experiences following their engagement in a palliative exercise programme using semi-structured interviews. Similar themes were identified across all of these studies including improvements in physical and psychological wellbeing, hope, a sense of purpose and support from physiotherapists. However, participants in the study completed by Dahlin and Heiwe (2009) reported that they also had an unclear understanding of the role of physiotherapy within SPC and were offered an insufficient number of interventions.

Individuals value expert guidance regarding their health in relation to physical activity (Sheill et al., 2017b). Individuals with metastatic prostate cancer have identified that their preference is to follow a tailored exercise plan which considers relevant physical and psychological side effects of their illness and that is developed by an expert in the field of oncology exercise prescription (Sheill et al., 2017b). Exercise prescription is a core component of physiotherapy and therefore in the clinical setting, physiotherapists provide exercise interventions for people under the care of SPC services. Individuals receiving specialist palliative care have identified physiotherapists as being able to motivate them to engage in physical exercise as they were able to and felt confident in their knowledge and ability to manage their individual needs (Gulde et al., 2011, Turner et al., 2016).

Physiotherapy, as with all disciplines in SPC is concerned with both the physical and psychosocial wellbeing of patients. Psychosocial distress can present as anxiety, depression, suffering, helplessness, vulnerability, existential or spiritual crisis (Vachon, 2011). The presence of these symptoms may limit individuals' engagement in physiotherapy and may increase the severity of symptoms experienced, such as pain (Novy and Aigner, 2014). Health promotion within palliative care aims to actively involve people in their treatment choices and decision making (Stajduhar et al., 2010). Self-efficacy and health promotion in SPC can give people a sense of control and hope within their illness, which can improve QOL (Stajduhar et al., 2010, Feuz, 2012). Ryan et al. (2014) outlined the competences associated with SPC physiotherapy in managing these

symptoms. This includes creating a “holistic and person centred plan that acknowledges the psychosocial impact of diminishing function and sets realistic goals that have to be continually adapted to individual need”. Evaluation of participants experience of engaging in SPC physiotherapy services identified the following positive outcomes: hope, a sense of meaning and control over their illness (Dahlin and Heiwe, 2009, Gulde et al., 2011, Malcolm et al., 2016, Turner et al., 2016).

2.6. Engagement with SPC Physiotherapy Services

Accessing physiotherapy services within the SPC context is recommended across a wide number of clinical guidelines. NICE guidelines recommend referral to physiotherapy in the management of metastatic spinal cord compression, head and neck cancer, lung cancer, breast cancer, prostate cancer and colorectal cancer. NICE guideline ‘Improving supportive and palliative care for adults with cancer’ and NICE guideline ‘End of Life Care for Adults’ also recommend including physiotherapists as part of the specialist palliative care team (NICE, 2004, NICE, 2011).

2.6.1. Referral Rates

Despite the evidence to support the effects of SPC physiotherapy in optimising many aspects of care in those with advanced cancer and recommendations to include physiotherapy in SPC services, the referral rate to physiotherapy services in SPC varies widely across the literature. Jensen et al. (2014) reported a referral rate of 68% in a SPC inpatient unit when a physiotherapist was included in the SPC team. However, referrals to outpatient based services are reliant on other healthcare professionals recognising the need for physiotherapy and referral rates are considerable lower. The ability to recognise the need for physiotherapy is based on individuals’ understanding of the role of physiotherapy in SPC services.

A small rural based SPC service in the USA which provided both inpatient and community based services for approximately 10,000 people analysed the usage of physiotherapy service, including the referral rate (Mueller and Decker, 2011). Over a one-year period, one hundred and sixty-four people were referred to the SPC community service, of which fifty-two (32%) of them were suitable for community based

physiotherapy. Of note, sixty-six people (40%) were deemed unsuitable for referral as they were actively dying or too weak at the time of initial assessment. The authors hypothesised that the economic climate at the time and associated changes to the healthcare service may have contributed to the late presentation of service users to hospice care and as such reduced the number of suitable referrals to SPC physiotherapy.

In Ireland, a review of community based SPC physiotherapy services in a mixed urban and rural area, servicing a population of approximately 378,000 reported a referral rate of 24% of 682 service users over a six month period (Cobbe et al., 2013). Due to the large geographical area, the community service was provided from one central location and three smaller remote bases. On further examination of the referral patterns, it was noted that the central base, where a physiotherapist was on site five days a week, the referral rate was 37%. This was in contrast to the remote bases without the physical presence of a physiotherapist, where the referral rate ranged from 5% to 10%. With the presence of a SPC physiotherapist in the community team, there is the potential for an increased awareness of the role of physiotherapy in SPC, as evident from the higher referral rates from the central base (Cobbe et al., 2013). Nelson et al. (2012) also suggested that the presence of a physiotherapist within the team could improve referral rates as clinical staff could discuss the appropriateness of the referral.

There are potentially many reasons for the low referral rate to physiotherapy in these studies. These include poor detection of rehabilitation problems by frontline practitioners, poor understanding of the role and benefit of rehabilitation in SPC including the potential for some clinicians to believe that rehabilitation is of limited benefit in SPC (Franklin and Cheville, 2011). Limited access to rehabilitation services and the lack of a clearly defined referral pathway have also been identified as a challenge when discussing the role of rehabilitation services in SPC (NICE, 2004, Nelson et al., 2012, McCartney et al., 2011, Sheill et al., 2017a).

2.6.2. Referral Practices

Nelson et al. (2012) examined the referral practices of public health nurses (PHN) in Northern Ireland in relation to palliative care physiotherapy. Sixteen PHN's participated in focus group interviews. They found that PHNs believed that physiotherapists lacked palliative care skills and may foster false hope. A lack of resources were also raised as a reason not to refer to physiotherapy including long waiting lists and limited number of interventions.

McCartney et al. (2011) also noted similar themes when exploring the barriers to rehabilitation services for people with high grade brain tumours. Following individual interviews with eight healthcare professionals, they found that some professionals reported that referring this group to rehabilitation services could promote unrealistic expectations. The lack of a clear referral pathway and under resourced services which resulted in waiting lists were also identified as potential reasons for this cohort experiencing difficulty accessing rehabilitation services.

Within the physiotherapy profession there is also a poor understanding of the role of physiotherapy with advanced cancer (Taylor and Bryan, 2014). A small qualitative study of non-specialist palliative care physiotherapists attitudes to palliative cancer patients was undertaken at a large UK based acute hospital (Taylor and Bryan, 2014). Twelve physiotherapists participated in the study. The results demonstrated knowledge gaps in relation to the role of physiotherapy in individuals with advanced cancer and poor understanding of how to apply physiotherapy skills to this cohort (Taylor and Bryan, 2014). These physiotherapists also highlighted uncertainty with how to effectively communicate with these individuals in relation to managing their expectations and end of life questions. The NICE guideline on improving supportive and palliative care for adults with cancer also highlighted a lack of appropriate training for allied health professionals in the management of needs of this cohort (NICE, 2004).

In exploring the beliefs of physiotherapists in Ireland working with individuals with advanced cancer, Sheill et al. (2018) also identified knowledge gaps, specifically in relation to exercise prescription for individuals with bone metastases. They found that some physiotherapists based their knowledge on older practices and did not reflect the

recent developments including the work of Cormie et al. (2013), which demonstrated that individuals with prostate cancer and bone metastases were able to safely engage in resistance exercise. These physiotherapists however did acknowledge the importance of individuals with advanced cancer engaging in physical activity and agreed with the idea that these people were capable of engaging in exercise programmes.

As individuals approach end of life, healthcare professionals are often concerned that they are unable to engage with SPC physiotherapy services (McCartney et al., 2011). However Jensen et al. (2014) reported that 92% of individuals under the care of SPC services who were offered physiotherapy in a SPC inpatient setting in the United States were able to engage in at least one session, with the average being 4.2 sessions. Furthermore, exercise intervention studies for those with advanced cancer report no adverse effects suggesting that exercise is safe in this cohort (Chasen et al., 2013, Oldervoll et al., 2011, Van den Dungen et al., 2014). Interventions prescribing resistance exercise training for men with advanced prostate cancer and bone metastasis reported no fractures or increase in bone pain with tailored exercise prescription (Cormie et al., 2013, Galvão et al., 2017). McCartney et al. (2011) highlighted that non-rehabilitation professionals waited until there was a deterioration in function prior to referral to SPC physiotherapy as opposed to referring individuals who are able to avail of the preventative and preparatory work of SPC rehabilitation. Many exercise interventions have demonstrated improvements in physical functioning, as outlined in section 1.4.4, which would support the role of SPC rehabilitation.

In addressing the issues raised regarding engagement in SPC physiotherapy services, recommendations from studies discussed include ongoing education to other healthcare professionals regarding the positive role of SPC physiotherapy, improved communication between service providers and the development of referral pathways (Taylor and Bryan, 2014, Nelson et al., 2012, McCartney et al., 2011). Increasing resources to include a SPC physiotherapist for community based SPC services may also increase the number of individuals benefitting from rehabilitation and support.

2.7. Conclusion

There is emerging literature that supports the role of physiotherapy in SPC in the management of symptoms that are commonly experienced by those with advanced cancer including pain, breathlessness, fatigue and decreased physical function. Many studies are single arm in design with low numbers of participants but they have demonstrated small improvements in physical, psychological and QOL measures. These studies also demonstrated that despite living with advanced cancer, these individuals can participate in SPC physiotherapy, including group exercise interventions.

There are also clear recommendations from government papers and professional bodies that patients with advanced cancer should be referred to, or have access to, physiotherapy. Despite this, it appears that referrals to SPC physiotherapy remain low. The reasons for low referral rates are often proposed as poor understanding of the role and benefits of SPC physiotherapy and therefore a difficulty in identifying individuals who may benefit from interventions. A lack of available resources within the health service has also been cited as a potential reason for low referrals to SPC physiotherapy.

In recent years, the National Clinical Programme for Palliative Care (2014) has developed a needs assessment framework to identify an appropriate time point at which to refer individuals to SPC services in response to a change in symptoms or circumstances. However, there are no published guidelines in which to help identify those who may benefit from SPC physiotherapy interventions.

The overall aim of this research is to explore the referral pattern of members of the community palliative care team to SPC physiotherapy for individuals with advanced cancer. This will assist in the development of the physiotherapy practice in SPC in order to meet the needs of those under the care of SPC services. The first phase of this research describes the profile of individuals who are referred to SPC outpatient physiotherapy from the community SPC team and compares the profile to those who are not referred by completing a retrospective medical chart audit. Individuals are described in terms of demographic details, cancer diagnosis and other pertinent information

available. The purpose of this medical chart audit is to clearly describe those individuals who are currently being referred to SPC physiotherapy outpatient based services, which may guide the future development of physiotherapy services.

As referrals to outpatient SPC physiotherapy are dependent on community based staff within the research site, their views were also explored through semi-structured interviews. These interviews examined the profile of individuals who require SPC physiotherapy and the overall role of SPC physiotherapy in an outpatient setting according to community staff. The purpose of this phase of the research was to complement the findings of the medical chart audit.

3. Methodology

3.1. Introduction

This chapter will describe the methods used to collect and analyse the data for this study. An outline of the research question, aims and objectives of the study will be provided. A description of the research methodology, sampling, data collection and analysis will be detailed for both phases of the research study. Comments on the ethical considerations and rigor of the studies will also be discussed.

3.2. Aim of Research

The overall aim of this research was to understand the referral patterns of the community palliative care (CPC) team to specialist palliative care (SPC) physiotherapy for community based individuals with advanced cancer.

The specific objectives were:

1. To describe the profile of individuals under the care of the CPC team who are referred to SPC physiotherapy and those who are not.
2. To compare the profiles of those who are referred to SPC physiotherapy and those who are not, in terms of demographic details, disease profile and symptoms experienced.
3. To explore the CPC teams' understanding of the role of physiotherapy in a SPC service.
4. To identify what factors members of the CPC team consider when referring individuals who they believe may benefit from SPC physiotherapy.

Objectives 1 and 2 were examined as part of a quantitative study (Phase 1) involving a retrospective medical chart audit of patients under the care of the SPC service. Objectives 3 and 4 were examined as part of a qualitative study (Phase 2) comprising focus group interviews with community palliative care teams.

3.3. Research Design and Approach

This study used a mixed methods design, which incorporates both quantitative and qualitative techniques. Mixed method design can be used to describe different, non-competing representations of the same phenomenon, i.e. referrals to SPC physiotherapy (Adamson, 2005). Doyle et al. (2009) propose that some of main advantages of conducting mixed method research are as follows:

- i. Triangulation. This is the mutual corroboration of both the qualitative and quantitative data (Doyle et al., 2009)
- ii. Completeness. This suggests that by combining the research methods, a comprehensive and in-depth overview of the research topic is presented (Doyle et al., 2009)
- iii. Offsetting weaknesses and providing stronger inferences. This suggests that the combination of the strengths of the different research approaches can offset their weakness (Bryman, 2006)
- iv. Answering different research questions. Mixed methods help to answer research questions that can not be answered by one method alone, especially in terms of complex phenomena (Doyle et al., 2009)
- v. Explanation of findings. Mixed methods can use one research approach (i.e. quantitative or qualitative) to explain the findings of the other method, especially in the case of unexpected findings (Doyle et al., 2009)
- vi. Illustration of data. This occurs when a qualitative approach is used to describe in more detail the findings of the quantitative phase i.e. 'meat on the bones' (Bryman, 2006)

The mixed method design used in this study was an explanatory sequential design, involving quantitative data collection initially, followed by qualitative data collection which aimed to further explore the findings of the quantitative phase (Creswell, 2011). This inter-method approach uses the most appropriate research method for each phase of data collection to answer sub questions of the overall research question. During the interpretation phase, the data are analysed concurrently, and the relationships between the qualitative and quantitative data is explored. In this approach, it has been suggested that a structured approach to qualitative data collection is required to assist with the integration of the different phases of the research (Adamson, 2005).

3.4. SPC Services at research site

St. Francis Hospice Dublin (SFHD) provides SPC services for Dublin North city and county, encompassing a population of approximately 621,000 people. The services provided are community care, inpatient admission for symptom control or terminal care, outpatient services and hospice day care across two sites. Individuals can be referred to and from all aspects of the service as required based on their needs. Inpatient admission is also available for people in the surrounding counties, where there are no inpatient palliative care beds. Referrals to SFHD are received from hospitals teams, general practitioners and SPC community teams from the surrounding counties.

The disciplines that support these services are medical, nursing, physiotherapy, occupational therapy, complementary therapy, lymphodema therapy, medical social work, chaplaincy and healthcare assistants in varying degrees. Within SFHD, all of these disciplines are considered clinical as they are actively involved in providing care to the individual. With the exception of the inpatient unit, referrals are required for individuals to avail of the expertise of each discipline.

The outpatient department consists of physiotherapy, complementary therapy and lymphedema therapy. The outpatient department offers a service to community based individuals and it is a service in its own right and therefore not considered within the remit of CPC service.

During the time frame of the research, SPC physiotherapy was provided in the inpatient units and the outpatients departments only.

3.5. Phase I

3.5.1. Research Design

The first objective of this research was to describe the profiles of people with advanced cancer, under the care of the CPC team who were referred to SPC physiotherapy and those who were not as well as identify similarities and differences of these two cohorts. As it is possible for people to be referred to SPC physiotherapy at any time while under the care of the CPC team, complete data were only available once the episode of care is completed, i.e. the individual had died. Therefore, phase one of this research was a retrospective cross-sectional descriptive medical chart audit. The chart review was conducted over a time period during which care was standardised and did not change. Descriptive and comparative analysis were completed to depict the results which are described in detail in Chapter 4.

Medical chart audit is a research design that uses patient information to answer the research questions (Vassar and Holzmman, 2013). Clinical audit has been defined as “a clinically led, quality improvement process that seeks to improve patient care and outcomes through the systematic review of care against explicit criteria” (Health Service Executive, 2013b). Medical chart audits are routinely used in many areas of healthcare, including SPC services (Charlton et al., 2002). Medical chart audits can be used to identify patterns of behaviour relating to the population and for healthcare organisations to understand the service they provide (Health Service Executive, 2013b, Barisic, 2017).

Descriptive studies are used to describe the characteristics of a population of interest at one point in time, explore the association between the variables collected and establish trends (Bowling, 2005). The medical chart audit allows for the same information to be collected from each participant which means that it is reproducible at another time and results can be compared, therefore improving the external validity of the study (Bowling, 2005). However, a limitation of a descriptive study is that it is not possible to conclude the direction of association i.e. cause and effect.

3.5.2. Medical Chart Selection Criteria

In 2016, 76.7% of individuals (n=1546) under the care of the SPC services in the research site had a diagnosis of advanced cancer (SFH Annual report 2016). The remaining individuals had a non-malignant diagnosis including advanced cardiac disease, advanced respiratory disease, renal failure and motor neuron disease (MND). Therefore, this study focused on those with a diagnosis of advanced cancer only in order to ensure a homogenous cohort.

As a referral to SPC physiotherapy can occur at any time while the individual is under the care of the SPC services, the study was limited to individuals who were no longer under the care of the service i.e. had died. Therefore, this study limited selection to individuals who had died under the care of the service during the identified time period.

As the research question focused on the referral process from the CPC teams, referrals from these teams only were considered for inclusion. Individuals who attended the outpatient department (OPD) for ongoing SPC physiotherapy input upon discharge from the inpatient unit were excluded as it was considered continuation of treatment rather than a new referral.

On reviewing the published literature in relation to SPC physiotherapy interventions, improvements have been reported following interventions which range in time from three weeks to eight weeks (Farquhar et al., 2014, Oldervoll et al., 2011). The study therefore only considered those who were under the care of the CPC team for thirty days or more. This time frame was chosen as it allowed adequate time for individuals to be referred and potentially benefit from physiotherapy interventions.

Inclusion Criteria:

- Died under the care of the SPC services during 2016
- Diagnosis of advanced cancer
- Under the care of the CPC team for 30 days or more
- Over 18 years of age

Exclusion Criteria:

- Non-cancer diagnosis
- Not under the care of CPC team or under the care of the CPC < 30 days
- Under 18 years of age
- Continuation of SPC physiotherapy in the outpatient department following an inpatient unit admission

3.5.3. Sampling

A mixed methods sampling technique was applied in Phase 1 of this research. Mixed methods sampling combines both probability and purposeful techniques (Teddlie and Tashakkori, 2009). Purposeful sampling is selecting a particular group based on specific criteria (Carter, 2005). A purposeful selection was identified based on the inclusion and exclusion criteria. This group was known as the selection sample (Martin, 2005). It was necessary to use a purposeful selection prior to the randomisation as the research question identifies the cohort of individuals that this research focuses on. A random selection of this group was included in the final study selection. The randomisation of the selection sample was probability sampling (Teddlie and Tashakkori, 2009).

3.5.4. Data Extraction Tool

The data extraction tool (Appendix 1) used in this study was developed in order to answer the research question and following a review of published literature, while being cognisant of the information available in the medical charts in the research site.

The data extraction tool included demographic information, time period under the care of the community palliative care team, primary cancer diagnosis and metastatic disease, relevant medical history including previous and current cancer treatments, medications and social history. These categories were selected as they have been reported on by many studies that have evaluated SPC services (Zimmermann et al., 2014, Seow et al., 2010, Dhingra et al., 2016).

As discussed in the literature review (Chapter 2), there is evidence to support the role of physiotherapy in SPC services in terms of managing physical symptoms such as breathlessness and fatigue in individuals with advanced cancer (Higginson et al., 2014, Chasen et al., 2013). SPC Physiotherapy has also led to improvements in functional ability and quality of life (QOL) measures of individuals (Oldervoll et al., 2011, Van den Dungen et al., 2014). Therefore, outcome measures relating symptoms, symptom severity and functional ability which were routinely recorded by members of the CPC on each visit were included in the data extraction tool. These included the Palliative Care Phase, palliative performance scale (PPS) and the palliative care problem severity score (PCPSS). The data collection characteristics and psychometric properties of each tool will be discussed in the following paragraphs.

The Palliative Care Phase is a tool that has been developed to define five distinct clinically meaningful phases of palliative care; stable, unstable, deteriorating, terminal and bereavement (Appendix 2). The palliative care phase has substantial inter-rater reliability (kappa 0.67, 95% Confidence Interval (CI) 0.61 – 0.7) and was found to be an acceptable means to describe the phase of illness (Masso et al., 2015).

The Palliative Performance Scale (PPS) (Appendix 3) is based on the Karnofsky Performance Scale (KPS) which is a measure of functional capacity in cancer patients. The PPS is an observer rated score ranging from 0% to 100% in increments of 10%, incorporating the Karnofsky performance score, ambulation, self-care, intake and conscious level. Patients are assigned a PPS% based on the 'best fit' across each of the domains with higher scores indicating a better functional ability (Anderson et al., 1996). The PPS has been shown to be reliable (interclass correlation 0.96, 95% CI 0.919 – 0.987) and a valid measure to use in the palliative care population (Ho et al., 2008). Validity studies were completed using content validation interviews of fifteen palliative care experts and found to be a valuable tool in palliative care assessment.

The Palliative Care Problem Severity Score (PCPSS) (Appendix 4) is a clinician rated tool which assesses the severity of four domains: pain, other symptoms, psychosocial/spiritual distress and family/carer problems. Severity is rated as none, mild, moderate or severe. The overall reliability of the tool is moderate (kappa 0.45, 95% CI 0.4 – 0.51). There is moderate reliability across three domains: pain (kappa 0.42, 95% CI 0.4 – 0.52), psychosocial/spiritual distress (kappa 0.48, 95% CI 0.42 – 0.54) and family carer problems (kappa 0.45, 95% CI 0.4 – 0.52). Other symptom reliability was classified as fair (kappa 0.38, 95% CI 0.32 – 0.45) (Masso et al., 2016).

In addition to the categorical and continuous data collected, verbatim comments on patients' functional ability as documented on the initial assessment by the initial assessor and any comments that referenced physiotherapy throughout the medical chart were also recorded.

For the individuals who were referred to SPC physiotherapy, the following data were also collected from their medical charts: reason for referral, number of physiotherapy interventions, reason for stopping physiotherapy and if patients were re-referred to physiotherapy. This information was comparable to that collected by Cobbe et al. (2013) who described the profile of patients referred to community based SPC physiotherapy. Any changes in disease, cancer treatment, phase classification, PPS and problem severity score between initial assessment and referral to physiotherapy were also recorded. Recent falls, hospitalisation, infections or other pertinent information during the four-week period prior to referral to physiotherapy were also recorded.

The information required to complete the data extraction tool was based on the individuals initial comprehensive assessment completed by either a doctor or clinical nurse specialist upon referral to SPC services. Following this assessment, a plan of care was developed which was tailored to meet the individual's needs. As such, each person's engagement with the SPC services was unique in terms of frequency and number of visits and referral to other aspects of the service. The initial assessment was identified as the time point to collect the data as this is the only comparable intervention.

3.5.5. Pilot Evaluation

In completing medical chart audits, it was recommended by Vassar and Holzmann (2013) and Gearing et al. (2006) to complete a pilot study using the data extraction tool. The purpose of the pilot study was to assess the feasibility of the research and to highlight any methodological pitfalls in relation to the quality of the data that was retrieved.

The data extraction tool was piloted on ten charts – five of which were referred to SPC physiotherapy and five who were not. Changes made to the data extraction tool included the addition of 'locally advanced' as an option in the metastatic disease section, if a referral to SPC outpatient physiotherapy was offered and declined and other references to a referral to physiotherapy within the chart. These charts were included in the final data analysis.

3.5.6. Medical Chart Selection and Screening Methods

A list of all individuals who died under the care of the SPC service in 2016 was generated from the Patient Administration System (PAS) into a Microsoft Excel spreadsheet and the inclusion and exclusion criteria were applied. The information available on the PAS included diagnosis, age, services used and dates of use of each service. The time under the care of the community service was calculated from the date of the initial assessment until either death, admission to the hospice for end of life care or admission to another health care facility until death. The date of the initial physiotherapy assessment date was cross referenced with admission dates, if any, to the hospice, to ensure that those who continued to attend physiotherapy following an admission to the hospice were not considered as a new referral.

This list was then separated into two separate groups: those who were referred to SPC outpatient physiotherapy and those who were not. A unique identification number for each chart was inputted into a computer generated randomiser (random.org) which randomised both categories.

Sample size was selected based on literature which has detailed SPC services and the profile of SPC service users. Jülich et al. (2017) completed a retrospective chart audit of 148 SPC in-patient service users to describe the effect of an integrated multidisciplinary palliative care programme. The profile of individuals who were referred to SPC physiotherapy as reported by (Cobbe et al., 2013) is based on a sample size of 165 individuals over a 6 month period. A total sample size of 140 medical charts was chosen for this study. This represented approximately 33% of the available medical charts for each group; 102 charts not referred to SPC physiotherapy and 38 charts referred to physiotherapy. This sample size was also chosen as this number was manageable within the timeframe of the study.

3.5.7. Data Analysis and Management

Data extracted from the charts was coded and inputted into IBM SPSS Statistics version 24 (data dictionary, Appendix 5). The types of data collected were categorical, continuous and qualitative.

Categorical data were used to represent the characteristics of the individuals such as primary diagnosis, or gender. Categorical data were presented in terms of frequency and percentage. The Chi Square test for independence was used to compare the difference in proportions between those who were referred to SPC physiotherapy and those who were not. The significance level was set at <0.05 . Where required, categorical data were collapsed into fewer categories to ensure that the assumptions that underpin the Pearson Chi Square test were met i.e. that more than 80% of the cells had a count of more than 5 (Pallant, 2013).

Continuous data included interval data and ratio data. The PPS was considered interval as each rank on the scale was considered to be of equal intervals (Bowling, 2014). Age and length of time under the care of the CPC team was considered to be ratio data as this data was of equal intervals and had a true zero point (Bowling, 2014). The data were described as mean (standard deviation) or median (interquartile range) as appropriate. To ensure that the data did not breach the assumptions underpinning statistical testing, the Kolmogorov-Smirnov test for normal data distribution were completed (Pallant,

2013). The data for age and PPS were normally distributed, therefore independent sample t-tests were used to determine whether there was a statistical difference between groups. The significance value was set at 0.05. Levene's test for equality of variances was completed for independent sample t-tests. The Mann Whitney U test was used to determine difference in length of time under the care of the community palliative care team between groups as the data were not normally distributed. The significance value was also set at 0.05.

Qualitative data is data that creates a narrative or non-numeric information (Carter, 2005). Within the data extraction tool, this type of data was limited to the verbatim comments regarding functional status and reference to physiotherapy within the medical charts. These comments were summarised and presented as a description within the results. This approach used the initial step in semantic theme analysis, which describes the patterns of what is documented 'at a surface level' only (Braun and Clarke, 2006). However, there was no attempt to interpret these results or theorise their meanings or implications (Braun and Clarke, 2006).

3.5.8. Ethical Permission and Consideration

Permission to complete the retrospective chart audit was granted by St. Francis Hospice Dublin (SFHD) (Appendix 6) and Trinity College Dublin Faculty of Health Science (Ref:161103) (Appendix 7).

As this review required access to deceased patients' medical charts, it was not possible to gain patient consent. The researcher however, sought permission from the medical director of SFHD, who has overall responsibility for patient care in the organisation to access the medical charts (Appendix 8). The data extracted from patients' medical charts was routine clinical information which was anonymised and collated during the collection process, therefore protecting patients confidentiality. Anonymous data is beyond the scope of the Data Protection Act and therefore consent is not required for this type of research according to the national consent policy (Health Service Executive, 2013a).

3.6. Phase II

3.6.1. Research Design

Qualitative data is considered to be any type of data that generates narrative or non-numeric information. It attempts to gain insight into participants views without judgement (Carter, 2005). Qualitative research can be used to supplement quantitative research as it can place a meaning in a social context on the findings (Bowling, 2014).

The objective of the qualitative phase of this study was to explore the members of the CPC team's understanding of the role of SPC physiotherapy and the criteria that they use to refer patients to SPC physiotherapy. As this question focused on the beliefs and behaviours of the CPC team, a qualitative descriptive approach was used (Sandelowski, 2000). Qualitative description describes in detail the perceptions of a phenomena in everyday language (Neergaard et al., 2009).

There are many methods that have been used in undertaking qualitative research including observational studies, interviews and discussions and analysis of narrative sources such as reports and diaries (Carter, 2005). Some of the core characteristics relating to qualitative research includes an in-depth approach to understanding the view of the participants and a close interactive approach that facilitates exploration of themes raised (Bowling, 2014). The methods that addressed the research question while being cognisant of these characteristics were focus group and individual interviews in the case where those interested in participating were unable to attend the focus group. These approaches use open ended, minimally structured questions to gather the information (Sandelowski, 2014).

3.6.2. *Focus groups*

Focus groups are discussions which explore a specific topic. Focus groups, especially when participants know each other, can be useful in stimulating in-depth discussion and ideas with regards to the topic. The aim of the focus group is not to change opinion or correct knowledge, however it allows the facilitator to explore participants beliefs and attitudes towards the topic (Carter, 2005). Focus groups can explore how participants make sense of information and why they respond in a particular way. This can be done by exploring the similarities and differences within the group (Carter, 2005).

The purpose of the focus group interviews were to establish the attitudes and beliefs of members of the CPC team regarding the role of physiotherapy in SPC and how they may identify those who are referred. The advantage of focus group interviews is the dynamic interaction between the facilitator and the participants that can be useful as prompts of previous beliefs or generating new thoughts (Holloway, 2008). Focus groups have also been found to be a cost effective method of gathering qualitative data (Holloway, 2008). The limitations of focus group interviews are that some participants may be reluctant to share certain opinions or that the group may be dominated by particular views or individuals. These issues can be addressed through using an experienced and impartial facilitator (Bowling, 2014).

As recommended by Neergaard et al. (2009), the interview guide for qualitative description was semi-structured but allowed for more in-depth questioning as themes emerged. The interview guide (Appendix 9) was developed based on the aims and objectives of the qualitative phase of the research and the results of the quantitative findings of the medical chart audit. The questions began with a general overview of SPC services and those who are referred and then proceeded to focus specifically on the role of physiotherapy.

3.6.3. Participants

As the focus of this phase of research was on the referral practices of the CPC team to SPC physiotherapy for community based patients, a purposive sample was required. A purposive sample is a deliberately chosen sample where the participants reflect a particular area of interest, i.e. providing SPC to individuals within the community (Carter, 2005). In the current configuration of services in the research site, the members of the CPC team are doctors, nurses, medical social workers and chaplains. Any member of the CPC team can refer people to SPC physiotherapy at any time while under the care of services. Within the research site, any discipline who are actively involved in providing care to the individual, including their spiritual needs are considered clinical. Therefore, the inclusion criteria included all clinical staff working in the CPC team.

3.6.4. Recruitment and Data Collection

A successful focus group requires participants to actively engage in the group discussion which aims to identify beliefs and attitudes with regards to the topic (Bowling, 2005). To reduce the sense of coercion to participate, a gatekeeper was identified to contact all members of the CPC team regarding participation in the research.

Letters of invitation (Appendix 10) and participant information leaflets (Appendix 11) were distributed to all members to the CPC team by the gatekeeper in both clinical sites requesting those who were interested in participating contacted the researcher directly. A letter regarding potential dates for the focus group interview (Appendix 12) was distributed by the gatekeeper within two weeks of the initial letter of invitation. This also served as a reminder to potential participants.

The researcher maintained a list of interested participants and confirmed their ability to attend either of the two focus group interviews. The focus group interviews were facilitated at the research sites during working hours. The management team was aware of the research and facilitated staff to attend during their working hours.

Two focus group interviews were facilitated, one at each clinical site. As the researcher works clinically in the research site, it was decided that the research supervisor, who was not affiliated with the research site would act as the focus group facilitator. This was to reduce the risk of bias (Mitchell and Branigan, 2000). Prior to the focus groups, the purpose of the research was explained and participants' questions were answered. Participants were then asked to sign a consent form (Appendix 13). The focus groups were audio recorded and lasted between 39 minutes and 52 minutes.

One individual interview was conducted as the participant was unable to attend the focus groups. Their contribution was actively sought as they represented a discipline whose views were not obtained during the focus groups. The interview was also audio recorded and lasted 27 minutes.

3.6.5. Data management and Analysis

The interviews were transcribed verbatim by the researcher. The completed transcriptions were checked for accuracy against the audio recordings. This improved the credibility of the data which was analysed (Bowling, 2014). The contribution of each participant was emailed to them for review, allowing them to make any changes or additions prior to analysis. This step was considered to be formal 'member checking' which adds to the credibility of the data collected (Teddlie and Tashakkori, 2009). There were no adjustments made to the data following this step.

Thematic analysis is a method for identifying, analysing and reporting patterns, i.e. themes and it is often used in the analysis of focus group data (Braun and Clarke, 2006). An inductive approach was used which means that the codes and themes are derived from the data rather than trying to fit the data to pre-existing code framework (Braun and Clarke, 2006). The six stage methodological approach to thematic analysis as described by Braun and Clarke (2006) was applied to the transcripts.

Stage 1: Familiarisation with the data. This step included transcribing the focus groups and repeated reading of the transcripts while noting initial ideas and thoughts. These ideas helped to form the initial codes.

Stage 2: Generating the initial codes. This step involved further reading of the transcripts and identifying codes. Codes are considered to be an interesting feature of the data. Codes were descriptive of what the data was saying. Multiple codes were used where that data described more than one idea. Appendix 14 lists the initial codes that were generated.

Stage 3: Searching for themes. This step consisted of attempting to group the codes together in a meaningful manner to generate the initial themes. Mind maps were used to help with this process. Appendix 15 presents the initial themes that were identified.

Stage 4: Reviewing the themes. This step reviewed the themes identified in relation to the data. Each piece of data for each code was reviewed to ensure that it fit in a coherent manner to the code and themes that the codes describe. Codes and themes were refined at this point to ensure that the themes accurately represented the data. Themes were reviewed to ensure internal homogeneity and external heterogeneity. Internal homogeneity means that all codes within the theme work together in a meaningful way to describe the theme. External heterogeneity refers to a clear distinction between each theme. At this point, the themes that were relevant to the research question were developed and data which did not contribute to this was discarded. This stage was repeated until the themes were clearly identified.

Stage 5: Defining and naming the themes. This step focused on defining the themes in relation to the research question. This included clearly defining each theme and commenting on why it was of interest in the broader picture of the research aim. Appendix 16 lists the final themes identified and the subthemes within each one.

Stage 6: Producing the report. This step involved summarising and interpreting the themes using relevant extracts from the data to reflect the research question. The final report is presented in Chapter 4.

The thematic analysis approach used in this research was primarily at a semantic level. This means that the data was described at a surface level, to show patterns and interpretation is limited to theorising the significance of these (Braun and Clarke, 2006).

3.6.6. Rigour in Qualitative Research

In contrast to quantitative research, the quality of qualitative research is assessed in terms of rigour. Rigour has been defined by Aroni et al. (1999) as 'the means by which we show integrity and competence' as cited in Holloway (2008). Rigour refers to the process in which the data is collected as well as how the data is analysed and presented and should be an accurate reflection of the participants' attitudes and beliefs. Trustworthiness is the term that is often used when discussing the rigour of a study. Trustworthiness is assessed using the following categories; credibility, transferability, dependability and confirmability (Teddle and Tashakkori, 2009). The trustworthiness of this study is discussed in these terms in the paragraphs below.

Credibility refers to the extent to which the findings can be considered a true and accurate reflection of the focus groups being studied (Teddle and Tashakkori, 2009). The following steps were taken to ensure the study was credible:

- The researcher was actively providing physiotherapy services within the research site where the focus group participants were recruited from. Therefore, in order to reduce the possibility of bias, the research supervisor, who was independent of the clinical service, facilitated the focus groups. Bias can occur when the participants want to agree with the facilitator (acquiescence bias) or want to be regarded in a positive manner (desirability bias) (Mitchell and Branigan, 2000)
- Interviews were audio recorded and transcribed verbatim to ensure accuracy of the data recorded (Bowling, 2014)
- The researcher engaged in peer review with the research supervisor during the coding of the data to validate the accuracy of the themes identified (Creswell, 2011)

- Member checking refers to the participants commenting on the accuracy of the data collected (Teddlie and Tashakkori, 2009). This occurred both formally and informally during the study. During the focus groups, the facilitator sought clarity through questioning and summarising the discussion points (Liamputtong, 2009). The participants also received a copy of their contribution to check for accuracy and were offered an opportunity to make further comments prior to the data analysis phase.

Transferability refers to the degree in which the findings from the study can be compared with or generalised to other situations or studies (Shenton, 2004). For readers to make a judgement with regards to the transferability of the study, a detailed or 'thick' description regarding the contextual information was provided (Shenton, 2004). This included information regarding

- The study site and the context and purpose of the focus group
- The research methods, data collection and analysis
- The researcher's role within the study site and the involvement of the research supervisor in facilitating the focus groups and their involvement in peer support

Dependability of the research process relates to issues such as suitability and transparency of research methods and analysis used. It aims to show that if the work were to be repeated in a the same way, similar results would occur (Shenton, 2004). It is concerned with the research methods matching the research question (Miles, 2014). Within this study, detailed information relating to the research methodology, data collection and analysis have been provided. This allows the reader to assess the extent to which appropriate research methods have been followed (Shenton, 2004).

Confirmability refers to the steps taken to ensure that the findings are clearly linked to the data and not derived from bias of the researcher (Liamputtong, 2009). This included detailed description of the methodology to allow the integrity of the results to be examined. It also recognised the limitations of the use of focus groups, in particular, the risk of alternative opinions not being voiced in a dominant group (Bowling, 2014).

3.6.7. Ethical Permission and Consideration

Permission to complete focus group interviews with members of the CPC team was granted by SFHD (Appendix 17) and Trinity College Dublin, School of Medicine Committee (Ref:20171101) (Appendix 18).

3.7. Conclusion

As the overall aim of this study focused on exploring a complex phenomenon, i.e. understanding the referral patterns of the CPC team to SPC physiotherapy for community based individuals with advanced cancer, a mixed methods approach was utilised. The mixed method design used was an explanatory sequential design, involving quantitative data collection initially, followed by qualitative data collection which aimed to further explore the findings of the quantitative phase (Creswell, 2011).

Phase one of the study focused on describing the profile of individuals with advanced cancer who were under the care of SPC community services. It identified the similarities and differences within the profiles of those who were referred to SPC physiotherapy and those who were not. A retrospective chart audit, using a purposeful randomised sample was identified as the most appropriate research approach. The data extracted from this phase were categorical, continuous and qualitative. Quantitative data were analysed while being cognisant of the assumptions underpinning statistical analysis.

Phase two of this study explored members of the CPC team's understanding of the role of SPC physiotherapy and the criteria that they use to refer patients to SPC physiotherapy. A qualitative descriptive approach was utilised as the question focused on the beliefs and behaviours of the research participants (Sandelowski, 2000). A purposeful sample of members of the CPC team were invited to participate in focus groups where the research supervisor acted as an impartial facilitator. The focus groups were analysed using a thematic analysis approach. The results of both phase one and phase two of this study are presented in detail in Chapter 4.

4. Results

4.1. Introduction

This chapter outlines the results of both the retrospective medical chart audit and the focus group interviews. The results of the chart review will describe the profile of individuals under the care of the community palliative care (CPC) team and highlight any significant differences between those who are referred to specialist palliative care (SPC) physiotherapy and those who are not. Analysis of the focus group interviews, which aimed to explore the understanding of the members of the CPC team regarding the role of SPC physiotherapy in an outpatient setting, will be presented. The themes that were identified through thematic analysis and will be described in detail.

4.2. Phase 1: Retrospective Medical Chart Audit

During 2016, 1115 people died under the care of St. Francis Hospice Dublin (SFHD). Following the application of the inclusion and exclusion criteria, 432 medical charts were identified. Of the 692 medical charts that were excluded, 229 were not under the care of the CPC team for more than four weeks, 240 did not have a diagnosis of advanced cancer, 222 did not have any involvement from the CPC team and one was excluded as was under the age of 18. Figure 1 outlines the medical chart selection.

Figure 1: Medical Chart Selection

Of the 423 medical charts that met the inclusion criteria, 116 were referred to SPC outpatient based physiotherapy which is equivalent to an overall referral rate of 27.4%. Results of the cross-sectional retrospective medical chart audit are based on 38 people who were referred to SPC outpatient physiotherapy and 102 who were not.

4.2.1. Disease Information

Individuals with a cancer diagnosis were included in this study. These were categorised into breast cancer, prostate cancer, lung cancer, colo-rectal cancer, pancreatic cancer, upper gastro-intestinal (GI) cancers, gynaecological cancers, urological cancer excluding prostate cancer, brain tumours, head and neck cancer and 'other cancers'. 'Other' cancers included multiple myeloma, hepatocellular, malignant melanoma, acute myeloid leukaemia, chronic relapsed leukaemia, thyroid cancer and high grade rhabdomyosarcoma. Table 1 describes the frequency of diagnosis within both groups. There was no difference between those who were referred to SPC outpatient based physiotherapy and those who were not except for prostate cancer ($p=.03$), however this is based on a very small sample.

Diagnosis	Referred to Physiotherapy N=38	Not referred to Physiotherapy N=102	pValue
Breast	3(7.9)	9(8.8)	1.00
Prostate	5(13.2)	3(2.9)	0.03
Lung	11(28.9)	24(23.5)	0.66
Colo-rectal	3(7.9)	9(8.8)	1.00
Pancreatic	2(5.3)	8(7.8)	0.73
Upper GI	2(5.3)	14(13.7)	0.24
Gynaecological	2(5.3)	10(9.8)	0.51
Urological (excluding Prostate)	2(5.3)	5(4.9)	1.00
Brain	5(13.2)	5(4.9)	0.14
Head & Neck	1(2.6)	3(2.9)	1.00
Other	2(5.3)	12(11.8)	0.35

Table 1: Comparison of diagnosis of individuals referred to physiotherapy and not referred. Data presented as frequency (Percentage)

Individuals' cancer was documented in terms of the primary cancer type and the location of documented metastasis or local spread of the disease into the surrounding tissues as documented in their initial assessment notes. Thirteen patients (primary brain tumours n=10, haematological cancers n=3), did not have any documented metastasis or local spread of disease, however these patients were deemed to be palliative as there was no further curative treatment available to them.

For the purpose of analysis, disease was categorised into no metastatic disease, locally advanced disease, one category of metastatic disease, two categories of metastatic disease and three or more categories of metastatic disease. There was no significant difference between individuals referred to SPC physiotherapy compared with those who were not referred to physiotherapy in relation to metastatic disease burden (p=.460) (Table 2).

	Referred to Physiotherapy	Not referred to Physiotherapy	pValue
	N=38	N=102	
Disease			.460
No metastatic disease	5(13.2)	8(7.8)	
Locally Advanced disease	7(18.4)	31(30.4)	
One category	11(28.9)	20(19.6)	
Two categories	5(13.2)	17(16.7)	
Three or more categories	10(26.3)	26(25.5)	

Table 2: Comparison of burden of disease in individuals referred to physiotherapy and not referred. Data presented as frequency (Percentage)

4.2.2. Cancer Related Treatment

Individuals were treated according to a variety of treatment regimens including surgery, chemotherapy, radiotherapy, hormone therapy and 'other disease modifying treatment' namely, stenting, effusion drainage, bisphosphonates, immunotherapy or blood product transfusions. Table 3 outlines both treatment history and any ongoing treatment at the time of initial assessment by the CPC team. With regard to previous treatments completed prior to referral to the CPC team, there was a significant difference between the number of different treatment modalities completed by those referred to physiotherapy compared with those who were not referred ($p=.045$). Individuals who had completed a greater number of treatments were more likely to be referred to SPC physiotherapy. With regard to the number of treatment modalities being undertaken at the time of their initial assessment, there was also a significant difference in individuals who were referred to physiotherapy compared with those who were not ($p=.005$). Once again, with those receiving more treatment more likely to be referred to SPC physiotherapy. In people who were referred to physiotherapy, the most common treatment regime was a combination of surgery and chemotherapy ($n=5$, 13.2%) and a combination of surgery, chemotherapy and radiotherapy ($n=5$, 13.2%). In those not referred to physiotherapy, surgery, chemotherapy and radiotherapy was most common treatment combination ($n=12$, 11.8%).

	Referred to Physiotherapy N=38	Not referred to Physiotherapy N=102	pValue
Previous Treatment			.045
No Treatment	5(13.2)	32(31.4)	
One treatment modality	8(21.1)	28(27.5)	
Two treatment modalities	12(31.6)	24(23.5)	
Three or more	13(34.2)	18(17.6)	
Ongoing Treatment			.003
No treatment	14(36.8)	68(66.7)	
Ongoing treatment	24(63.2)	34(33.3)	

Table 3: Comparison of previous treatment and ongoing treatment for individuals referred to physiotherapy and not referred to physiotherapy. Data is presented as frequency (percentage)

4.2.3. Socio-demographic Information

There were no differences between the groups in terms of gender, social supports or place of death (Table 4). Individuals who were nursing home residents (n=11) were excluded from the analysis in terms of place of death, as their physical care needs at time of death could be met by the nursing home. These individuals (n=10) were also excluded from the analysis for social supports as they were in a place of care. Social supports were classified as having formal supports, i.e. a home care package or not having formal supports. One individual was admitted to a nursing home during the period of time that they were under the care of the CPC team.

	Referred to Physiotherapy	Not referred to Physiotherapy	pValue
<i>Gender</i>	N=38	N=102	
Male	23(60.5)	45(44.1)	.124
Female	15(39.5)	57(55.9)	
<i>Social Supports</i>	N=38	N=92	
No Formal Supports	34(89.5)	71(77.2)	.170
Formal Supports	4(10.5)	21(22.8)	
<i>Place of Death</i>	N=38	N=91	
Home	13(34.2)	34(37.4)	.942
Hospital	6(15.8)	14(15.4)	
Hospice	19(50)	43(47.3)	

Table 4: Comparison of gender, social supports and place of death for individuals referred to physiotherapy and not referred. Data is presented as frequency (percentage).

There was a significant difference in age between the groups (Mean Difference -6.77 years, 95% Confidence Interval (CI) -11.8 to -1.74, $p=0.009$), with younger people being referred to physiotherapy over older individuals. The average age of individuals referred to physiotherapy was 66.38 years (Standard Deviation (SD) 13.4) while the average age of those not referred to physiotherapy was 73.15 years (SD 13.4).

There was no difference between those referred to physiotherapy and those who were not referred in terms of their past medical history (PMedHx) as outlined in Table 5. People were grouped as having no relevant past medical history, having one relevant medical condition or having two or more relevant medical conditions. Relevant medical conditions were categorised as chronic cardiac disease, chronic respiratory disease, chronic musculoskeletal condition, a previous history of cancer, mental health illness, neurological disorder or a cognitive impairment. Past medical history data was not documented in seven medical charts.

	Referred to Physiotherapy	Not referred to Physiotherapy	pValue
	N=36	N=97	
No relevant PMedHx	12(33.3)	18(18.6)	.086
One relevant condition	15(41.7)	37(38.1)	
Two or more relevant conditions	9(25.0)	42(43.3)	

Table 5: Comparison of past medical history (PMedHx) for individuals referred to physiotherapy and not referred to physiotherapy. Data is presented as frequency (percentage)

Individuals who were referred to physiotherapy were under the care of the CPC team for a significantly longer period of time compared with those who were not ($p=0.023$). The median number of days under the care of the CPC team for people referred to physiotherapy was 121.5 (30 – 2024) days compared with those who were not referred 92.5 (34 – 738) days. The result remained significant even when one outlier, who availed of the support of the community palliative care team for 2024 days, was removed from the analysis (Table 6).

	Referred to physiotherapy	Not referred to physiotherapy	pValue
	N=37	N=102	
Median number of days under the care of CPCT	115 (30 – 601)	92.5 (34 – 704)	.039

Table 6: Comparison of length of time under the care of CPCT of individuals referred to physiotherapy and not referred, excluding outlier. Data is presented as no. of days (range)

There was no difference between the groups in terms of the phase of illness of the individual at the time of the initial CPC assessment ($p = .383$). Of those who were referred to physiotherapy, 23 people (61%) were described as stable, 5 people (13%) were unstable and 8 people (31%) were deteriorating. In those not referred to physiotherapy, 51 (50%) were considered stable, 19 people (19%) were unstable and 31 people (30%) were deteriorating. Data is missing from two individuals referred to physiotherapy and one not referred to physiotherapy.

4.2.4. Pain

Individuals' pain was recorded at initial assessment as either none, mild moderate or severe in nature. There was no difference in patient reported pain descriptions between those who were referred to physiotherapy and those not referred to physiotherapy ($p = 0.212$). There was also no difference between the groups in relation to opioid medication or adjunctive analgesia usage, which included neuropathic agents and non-steroidal anti-inflammatory drugs (Table 7).

	Referred to Physiotherapy N=38	Not referred to Physiotherapy N=102	pValue
Pain Score			.212
No pain	14(38.9)	24(23.8)	
Mild pain	12(33.3)	39(38.6)	
Moderate pain	7(19.4)	33(32.7)	
Severe pain	3(8.3)	5(4.9)	
Missing Data	2(5.3)	1(1.0)	
Pain medication			
Opioids	19(50)	56(54.9)	.744
Adjunctive medications	22((57.9)	71(69.6)	.270

Table 7: Comparison of pain scores and pain medication for individuals referred to physiotherapy and not referred to physiotherapy. Data is presented as frequency (percentage)

4.2.5. *Symptom burden*

Staff completing the initial assessment identified one or two symptoms that were problematic for individuals. This is part of the Palliative Care Problem Severity Score (PCPSS), which is routinely completed with all patients at each visit from the CPC team as part of a documentation standard within St Francis Hospice Dublin (SFHD). Open-text comments describing symptoms identified are documented verbatim, and for the purpose of analysis they were categorised into the following: 1. Decreased mobility (reduced mobility, decreased mobility); 2. Respiratory Symptoms (breathlessness, dyspnoea, shortness of breath, cough, respiratory tract infection, haemoptysis, secretions); 3. Upper GI dysfunction (Anorexia, early satiety, heartburn, belching, dysphagia, nausea, nausea & vomiting, hiccups); 4. Lower GI Dysfunction (Constipation, diarrhoea, bowels); 5. Neurological Symptom (Right sided weakness, hemiparesis, dysphasia, arm weakness, seizures, headaches); 6. Cognitive Issues (Dementia, cognitive impairment, poor memory, confusion); 7. Fatigue; 8. Weakness; 9. Mood disorder (Anxiety, depression, low mood); 10. Urinary symptoms (Urinary frequency, urinary symptoms); 11. Sleep difficulties (Insomnia, somnolence, night time agitation); 12. Oedema (Oedema, facial oedema); 13. Other (Delirium, frailty, sweats, wound, prolonged vaginal (PV) bleeding, Itch, Dizziness, toxicity, hot flushes). There was no data documented in relation to problematic symptoms for 5 patients referred to physiotherapy and 3 not referred to physiotherapy, as these initial assessments were completed prior to the introduction of this measure into the clinical pathway.

The four most common symptoms identified in both groups were fatigue, decreased mobility, respiratory symptoms and upper GI dysfunction. Frequency of the symptoms did not differ between the two groups. Upper GI dysfunction was managed primarily with medication, which was evident from the percentage of patients taking anti-emetic medication in both groups; 27(71.1%) individuals referred to physiotherapy and 78(76.5%) individuals not referred to physiotherapy.

The symptoms identified during the initial assessment were given an overall rating of mild, moderate or severe regardless of the number or symptom identified. There was no difference between those who were referred to physiotherapy and those who were not in terms of this rating (Table 8).

	Referred to Physiotherapy	Not referred to Physiotherapy	pValue
	N=33	N=99	
Symptom			
Fatigue	14(42.4)	38(38.4)	.84
Decreased mobility	8(24.2)	21(21.0)	.90
Respiratory Symptoms	10(30.3)	18(18.2)	.22
Upper GI Dysfunction	8(24.2)	33(33.3)	.45
Overall Symptom Severity Score			.43
Mild	9(27.3)	17(17.2)	
Moderate	20(60.6)	66(66.7)	
Severe	4(12.1)	16(16.2)	

Table 8: Comparison of symptoms identified and symptom severity score at referral between individuals referred and not referred to physiotherapy. Data is presented as frequency (percentage)

4.2.6. Functional Ability

The palliative performance score (PPS), a measure of functional capacity in palliative care, was significantly higher in individuals referred to physiotherapy (62.8%, SD 12.3) compared to those who were not referred to physiotherapy (57.6%, SD 12.5) (Mean Difference 5.15, 95% CIs .372 to 9.936, $p=0.035$). A higher score in the PPS indicates a better functional ability.

Although there was no measure of mobility recorded during initial assessment, observational comments or patient reported ability as documented by the initial assessor were transcribed verbatim. Comments regarding mobility were made in the medical charts of 35 individuals who were referred to SPC outpatient physiotherapy and in the medical charts of 100 individuals who were not. It was not possible to quantitatively

compare the functional status between the two groups and for both groups, functional ability was described in four main ways.

The first way was how their mobility of function was limited due to symptoms. Comments such as “dyspnoea on moderate exertion” and “decreased mobility due to fatigue” illustrate this. The second way function was described was in terms of what the individuals were able to do. There was a wide range in the comments which referenced the level of assistance required for activities of daily living (ADL’s) “needs 2 to transfer, dependent on carers for al ADL’s” to paid employment “Independently mobile, continuing to work”. The other interpretations of function and mobility were in relation to the use of mobility aids and episodes of falls.

4.2.7. Comments referencing Physiotherapy

Of the 102 individuals who were not referred to SPC outpatient physiotherapy, 15 (15%) people were offered a referral but declined. Eleven of these offers occurred during the initial assessment. The reasons for declining physiotherapy was not documented in the majority of the medical charts. One individual declined appointments as they reported having “too many appointments”. Another individuals family declined appointments on their behalf as they did not want the individual to physically attend the hospice. This may represent a fear of SPC services which may also have been the reason for other individuals not to avail of the service.

In 6 (6%) of medical charts of those who were not referred to physiotherapy, a referral to SPC physiotherapy was recommended. Examples of this included “physio to be considered once toxicity resolves” and “offer OPD (outpatients) appointments on next visit”. However, there is no documented evidence that these referrals were offered, or offered and declined based on the individuals preference.

4.2.8. Timing of referral to SPC physiotherapy

The median length of time between initial assessment and referral to SPC physiotherapy was 21.5 days (range -18 – 391 days). Seven people (18.4%) were referred to SPC physiotherapy during their initial assessment with a further 17 (44.7%) being referred

within 30 days of their initial assessment. One individual was referred directly to outpatient physiotherapy from a SPC team in an acute hospital, which led to their initial physiotherapy assessment occurring 18 days prior to their CPC team assessment.

For the 38 individuals who were referred for SPC physiotherapy, further analysis was completed to establish if there were any precipitating factors prior to referral which may have prompted a referral. Eleven patients (28.9%) experienced a fall, 10 (26.3%) had been admitted to hospital and 8 (21.1%) required antibiotics for an infection in the four weeks prior to referral. This was based on documented evidence of these events.

4.2.9. Changes between initial CPC assessment and referral to physiotherapy

Individuals who were referred to SPC physiotherapy (n=7) at the initial CPC assessment and the one individual who was referred prior to their CPC assessment were excluded from the following analysis, which investigates changes in patients' profile between their initial CPC assessment and their referral to SPC physiotherapy. A total of 30 medical charts were included.

Overall, individuals were stable from a disease progression perspective prior to referral to SPC physiotherapy. There was documented disease progression in three individuals (10%). One developed new bone metastases, one individual had evidence of increasing lung metastases and one individual developed new bone and liver metastasis.

Similarly, the treatment regime remained the same for the majority of these individuals. Chemotherapy was initiated for one person (3.3%) and stopped for two people (6.6%). Two people (6.6%) commenced radiotherapy and both of these also commenced on bisphosphonate therapy.

There was no difference in the phase of illness for 17 (56.6%) individuals when comparing their initial CPC visit assessment to when they were referred to SPC

physiotherapy. The phase of illness improved for six individuals (20%), moving from either an unstable or deteriorating phase into a stable phase. A deterioration was noted in 4 individuals (13.3%), moving into either an unstable or deteriorating phase. Data was missing for three (10%) individuals.

There was no difference in pain scores for 17 (56.6%) individuals between the time of initial assessment and referral to SPC physiotherapy. There was an improvement in pain scores for 7 (23%) individuals and a deterioration in the pain score for 2 (6.6%) individuals. Data was not recorded in four (13.3%) of the medical charts.

There was no difference in the symptom severity score for 14 (46.6%) individuals between the time of initial assessment and referral to SPC physiotherapy. There was an improvement in symptom severity score for 3 (10%) individuals and a deterioration in the symptom severity score for 6 (20%) individuals. There was incomplete or missing data from 7 (23.3%) of the medical charts.

There was also no difference in social supports for 27 (90%) individuals between initial assessment with the CPC team and referral to SPC outpatient physiotherapy. For 3 (10%) individuals, a home care package was initiated.

4.2.10. Reason for referral to SPC Physiotherapy

Based on the 38 referrals to SPC outpatient physiotherapy, problems with mobility was the most common reason that individuals were referred (n=20, 53%). Nine (24%) individuals were referred with breathlessness, 2 (5%) were referred with neurological problems and 7 (18%) were referred with musculoskeletal related problems.

4.2.11. *Engagement with SPC Physiotherapy Service*

The median number of SPC physiotherapy appointments attended by individuals was 2 (range 1 – 30). The average number of appointment cancellations was 0.92 (SD 1.24). Table 10 presents the reasons for individuals not continuing with SPC physiotherapy. Other reasons included death and being transferred to hospice day care, for which there is no physiotherapy service available due to staffing resources.

Reason	
Too unwell to attend	12 (31.6)
Admitted to hospital/hospice	8 (21.1)
Symptom resolved	3 (7.9)
Independent with self-management	11 (28.9)
Other	4 (10.5)
Total	38

Table 9: Reasons for not continuing with SPC physiotherapy. Data is presented as frequency (percentage).

4.3. **Summary of Findings from Phase 1**

There was no difference between those who were referred to physiotherapy compared with those not referred in terms of cancer diagnosis (excluding prostate cancer) or spread of disease. There were also no differences in gender, co-morbidities, social supports, place of death, pain, phase of illness, symptoms experienced or symptom severity scores.

Results demonstrate that those referred to physiotherapy were younger, had a higher PPS score and were under the care of the CPC team for a greater length of time compared to those who were not referred. Individuals who were referred to SPC physiotherapy also completed more disease modifying treatment prior to and at the time of referral to SPC services compared with those who were not referred.

4.4. Phase 2: Focus Groups

4.4.1. Participants

Invitations to participate in focus groups were sent to all members of the community palliative care (CPC) teams in both sites. A total of 38 invitations were sent including 30 to nursing staff, 3 to medical social workers, 4 to medical staff and one to chaplaincy. Seven nurses, one medical social worker and one chaplain took part in the focus group interviews. An individual interview was carried out with a doctor, as they were unable to attend the focus groups.

4.4.2. Themes

Three main themes were identified through thematic analysis of the transcripts of the focus groups and the individual interview. These were 'Referral to physiotherapy', 'Physiotherapy practice within SPC services' and 'the development of SPC physiotherapy services'.

Figure 2: Summary of Themes

4.4.3. Theme One: Referrals to physiotherapy

This theme presents the findings related to the reasons that the participants consider a referral. They include the management of physical symptoms, psychological reasons and as a stepping stone to the wider SPC services. There was also a cohort of people whom the participants did not refer to physiotherapy and symptoms for which they did not consider a referral to physiotherapy.

Subtheme 1: Management of Physical Symptoms

In both focus groups, when discussing referrals to physiotherapy, all of the participants referred to the role of physiotherapy primarily in terms of the persons mobility.

“Mobility is the instant one when you think in relation to physio” (P2)

When discussing mobility, the participants focused mainly on the person’s ability to maintain their independence.

“physiotherapy to protect function because their legs are so heavy to try and get up the steps and mobilise” (P9)

A small number also considered the impact that deteriorating functional ability may have on the person and their families in terms of continuing to live independently and carer burden.

“for people living on their own, your first thought is actually maintaining people at home for as long as possible. So physio would come on board to make sure that their mobility is maintained” (P3)

“The loss of independence that’s coming in as well and the carer dependence heightening with the families” (P9)

Their understanding of how physiotherapy achieved this was through exercise to maintain muscle strength, the use of mobility aids and educating both the person and their families regarding safety.

“maintaining their muscle function, their mobility, assessing them when they are unsteady re falls and re aids” (P10)

“for the relatives as well, under supervision they could learn to adapt to things, say, safe walking or transferring or going up the stairs” (P9)

The participants recognised the non-pharmacological approaches that physiotherapy provided for the management of physical symptoms. This was particularly evident in relation to respiratory symptoms, namely breathlessness management and oxygen assessments.

“around the breathlessness, they really help people, not just with whether they need oxygen or not, but how they pace and manage their breathing, how they clear when they get into coughing bouts” (P10)

“exercises to help better manage their breathing” (P2)

In relation to oxygen assessment, the participants valued the expertise of the SPC physiotherapists as it was something additional that they could offer.

“assessments for oxygen, that’s massive to have that. I think that’s been really helpful. The physios will assess oxygen levels on exertion, that kind of thing and then refer for oxygen therapy if they felt they needed it” (P5)

“That’s something we couldn’t do that I certainly found very beneficial” (P5)

The participants tended to focus on a medical approach to the management of pain. When asked about pain, only two participant were able to give clear examples of how physiotherapy contributed to complex cancer related pain.

“we were using opioids and all sorts of things and she said let’s try a TENS on that specific spot that you’re talking about and it was bingo like, this was something that he really found helpful” (P9)

The majority of participants, when prompted could only reference the use of slings or supports as to how SPC physiotherapy may contribute to the management of cancer pain.

“To provide different splints or supports” (P2)

“do some work with immobilising limbs” (P4)

Some participants identified that SPC physiotherapists had the expertise in managing pain caused by pre-existing medical conditions.

“it’s a non-malignant, it was a pre-existing condition, get the physios to see them to give them advice about managing the pain” (P9)

Participants identified that the role of physiotherapy in the management of physical symptoms can often complement their medical approach. This was discussed particularly in relation to providing individuals an alternative to medication to manage their symptoms.

“When we think about managing symptoms, medical and nursing, we’d go straight for a drug, we have drugs that work for certain symptoms like pain or like nausea” (P10)

“the breathing exercises, they find that very helpful” (P1) “and it’s not just medication management” (P2)

Subtheme 2: Psychological Support

Participants reported that physiotherapy was part of the overall holistic approach of palliative care which encompasses the physical, psychological and spiritual aspects.

“Particularly for palliative care patients, yes it’s for strengthening and their mobility and all of that however it is as much for their mental wellbeing – it’s a balance between both” (P7)

They identified that physiotherapy could give individuals a sense of control. This was often discussed in relation to the perception that these individuals did not have control over other aspects of their health, including cancer treatments.

“They’ve lost control of a lot their body, like they’ve lost control of what’s happening. They have control over managing their own [physiotherapy] exercises rather than just attending an appointment. That’s within their power, that it’s a huge thing for people (P3).

The idea of control was also discussed in relation to techniques that physiotherapy could give to individuals to help manage their symptoms.

“I think people cope when they know they can do something, getting techniques or tips, it gives people a sense of control they can do something” (P10)

“it’s not just medication management, they can do something to help themselves rather than take a tablet or something, It gives them power, empowerment” (P2)

Another reason that was identified through the focus groups was the idea that having an outpatient physiotherapy service was something positive to offer individuals.

“that’s real positive thing, we can offer that to people” (P4)

The positivity associated with physiotherapy that participants described was in relation to *“living, and not dying” (P6)*. The participants identified a role that physiotherapy played in offering hope to individuals under palliative care services.

“you’re offering them something, you’re giving them hope that there’s something that we can do to make them feel better” (P1)

One participant, when recalling an individual who was very invested in physiotherapy, described what physiotherapy meant to that person.

“because physio is representative of living to him and that I’m not quite going” (P3)

The participants also discussed how physiotherapy could give these individuals a sense of confidence, through engaging in physical activity.

“the feedback is like ‘God I did a bit of cycling’ and all this gives them more, it gives them a sense of confidence” (P10)

“would been seen [by physiotherapy] and maximising their independence, because confidence is hugely affected by a lot of our patients” (P9)

Participants also discussed that engaging in physiotherapy group exercise classes could be an enjoyable experience for individuals and provided a distraction from living with a life limiting illness.

“exercise classes with them and they’d just do gentle stretches and things in the day room and it was a great atmosphere, and they’d just do gentle stretches and exercises it was fun and it focused them a little bit as well that it wasn’t all sombre and “we’re all dying of cancer”” (P9)

“it was like YMCA or whatever it is but its levity” (P4)

Subtheme 3: As a stepping stone into SPC services

While the participants often discussed referral to physiotherapy in terms of managing physical symptoms with individuals, they also identified that having an outpatient physiotherapy services could be used also be a means for them to engage with other aspects of the SPC service.

“We’d kind of camouflage the hospice under this treatment” (P4)

“For a lot of people it can really be the first step of getting them into the hospice” (P3)

There was an awareness that some individuals were reluctant to engage with SPC services as they were perceived as representing death.

“his fear of hospice, he’s just resistant to the word hospice and coming in here is a big deal” (P2)

“people associate the hospice with death and dying” (P4)

As discussed previously, having an outpatient physiotherapy service was seen as something positive to offer these individuals. The participants reported that this service was valuable as an introduction to the hospice, especially for those who potentially may require inpatient admission for end of life care.

“there could be multiple reasons as to why someone couldn’t be maintained at home but it would be a last case. Someone like that would be identified very early on so that things like outpatients and day care, the stepping stones into the hospice would be worked on” (P3)

Subtheme 4: Reasons not to consider referral to physiotherapy

While participants were able to describe those who they referred to physiotherapy, they also identified a cohort of people that they considered would be unable to attend physiotherapy. They reported that they would not consider a referral to physiotherapy if they felt an individual was *“too unwell” (P4)*.

They tended to consider individuals with high fatigue levels as not being able to attend physiotherapy.

“Too fatigued” (P8) “Yeah too fatigued” (P4) “It wouldn’t be worth it, they’d be too exhausted afterwards” (P8)

“they kind of need to be up to it” (P1)

When asked directly regarding referral to physiotherapy for fatigue management, the majority of participants reported that they did not tend to consider this as a reason for referral.

“chronic fatigue management in cancer patients, not so much. It wouldn’t have triggered me for physio” (P2)

Although one participant did report that they would consider a referral to physiotherapy for fatigue management, particularly as they are limited in what they can offer in terms of medication management.

“But when it comes to symptoms more like breathlessness or weakness or fatigue, then actually our drugs are very limited and that’s when we’d need our allied health professionals” (P10)

The majority of participants also reported that they did not immediately consider a referral to physiotherapy for pain management, despite previously describing an effective physiotherapy intervention for the management of cancer related pain.

“it would be unusual to refer for pain” (P5)

Another aspect that the participants consider prior to referring to physiotherapy was whether there was a potential for improvement.

“or there may not be an achievable outcome in terms of the physio role if they’re too unwell, so it depends on the person’s ability whether it’s appropriate or not to refer” (P2)

Other reasons that the participants shared for not referring to physiotherapy included the person's preference and their readiness to engage with SPC services.

"they feel they've enough appointments going on" (P10)

"she wasn't psychologically ready to come into outpatients" (P1)

The final reason that the participants raised regarding not referring to physiotherapy was the assumption that another team member within the outpatient department would make the referral. This finding may be unique to this service, due to the configuration of the outpatient department in relation to the community palliative care team.

"I think, once we refer to [outpatients] full stop, they're picked up by the physio there and I don't have to" (P7)

Subtheme 5: Self-referral to Physiotherapy

Within all the focus groups, the participants identified a certain cohort of individuals who actively sought a referral to physiotherapy.

"First of all the person who asks, who is very anxious to have a physio referral" (P8)

They recognised that a referral to physiotherapy could be important both to the individual and their families.

"The patient and their families, they feel the need to see a physio and have an assessment and that's OK too" (P1)

In summary, as outlined above, there are many factors, including physical symptoms and psychological reasons that the participants identified in relation to who they would consider a referral to physiotherapy for and for what purpose.

4.4.4. Theme 2: Physiotherapy Practice within SPC services

This theme presents the CPC team's perceptions of the expert knowledge and clinical experience of the SPC physiotherapists and how it aligns with the principals of SPC. It also discusses the role of the SPC physiotherapist as an expert resource for both the wider SPC team and other physiotherapy colleagues, particularly within primary care services.

The participants referred to speciality of palliative care throughout the focus groups and identified that many of the skills of the physiotherapists aligned with those of the wider team which included a holistic individualised approach, which aims to meet the wishes and needs of the person.

"we have the specialist skills, in each department, to provide specialist palliative care for the community" (P4)

"within the palliative care team, the holistic care of the patient, so it's not just about the pain" (P6)

Subtheme 1: Experience of SPC physiotherapists

The participants reported that physiotherapists working within SPC services had valuable experience in providing holistic care to these individuals. They recognised that SPC physiotherapists were able to assess the overall individual and provide a tailored approach to their interventions.

"they always, they fit the [physiotherapy exercises] to the purpose of, what the patient wants" (P4)

Particularly, when comparing SPC physiotherapists and primary care based physiotherapists, the participants highlighted the holistic approach which is the essence of SPC service provision.

"I think our [SPC] physio's are much more appropriate in what they see" (P5)

Collaborative working between the SPC physiotherapists and the individual, in order to achieve their goals, was seen as an example of their experience.

"some people have said I just want to be able to walk from here to there. Their goals, and its working with that" (P3)

They described the importance of building a therapeutic relationship between the SPC physiotherapists and the individuals, especially as they begin to deteriorate.

“also planning ahead for when things aren’t as good and building that relationship with patients” (P10)

“And knowing and being able to speak – things are going to change and generally deteriorate” (P5)

One participant described the ability of SPC physiotherapists as *“looking at them psychologically and nurturing them” (P1)*.

Subtheme 2: Clinical knowledge of SPC physiotherapists

The SPC physiotherapists’ understanding and knowledge of disease progression and establishing realistic achievable outcomes for individuals was also identified throughout the focus groups.

“they have a very good sense of the trajectory, in terms of their functioning and how that can be. What equipment is needed to maintain function and health” (P10)

This knowledge was particularly relevant in the context of SPC service provision, which is an expert resource in supporting individuals at end of life.

“I think there would be huge awareness of what the quality of [SPC physiotherapists] experience is versus how people improve with mobility” (P3)

Participants acknowledged the SPC physiotherapists work collaboratively with both the CPC team and primary care physiotherapists for the benefit of the individual. The availability of the SPC physiotherapists to provide advice and support was valued, particularly in the context of reduced resources.

“There are times when you’d love [physio] to go out and in fairness she is great she’ll always give advice” (P10)

“our physio’s liaised with the nursing home, you know that kind of link is very good to support their colleagues in the community” (P10)

Subtheme 3: Primary Care physiotherapy services

The participants discussed the difference between the primary care physiotherapy service and the SPC physiotherapy service. They identified that primary care based physiotherapists were their primary link if they observe people to be at risk of falls or unsafe in their own environment.

“if we found somebody had difficulty or was a safety concern for us, that it was our responsibility to refer them to community physiotherapy” (P4)

However, the participants highlighted challenges with regards the community physiotherapy service. This included difficulty communicating with them, especially as the individual deteriorates.

“community physio is far more difficult for us to access” (P4)

“the patient deteriorates significantly, and they’re bed bound. It would be our remit to contact the GP, to contact the PHN but I would never think of contacting the physio to say that you know you don’t need to come out, whereas if it was one of our [physiotherapists], they’d know” (P4)

They also reported that they believed resources within community physiotherapy services impacted on the care provided to the individuals. This was in terms of waiting times and the number of interventions offered to people.

“you make a referral to community physio and its three weeks later, it’s a month later when they’re actually seen. The patient has changed so much in that length of time” (P7)

“Just from my experience, anyone who has had physio at home it tends to be a once off visit, that they come in, they can assess, give a recommendation and pull out” (P2)

Subtheme 4: SPC Physiotherapy Service Delivery

One of the positive aspects that the participants referred to in relation to outpatient physiotherapy was the overall experience of attending. One participant describes how different the outpatient department is compared with hospital based services.

“it’s so welcoming, everyone is so nice and makes eye contact” (P1)

The patient centred focus of SPC services is essential to the running of the SPC outpatient department. This includes maintaining appointment times as previous experience of long waiting times is seen as a barrier to attending. This is particularly important for individuals under the care of SPC services.

“it’s not like outpatients in the hospital, you won’t be sitting for hours, you come in, you have your appointment time, you’re seen on time, and you get out on time” (P1)

One important aspect of SPC service provision is ensuring the delivery of services in a timely manner. All the participants acknowledged flexibility of the current physiotherapy services in facilitating urgent reviews, particularly in relation to individuals who were deteriorating.

“accessible and gets appointments quick” (P2)

“in fairness they are very good at seeing the patients quickly” (P10)

The expert clinical knowledge and experience of the SPC physiotherapist provides individuals with care that is aligned with the ethos of SPC. The delivery of the SPC physiotherapy services, also aligns itself to the patient centred approach to SPC. The SPC physiotherapists also acts a resource to both the SPC team and primary care physiotherapy colleagues.

4.4.5. Theme 3: Developing the SPC physiotherapy service

This theme presents the opinions of the CPC team regarding the current SPC physiotherapy service and their views on the potential future developments particularly within the community services. It also address the current means of communication between the CPC team and the physiotherapy department.

Subtheme 1: Areas for development

All the participants reported that they would welcome a physiotherapy service in individual's homes as part of the community palliative care services but were cognisant of resources being the limiting factor to this.

"it was because of resources that it's not part of the community team" (P2)

"I think that would be wonderful" (P9)

"if we had the opportunity that they could go out in exceptional circumstances, that would be brilliant" (P10)

One participant also referenced the availability of equipment in the outpatient department that would not be in the individual's home.

"you don't have all the equipment [in the person's home]" (P10)

However, there was some differing opinions regarding how the limited resources of the physiotherapy department should be allocated. Some participants valued the outpatient service over a community based service for its economic value and also the value of the stepping stone into SPC services.

"You have to think about justice and resources as well. As it stands at the moment we need extra physios and if then we were using them to go out and not see as many patients, is that a good use of resources?" (P10)

"I think [community based SPC physiotherapy] would be really really good but at the same time, not with the absence of it in outpatients because I think that step to come in to physio is vital" (P3)

There were some participants who questioned the current configuration of the physiotherapy service which provides both inpatient and outpatient care. They were unsure of the value in providing a service to the inpatient department and would prefer the resources to be redirected to community based services such as hospice day care.

“I don’t understand what the role of having a full time physiotherapist in the inpatient setting is? Like what work do they do and is achievable? And I’m wondering about some of the other services that could do with it” (P9)

Facilitating exercise classes was another area that participants would like the physiotherapy service to develop. One participant spoke about a SPC day care service in Australia, where T’ai Chi classes were offered every morning.

“I thought wow, that is great, they were having great fun, but it was really centring doing T’ai Chi and gentle exercises and I thought I never even heard someone talk about something like that here” (P9)

A non-clinical area that was highlighted as an area to develop was the educational aspect of the physiotherapy service. This was particularly in reference to increasing the awareness of the role and benefit of physiotherapy to other members of the CPC team.

“we need a bit of education again about what physios do, even within a specialist team. Maybe it would be no harm if they just came just said these are the reasons for referral to us, just to remind people” (P10)

Subtheme 2: Communication

Currently within the community palliative care, discussions regarding the individuals care occurs primarily at the multi-disciplinary team meetings (MDM) which physiotherapists do not attend due to limited resources. There was mixed opinion regarding physiotherapists attending these meetings, with some participants reporting that is was not necessary unless they were in a position to also review people in their own homes.

“specifically if they were available to work in the community but to come in [to MDM] I don’t think it’s necessary” (P2)

However, other participants reported the presence of a physiotherapist at the meeting would prompt them to consider non-pharmacological approaches.

“if we had a presence of a physio at one of our MDM’s they could just prompt everybody to even think that way. Otherwise the MDT (multi-disciplinary team) becomes very much nursing medical, down the drugs route” (P10)

This participant also believed that individuals received a better service with all team members engaging in the MDM.

“I know it works very well in the inpatient unit when you have physio and OT there regularly at the weekly meetings, the patients get a better service basically” (P10)

The majority of the participants reported that the informal and ad hoc approach to communication was sufficient. They felt that the current arrangement which includes reading physiotherapy notes in the medical charts and informal conversation allowed them to communicate well with the physiotherapy service.

“get feedback from the notes, or maybe from verbal, kind of verbal handover or just to kind of check in” (P4)

“we communicate quite well” (P2)

Another facet of communication that was identified was the participants’ ability to promote and encourage individuals to attend outpatient physiotherapy.

“to help each other, what language to use [with patients], how to encourage them because I know we all work in the job it’s no harm for us all to be refreshed” (P10)

The main areas for development of physiotherapy services within SPC were focused on increasing the level of services that could be offered, including home assessments and exercise classes. A need for further education regarding the role of physiotherapy was also identified. There were mixed opinions about the need to improve or formalise means of communication between the physiotherapy department and the CPC team.

4.5. Summary of findings from Phase 2

Participants in the focus groups referred to physiotherapy primarily for mobility and respiratory issues. While there was some acknowledgement about the role of physiotherapy in the management of other physical symptoms, such as pain and fatigue, these symptoms were not readily identified as a reason to refer to physiotherapy. Some participants only considered a referral to physiotherapy if there was potential for improvement. Participants acknowledged the psychological benefits of attending physiotherapy and reported referring some individuals for this reason alone. The participants also valued the opportunity to be able to refer to physiotherapy as a means for individuals to engage with the wider hospice services.

The clinical knowledge and experience of the SPC physiotherapists was highlighted throughout the focus groups, especially how it aligned to the ethos of SPC. Participants also had ideas as to how they envisaged the physiotherapy department developing with increased resources.

5. Discussion

5.1. Aims of the research study

This study explored referral patterns to an outpatient specialist palliative care (SPC) physiotherapy from the community palliative care (CPC) team. The first phase of this study conducted a medical chart audit to examine the profile of individuals with advanced cancer who were referred to SPC physiotherapy and compared them to those who were not referred. The second phase of this study explored the CPC teams' understanding of the role of SPC physiotherapy and how they identified those to refer for physiotherapy. The results from both phases of the study contributed to the overall understanding of the referral pattern to SPC physiotherapy for community based individuals.

5.2. Reasons for referral to SPC services

The Palliative Care needs assessment guidelines published in 2014, outline the eligibility criteria for referral to SPC services and appropriate time points along the illness trajectory at which to consider the SPC needs of the individual (National Clinical Programme for Palliative Care, 2014). Eligibility for SPC services are limited to individuals with a life-limiting illness and “current or anticipated complexities relating to symptom control, end of life care planning, or other physical, psychosocial or spiritual care needs that cannot reasonably be met by the individuals current care providers” (National Clinical Programme for Palliative Care, 2014). Figure 3 outlines the algorithm proposed by these guidelines for healthcare workers to use when considering a referral to SPC.

Figure 3: Needs assessment algorithm regarding referral to SPC services

5.3. Demographics of Individuals under the care of SPC services

One of the main findings from the medical chart audit was that there was a significant difference in the age of those who were referred to physiotherapy compared to those who were not. The average age of those who were referred to physiotherapy in this study was 66.4 years compared with 73.2 years for those who were not. A difference in the age profile of those referred to physiotherapy was not identified within the literature reviewed for this study. Oldervoll et al. (2005) reported no difference in the age profile of

those who completed and those who dropped out of a physiotherapy led exercise programme for individuals with advanced cancer (65.2 years vs 58.1 years). Similarly, Johnson et al. (2015) also reported no difference in age of individuals who completed a breathlessness intervention compared with those who did not (69-70 years vs 67-68 years). The age profiles in these studies is similar to those who were referred to SPC physiotherapy in this current study.

Potential reasons why younger people may have been referred to SPC physiotherapy may relate to functional deficits being an unanticipated difficulty for younger people. Kokkonen et al. (2017) examined functional difficulties in individuals with advanced breast cancer and reported that functional deficits were evident in younger individuals when compared to expected age-related normal values. They found that dynamic balance was affected in 73% of individuals under 61 years of age compared with age related normal values. They also reported that 73% of individuals under the age of 55 demonstrated reduced muscle strength as measured by repeated squat test compared to age-related normal values. In contrast, there was only a 30% deficit compared to the age-related normal values in strength in those over 55 years of age. There may be an assumption that younger individuals should be able to complete everyday tasks such as shopping and climbing stairs and it is therefore highlighted as a problem when they are unable to do so. Further research to explore the possibility that functional deficits are easier to observe in younger patients and are therefore more likely to be referred to physiotherapy is warranted.

Perhaps the reason older people were not referred to physiotherapy is that functional deficits are considered a normal part of the aging process rather than a consequence of advanced cancer or its treatment. While age was not raised as a consideration when discussing physiotherapy within the focus groups, this may indicate that the participants were not aware that their referral practice lead to this finding. A decline in physical ability with age is well documented within the literature. For example, Steffen et al. (2002) reported that mobility, as measured by the 6 minute walk test, berg balance scale, timed up and go and gait speed declines with age. In older adults with advanced cancer, this finding was confirmed by Roh et al. (2014) who examined mobility in Korean individuals. They reported a significant decrease in the six-minute walk test distance between age groups (65-69, 70-79, ≥80). Further research could explore whether or not there is an assumption that older individuals may not be able to participate in physiotherapy.

Another potential explanation for the difference in the age profile may relate to younger people actively seeking physiotherapy. Results from the focus group highlighted that there are a cohort of individuals who request physiotherapy, i.e. self-referred to physiotherapy. According to Rothenbacher et al. (1997) younger individuals are more likely to actively participate in decisions regarding their care compared with older people. Snyder et al. (2008) reported a significant difference in the age of individuals, in how they were referred to physiotherapy, with younger people more likely to have self-referred to a diet and exercise intervention for cancer survivors compared with those who were recruited from a cancer registry. It is possible that in this study, the difference in age between the two groups was due to younger individuals requesting a referral to physiotherapy.

Another finding from this study was that people with a higher performance status as measured using the Palliative Performance Scale (PPS) were more likely to be referred to physiotherapy (62.8% vs 57.6%) than those with a lower PPS. The PPS incorporates an assessment of ambulation, self-care, activity and evidence of disease, intake and level of consciousness, with a higher score indicating a better performance status. The fact that individuals referred to SPC physiotherapy had a better functional status was also identified in the focus groups. The focus group participants spoke about an individual's ability to engage in physiotherapy primarily in relation to function. There are mixed findings within the literature in relation to the performance status of individuals' who are referred to physiotherapy or to exercise interventions. For example, Connors et al. (2007) reported that individuals who did not complete a physiotherapy led breathlessness programme were more likely to have a lower performance status and a shorter prognosis. Similarly, Johnson et al. (2015) also reported that those with a lower performance status were more likely to drop out of their breathlessness management study. Conversely, both Oldervoll et al. (2005) and Chasen et al. (2013) reported no difference in the performance status of the individuals who did and did not complete a physiotherapy led exercise intervention. Maddocks et al. (2011) acknowledged that individuals may drop out of exercise programmes but their ability to participate should not be a reason not to consider a referral.

For the 38 individuals referred to SPC physiotherapy, the mean number of appointments attended was 2 (range 1 – 30), as identified from the medical chart audit. Of these, 29% were discharged as they were independent with self-management strategies including individualised exercise programmes and a further 8% were discharged as their symptoms had resolved. This suggests that individuals are able to engage with SPC physiotherapy and may achieve meaningful benefit. The number of physiotherapy interventions were not reported by Cobbe et al. (2013) or Mueller and Decker (2011) but both authors report individuals had “at least one” intervention. The unpredictable nature of advanced cancer may pose challenges regarding engagement with physiotherapy services. This is evident from the medical chart audit where 32% of individuals were unable to continue with physiotherapy as they became too unwell to attend. However, there was no documented evidence that individuals discontinued SPC physiotherapy for if not being a beneficial experience.

The care needs of individuals was measured by the presence of formal supports, i.e. a home care package. Formal supports are required when individuals require assistance to complete activities of daily living (ADL's) or there is a safety concern regarding the individuals' ability to complete these tasks. While there was no significant difference in the care needs of those who were referred to SPC physiotherapy compared with those who were not, a high proportion of those who were not referred to SPC physiotherapy required formal supports. This is not an unexpected finding as those who were not referred to SPC physiotherapy had a lower PPS, which indicates that they require more physical assistance (Anderson et al., 1996).

Individuals with a lower performance status are more likely to have difficulty maintaining their independence, which is associated with a lower quality of life and increased carer burden. Cramarossa et al. (2013) reported that lower physical functioning was associated with a lower quality of life. Hanratty et al. (2013) reported that older adults with cancer were worried about losing their independence and the impact of this which included becoming a burden to family or needing to move to a place of care.

The PPS of individuals is an important assessment as it is a comprehensive overview of the person's ability across five different domains. It gives an overall sense of the person's abilities. The PPS of an individual impacts on many aspects of their care, including their ability to independently manage their own care needs which may impact on their overall quality of life.

Individuals who were referred to SPC physiotherapy were also under the care of the CPC team for a significantly longer period of time than those who were not referred. This finding was not unexpected as a higher performance status is linked to a longer prognosis (Anderson et al., 1996). The majority (79%) of referrals to physiotherapy occurred following their initial assessment by the CPC team. This could allow for the development of a trusting relationship between the individual and the CPC team. Van Vliet et al. (2015) reported that developing a trusting relationship with older individuals helps them to become involved in the decision making process of their care which may include a referral to physiotherapy.

The only significant difference in cancer type between those who were referred to physiotherapy compared with those who were not was prostate cancer. Many individuals with prostate cancer are treated with hormone modification, namely androgen deprivation therapy (ADT). The long term side effects of ADT include rapid loss of muscle and bone mass, which results in functional decline, increased fatigue and overall frailty (Hart et al., 2017). Due to these side effects, it could be hypothesised that mobility difficulties are easier to observe in this cohort. However, within this study, the total number of individuals with prostate cancer was 8 which represented only 8.6% of the total study population, 5 (62.5%) of whom were referred to SPC physiotherapy. Although there was no significant difference in the gender of those referred to physiotherapy compared to those who were not, there was a higher proportion of males referred. This may be explained by the number of individuals with prostate cancer being referred to physiotherapy.

There was a significant difference between those who were referred to SPC physiotherapy compared with those who were not in relation to cancer treatments, with those who were referred having completed more treatment prior to referral to SPC services. These individuals were also more likely to be receiving ongoing treatment interventions. It is not possible to determine the reason for this from this study, however, it could be hypothesised that these individuals were more likely to tolerate treatment due to their performance status. The performance status of an individual is often a factor in the decision making regarding whether to offer further treatment or not (Gajra et al., 2014).

5.4. Symptoms experienced

When reviewing the results from the medical chart audit, it did not appear that a referral to SPC physiotherapy was made in response to the symptoms experienced. This conclusion is based on the fact that there was no significant difference in the pain severity scores, the symptom severity scores or the types of symptoms experienced between those who were referred to SPC physiotherapy and those who were not. However, the participants in the focus groups indicated that they refer to physiotherapy for mobility problems and respiratory problems. Nelson et al. (2012) also described PHN's understanding of physiotherapy in terms of respiratory and mobility issues.

Decreased mobility was identified as the third most common symptom in both those who were referred to physiotherapy (24%) and those who were not (21%). Of those who were referred to physiotherapy, 53% were referred for mobility reasons as documented in their medical charts. A further 5% of individuals were referred with neurological deficits that impacted on their mobility. The focus groups also concentrated primarily on mobility issues when discussing referrals to physiotherapy and how physiotherapy may benefit individuals. This is similar to findings by McCartney et al. (2011) who also reported that healthcare professionals tended to consider physiotherapy primarily in relation to mobility.

Previous research demonstrated improvements in mobility and/or strength in individuals with advanced cancer who participated in a physiotherapy led exercise programmes (Oldervoll et al., 2011, Van den Dungen et al., 2014, Chasen et al., 2013). In a systematic review of exercise interventions for individuals with advanced cancer, Heywood et al. (2017) reported that the rate of completion of exercise programmes was 65 – 89% and attendance rate was 59 – 100%, indicating that many individuals are physically able to participate. They also reported that adverse events occurred in a total of 6 participants (n=1088), all of which were minor musculoskeletal injuries. This finding supports that exercise is safe for individuals with advanced cancer.

Despite evidence that referral to physiotherapy can improve mobility and that exercise is safe for individuals with advanced cancer, it warrants further exploration why more individuals in this study were not referred to physiotherapy to maximise their ability. Participants in the focus groups raised the concern that some individuals may not be physically able to engage in physiotherapy, particularly the exercise component. McCartney et al. (2011) also reported this finding when examining referrals to rehabilitation for individuals with high grade brain tumours.

Maddocks et al. (2011) suggested that offering exercise interventions at a lower intensity and a variety of exercise types could be beneficial to individuals with cancer cachexia. Similarly, there is evidence to suggest that older adults with advanced cancer can engage in physical exercise and gain measurable improvements. Lapid et al. (2007) reported a higher quality of life (QOL) in older adults with advanced cancer who engaged in an eight week multidisciplinary quality of life intervention, which included physiotherapy led exercise component when compared to the control group (79.3 vs 62.9, $p = 0.0461$). Quality of life was measured using the Spitzer QOL uniscale. There is also evidence to support that light intensity exercise can slow functional decline in older cancer survivors. Blair et al. (2014) concluded that increasing light intensity activities may reduce functional decline in individuals who are unable or reluctant to achieve the recommended physical activity levels. The competences of the SPC physiotherapist, as outlined by Ryan et al. (2014), demonstrate that SPC physiotherapists have the expertise to appropriately provide these interventions, tailored to the ability of the individuals, regardless of age or functional ability.

Another potential reason why some individuals may not be referred to SPC physiotherapy to improve their mobility is perhaps an assumption that they may not achieve a meaningful benefit and it may foster false hope. This concern was highlighted in the focus groups as a reason why the participants may not consider a referral to physiotherapy. The fear of fostering false hope for individuals was also highlighted by Nelson et al. (2012) who examined the reasons public health nurses may not refer individuals with advanced cancer to physiotherapy. They reported that the traditional perception of physiotherapy in relation to rehabilitation and improvement may lead to confusion for individuals and their carers. However, this idea is contradicted within the literature exploring the individuals experience of SPC physiotherapy. Both Turner et al. (2016) and Malcolm et al. (2016) reported that individuals found that the SPC physiotherapists were able to manage their expectations and physical ability in a supportive manner, particularly as their condition deteriorated.

Referrals to physiotherapy for the management of respiratory symptoms was evident from both the medical chart audit and the focus groups. In Phase 1 of this study, those with primary lung cancer (28.9%) were the largest cancer type referred to physiotherapy. This finding is similar to that of Jensen et al. (2014) who also reported that individuals with lung cancer were the largest cancer type referred to physiotherapy services in an inpatient palliative care unit.

Interestingly, in those who were not referred to SPC physiotherapy, individuals with lung cancer were also the largest group (23.5%) and respiratory symptoms were the fourth most common symptom identified (18.2%) using the palliative care problem severity score (PCPSS). It is well reported that individuals with lung cancer or metastatic lung disease have difficulties with breathlessness and mobility, especially as the disease progresses (Dhillon et al., 2012, Henke et al., 2014).

The role of physiotherapy in the management of respiratory issues was repeatedly discussed within the focus groups particularly in relation to breathlessness management and oxygen assessments. They highlighted the benefit to patients from both a practical and psychosocial point of view following physiotherapy interventions, however, it is unclear from the research completed, why some individuals with lung cancer or who had respiratory symptoms were not considered for physiotherapy. It may be that those with

lung cancer are often older and tend to have a lower performance status at time of diagnosis (Higton et al., 2010). As discussed previously, the reasons that these individuals may not have been referred could be based on their perceived inability to participate in physiotherapy due to a lower performance status.

Other symptoms associated with advanced cancer experienced by individuals did not appear to trigger a referral to SPC physiotherapy. This may relate to knowledge gaps regarding the role of physiotherapy other than for mobility and respiratory reasons. For example, only 18% of individuals referred to physiotherapy, were referred for pain management, primarily relating to musculoskeletal issues. The findings of this study suggest that a referral to physiotherapy for pain management is not routine. The participants within the focus group discussed pain in relation to musculoskeletal pain and the use of supportive devices such as slings. Despite discussing examples of successful physiotherapy interventions for cancer pain management, the participants tended to focus primarily on pharmacological approaches to pain. This may demonstrate a limited understanding of the role that physiotherapy can play in the non-pharmacological management of cancer pain which can include techniques such as exercise, joint mobilisation and the use of transcutaneous electrical nerve stimulation (TENS) (Jacox et al., 1994, Van den Broek et al., 2013).

Results from the medical chart audit demonstrate that there were no referrals to physiotherapy for fatigue management. In the focus groups, participants reported that they did not consider a referral to physiotherapy for fatigue management. This occurred despite fatigue being the most commonly identified symptom in both those who were referred to SPC physiotherapy and those who were not, as identified by the PCPSS in the medical chart audit. They also did not appear to be aware of the evidence to support physiotherapy in the management of cancer related fatigue. Evidence suggests that physiotherapy, particularly exercise based interventions can improve fatigue levels in people with advanced cancer (Chasen et al., 2013, Van den Dungen et al., 2014, McGrillen and McCorry, 2014).

There is a discrepancy between the evidence supporting the role of physiotherapy in the management of a wide variety of symptoms associated with advanced cancer and the referrals to physiotherapy observed in this study. SPC physiotherapists need to provide education which demonstrates the breadth of the role in the management of symptoms, regardless of perceived barriers such as age or performance status. The educational role of the SPC physiotherapy to both non specialist physiotherapist and other healthcare professionals is outlined in the palliative care competences (Ryan et al., 2014).

5.5. Other considerations regarding a referral to SPC physiotherapy

Psychological benefits of attending SPC physiotherapy were identified by the participants in the focus group. This included giving individuals a sense of hope, and control. They also recognised that many individuals associated physiotherapy as a positive treatment as it was representative of living as opposed to dying. These ideas are all supported by the literature that has examined individuals' experiences of attending physiotherapy in SPC services (Turner et al., 2016, Malcolm et al., 2016, Dahlin and Heiwe, 2009). This is in contrast to the findings of Nelson et al. (2012) who reported that PHN's believed that a referral to physiotherapy may foster false hope and that physiotherapists did not have ability to respond to the psychosocial and spiritual needs of the individuals. The competences of physiotherapy in palliative care, clearly outline the importance of a holistic approach to interventions (Ryan et al., 2014). This difference may be because the participants within this study work solely with individuals under a specialist palliative care service that had a physiotherapy department.

Despite the participants in this study being able to identify a psychological benefit from physiotherapy, they did not discuss a referral to physiotherapy for psychological reasons. There may be a number of explanations why psychological reasons alone may not trigger a referral to physiotherapy. As discussed previously, physiotherapy is usually associated with mobility and improvements in physical function (Oldervoll et al., 2011, Van den Dungen et al., 2014). The psychological benefit is often considered a secondary gain rather than the primary focus. Within healthcare, there is increasing demands for healthcare professionals to provide interventions which can demonstrate meaningful clinical improvements and as such, these tend to focus on physical symptoms such as

mobility and strength. However, with this approach, the psychological benefit of physiotherapy may be undervalued among healthcare professionals. This is particularly challenging within palliative care, especially when functional deterioration is inevitable. If physiotherapy services are only being offered to those who may achieve a measurable improvement, it may disadvantage a particular cohort of patients. This is particularly relevant to those who are considered physically unable for physiotherapy but may still benefit from a psychological wellbeing perspective. As identified by Nelson et al. (2012) However, with limited SPC physiotherapy services available within the research site, referrals primarily for psychological reasons may not be prioritised.

Another consideration regarding referrals to SPC physiotherapy is in relation to the timing of the referral. There is a difference of opinion regarding this, with many rehabilitation professionals advocating for an early referral within the disease process to prevent functional difficulties and disability in individuals with advanced cancer (Yoshioka, 1994, Laakso et al., 2003, Maddocks et al., 2011, Fialka-Moser et al., 2003). This is in contrast with non-rehabilitation professionals, who often wait for a deterioration prior to considering a referral to physiotherapy. This was identified within the focus groups, with many participants referring to physiotherapy in response to a functional problem, e.g. difficulty climbing stairs. McCartney et al. (2011) also highlighted that non-rehabilitation healthcare professionals waited for a deterioration prior to referral to physiotherapy. A potential negative consequence of waiting for a deterioration prior to referral to physiotherapy is that the individual may then be considered unable to engage in physiotherapy or the assumption that there may not be a meaningful physical benefit from physiotherapy. It is important that SPC physiotherapists encourage early referrals to physiotherapy to maximise individuals' functional ability (Maddocks et al., 2011, Laakso et al., 2003). This could be achieved through education and the development of a clear referral process which highlights the importance of early intervention, to maximise function and independence.

5.6. Resources

The data collected in this study were collected from one organisation, which provides SPC services for approximately 13% of the population of Ireland. Despite having no allocation of SPC physiotherapy for community based services, a local arrangement within the organisation provides approximately 30% of the physiotherapy service to the outpatient department. This equates to approximately a 0.7 whole time equivalent (WTE) physiotherapist. The significant deficits regarding SPC physiotherapy services is not limited to this organisation. Throughout Ireland, only two community health organisations have an allocation of community based SPC physiotherapists, although both are understaffed by 33 – 40%. The remaining seven community health organisations have no allocation of SPC physiotherapists for community based services (Health Service Executive, 2017).

Prior to this study, the research site had expanded the number of in-patient beds without an increase in the staffing levels to the physiotherapy department. This resulted in reconfiguration of the physiotherapy service, resulting in the withdrawal of physiotherapy provision to the day care services. At the time of this study, the physiotherapy department provided a service to both the inpatient and outpatient departments. It is important to acknowledge this reconfiguration within the discussion. It is evident that there was a breakdown in communication between the physiotherapy service and the CPC team as there were inaccurate assumptions regarding individuals attending both day care and outpatients, which may have impacted on the referrals examined in this study. For any further changes within the physiotherapy service, it is essential that the physiotherapy department communicates these with all stakeholders.

The limited resources of the physiotherapy department was debated within the focus groups particularly in relation to the allocation of services. Some participants questioned the role of physiotherapy in the inpatient department. They felt that the limited resources would be better utilised within the community services as these individuals would be better able to engage and would achieve a more meaningful benefit. However, there is evidence to support the role of physiotherapy in inpatient SPC services. Cobbe and Kennedy (2012) reported that 65% of inpatient hospice individuals (n=144) were referred to physiotherapy and 48% of these individuals demonstrated improvements in one or more functional outcome measures. Similarly, Jensen et al. (2014) reported that 92% of

individuals (n=572) in an inpatient SPC service were able to engage in one or more physiotherapy interventions. This suggests that hospice inpatient individuals are able to engage in SPC physiotherapy and can achieve measurable improvements. It is important for the physiotherapy department to examine ways in which to disseminate the benefit of SPC physiotherapy to SPC service providers including areas outside their own practice.

There were also differing ideas within the focus groups with regards to the development of physiotherapy services when asked about providing a physiotherapy service in the individual's home. While some participants would welcome physiotherapy assessments at home, others felt that developing the outpatient service was a more efficient use of resources. One participant spontaneously suggested the reintroduction of a group exercise programmes that previously ran in the day care services. This suggests that it would be advantageous for the physiotherapy service to engage in dialogue with the CPC team prior to changes within the physiotherapy service delivery being implemented. Engagement with those who refer to a service was highlighted as an important aspect by Freiburger et al. (2016) for the success of referrals to exercise programmes for frail, older adults.

SPC services are designed to encourage and enable individuals to live their lives to the greatest extent in the manner and setting of their choice (Department of Health and Children, 2001). With the stark staffing deficits within the organisation, there is no physiotherapy services to individuals in their own home or day care services. This ultimately impacts on the individuals choice regarding the setting in which they can access SPC physiotherapy services. Current evidence based also suggests that there are both physical and psychosocial benefits to individuals who attend group exercise programmes, however, it is not possible to offer this service at present due to limited staffing levels.

There was also differing opinion as to whether physiotherapists attending the CPC multi-disciplinary meetings would be of benefit. Some participants would welcome the attendance of a physiotherapist at multi-disciplinary team meetings as it may prompt a referral to physiotherapy for non-traditional symptoms such as pain, fatigue or anxiety. The potential for an improved referral rate is supported by Cobbe et al. (2013) who reported a higher referral rate to physiotherapy from a community palliative care team,

where there was a presence of a full time physiotherapist. Nelson et al. (2012) also reported that public health nurses identified that the lack of opportunity to discuss cases with physiotherapists was a barrier to referral. However, all participants acknowledged that the reason for them currently not attending was due to limited resources, but some questioned whether it would be the best use of their resources, if they were to attend.

An example of the efficient use of the limited physiotherapy resources was discussed in the focus groups in relation to the consultancy role of SPC physiotherapists. The competences of the SPC physiotherapist include acting as an expert resource within the profession (Ryan et al., 2014). Within the physiotherapy profession, Taylor and Bryan (2014) reported that physiotherapists who were not working with SPC services were unsure of how to transfer their skills and knowledge to support these individuals. The participants within the focus groups recognised the support that SPC physiotherapists provided to primary care physiotherapists looking after individuals with advanced cancer, especially to those who were unable to attend the outpatient department.

5.7. Recommendations for Practice

The main recommendations for practice from this study are: (1) education regarding the role of physiotherapy in SPC, (2) building a support network for non-specialist physiotherapists, (3) the development of a referral pathway to improve referrals to physiotherapy and (4) examining the communication between the physiotherapy department and the wider SPC services.

5.7.1. Education

There were some examples where the understanding of the role of physiotherapy in SPC was unclear in this study. One example of this was the role of physiotherapy in the management of functional decline, particularly in relation to older people and individuals with a lower PPS. This was also used as a rationale for physiotherapy services to be prioritised to community based individuals over those requiring inpatient care. Another example was a poor understanding of the benefit of SPC physiotherapy in the management of symptoms other than mobility and breathlessness. However, these are

not unique to this study. Nelson et al. (2012) reported that public health nurses did not believe that physiotherapists would have the knowledge or skills to provide expert palliative care. McCartney et al. (2011) also reported that other healthcare professionals were concerned about physiotherapists' ability to manage individuals with high grade brain tumours. They also reported that the healthcare professionals were not aware of the role of physiotherapy and how to access physiotherapy in this client group.

Education has been proposed as the primary means to address these concerns and knowledge gaps in all studies. The onus is on physiotherapists working in SPC services to promote the role and benefits of physiotherapy to all healthcare professionals. Education can occur in a variety of different means. Traditional education involves SPC physiotherapists presenting the evidence of physiotherapeutic interventions. This could occur during in-service education or at larger study days. Informal education can occur during multi-disciplinary meetings (MDM) or discussions around individuals' care. The feedback from the individuals regarding their experience of SPC physiotherapy could also be used as an educational medium to alleviate some of the fears regarding their ability to participate.

Another area that participants within the focus group identified as requiring education was how to discuss a referral to SPC physiotherapy with individuals. In particular, the challenge of promoting the benefits of physiotherapy, while being cognisant of the individual's fears regarding their ability to engage with physiotherapy or attending the hospice. Within the education remit of the SPC physiotherapist, it is worth incorporating into any educational session, communication strategies that including terminology that may explain the benefit of physiotherapy in terms that individuals understand.

5.7.2. Building a support network

The participants in the focus groups valued the support that was given to primary care physiotherapists in the management of individuals who were physically unable to attend SPC physiotherapy. The palliative care competence framework identifies that SPC physiotherapists should provide education, leadership and support to non-specialist physiotherapists (Ryan et al., 2014). The development of a support network should be individual to the needs of the primary care physiotherapists but should incorporate regular education and a communication plan.

5.7.3. Development of a referral pathway

When discussing referrals to SPC physiotherapy, some of the literature highlights the need to develop a referral pathway for individuals with advanced cancer (McCartney et al., 2011). Currently, within the study site, referrals to SPC are made by individual members of the CPC team, primarily nurses and doctors. Referrals are dependent on the healthcare professionals recognising physiotherapy needs. Given the complexity of SPC interactions, assessing physiotherapy needs may not always be possible. The development of a clear referral pathway, based on the needs and preference of the individuals, coupled with appropriate education of the role of physiotherapy in SPC may increase the referral rate. Cobbe et al. (2013) clearly described physiotherapy needs assessment criteria used when considering referrals to physiotherapy which includes symptom management, complications of advanced cancer and psychological distress.

Within the study site, the PCPSS is completed following each community assessment, which records the individuals pain score and rates other symptoms that they are experiencing. It may be possible to include a prompt, to consider a referral to physiotherapy for non-pharmacological management of symptoms such as pain, fatigue and breathlessness. A successful example of developing a referral pathway is reported by Chan et al. (2016). They developed a computer based referral system that prompted a referral to a multi-disciplinary breathlessness management programme for all individuals who scored 2 or more on their breathlessness score as measured using the medical research council scale. Referrals increased from 26.9% to 89.4% following this change. While this approach can be effective, it is dependent on integrated IT systems

which will generate an automated referral. The success of automatic referrals to a service is also dependent on having adequate resources to provide this service. Currently within Ireland, it may not be possible to implement this type of automated referral pathway due to the significant understaffing of allied health care professional within SPC services (Health Service Executive, 2017). For example, the staffing deficit for community based SPC physiotherapists is 87% and the staffing deficit for occupational therapists is 79% (Health Service Executive, 2017).

When developing a referral pathway to SPC physiotherapy services, addressing the reasons why individuals were not referred should be considered. This may include prompts to consider a pro-active referral to maximise function rather than waiting for a deterioration. It should also address the concerns that have been identified regarding older individuals and those with a lower PPS being able to engage in physiotherapy.

Another important aspect of a referral pathway, should include a record of when the referral was made and by whom. This may negate the assumption that it is someone else's responsibility to refer to physiotherapy. One of the findings from the focus groups was the assumption that if individuals were referred to one discipline in outpatients, then, that discipline was responsible then for referring to physiotherapy. McCartney et al. (2011) also identified that a lack of clarity about whose responsibility it was to refer people with brain tumours to physiotherapy as a reason for not referring. Another valuable aspect of a referral pathway includes a clear record of whether a referral has been made or not. In this study, a recommendation for SPC physiotherapy is documented in the medical charts of 6% of those who were not referred to physiotherapy but it was not possible to identify why these referrals were not made. A clear record of the referral may have reduced the number of these missed referrals.

5.7.4. Communication

Currently, within the study site, there are no formal communication channels to discuss individuals' care between the physiotherapy department and the CPC team. Sharing of information occurs through documentation in the medical charts or informal conversations. The main forum for discussing individuals care is at the MDM's, which physiotherapists are unable to attend due to limited resources. With an increase in staffing, it may be possible for physiotherapists to attend these meetings. However, as there is no funding for increasing resources at present, there needs to be a clear communication pathway between the physiotherapy department and the CPC team keeping the needs of the individual to the forefront.

5.8. Recommendations for further research

While the results of this study suggest that younger individuals with advanced cancer who have a higher PPS are more likely to be referred to physiotherapy, further research should examine reasons that individuals were not referred to physiotherapy, in particular older individuals and those with a lower performance status.

The results of this study are limited to a single organisation, with significant resource limitations regarding the availability of the physiotherapy service to community dwelling individuals. A similar study conducted in an alternative site may generate alternative conclusions or may confirm these findings regarding the profile of those who are referred to SPC physiotherapy.

The results of this study could be used as comparative data to evaluate the effectiveness of either an education programme or the development of a referral pathway as recommended by this study.

This study was limited to individuals with advanced cancer. SPC services are expanding their services to include individuals with a life limiting illness, regardless of diagnosis. Therefore the results of this study are not reflective of all individuals under the care of SPC services. Further research should examine the difference in the profiles of individuals under the care of SPC services with a non-malignant diagnosis who are referred to physiotherapy compared to those who are not.

5.9. Limitations of the study

There were a number of limitations to this study in both phases of data collection and interpretation of the results should be made while being cognisant of these. In Phase 1 of the study, the sample size selected was based on literature published which had described SPC services rather than statistical calculations, which may have led to type 2 errors (Bowling, 2014). Type 2 statistical errors can lead to a false conclusion of a significant difference where one does not exist. The numbers of medical charts included in this study is relatively small in relation to the overall service provision within the research site and as such may not be representative of the overall profile of individuals who require SPC input.

While the data extraction tool was developed based on available literature, it is not a validated instrument. The data extracted was based on the accuracy of documentation recorded in patient charts. Medical charts were not written for research purposes and as such, may be considered an untrustworthy source of data (Shaw, 2005). There were several examples of missing data. For example, there was no information regarding relevant medical history documented in seven medical charts. The use of the palliative care phase, PPS and PCPSS as routine measures was introduced in 2014, however, three people had their initial assessment prior to this, therefore this data were not available.

With regards to Phase 2 of the study, a notable limitation was the potential for bias. The nature of the focus group was clearly outlined in the letter of invitation and participant information leaflet. It is possible that those who chose to take part may have had a clearer understanding of the role of SPC physiotherapy and that those who did not participate may have a different understanding of the role of SPC physiotherapy. This may have resulted in a particular view regarding the role of SPC physiotherapy not being represented.

The thematic analysis of the focus groups was completed primarily by a physiotherapist who works clinically, solely in the area of SPC provision. Their knowledge and experience of physiotherapy in SPC and their belief that it is a valuable addition to all individuals under the care of SPC services may have influenced the interpretation of the data. At each stage of the thematic analysis process, discussions occurred with an academic supervisor who provided feedback which contributed to the final analysis. As recommended by Braun and Clarke (2006), the assumptions of the person completing the thematic analysis need to be declared.

The data collected for this study was from one research site, which has a significant understaffing of SPC physiotherapists. It is possible that the low referral rate is based primarily on the participants being aware of the limited staffing of the physiotherapy department.

5.10. Conclusion

The overall aim of this study was to explore the referral pattern of the CPC team to SPC physiotherapy for community based individuals with advanced cancer. This is the first study to our knowledge that explored the difference between those who are referred to SPC physiotherapy and those who are not. Referral rates to SPC physiotherapy for community based individuals range from 24 – 32%, despite evidence to support the role of physiotherapy in the management of the symptoms experienced by individuals with advanced cancer, including pain, fatigue, breathlessness and decreased mobility.

This study described and compared the profile of a sample of individuals with advanced cancer who were referred to SPC physiotherapy and those who were not. The descriptors used included age, gender, social supports, primary diagnosis, burden of disease, cancer treatments, performance status, pain score, symptoms experienced and symptom severity scores. From the results of the medical chart audit, there were significant differences in the age and performance status of those who were referred to SPC physiotherapy to those who were not. From the medical chart audit it was not possible to conclude that referrals were made in response to symptoms experienced, however, participants within the focus group discussed referrals for mobility difficulties and breathlessness. This would suggest that a referral to physiotherapy is based on individual factors rather than on any particular commonality of disease or symptom.

The findings from the medical chart audit were mostly corroborated within the focus group, with the participants referring to individuals being well enough to engage with SPC physiotherapy services. The participants were able to recognise that many people benefitted psychologically from engagement from SPC physiotherapy. An unanticipated finding from the focus groups was in relation to the individuals who were not considered for physiotherapy. A potential reason for this included knowledge gaps within the CPC team with regards to the role of physiotherapy in the management of symptoms other than mobility and respiratory issues. The participants also raised concern about the individuals' ability to engage in physiotherapy or that the individual may not achieve a meaningful benefit.

The findings from both phases of this study highlight the need for SPC physiotherapists to provide education to those who refer to the service. There were two distinct areas identified that may benefit from education from SPC physiotherapists. The main focus of education relates to the role and the benefit of SPC physiotherapy to people with advanced cancer. The other area that was identified within the focus groups was how to effectively communicate with individuals to promote the benefit of SPC physiotherapy while alleviating any fears they may have. The opportunity for physiotherapists to attend the MDM is a prime example of an opportunity to provide informal education to other team members, particularly in the context of a specific individual.

A lack of clear guidelines within this study site on how to identify SPC physiotherapy needs is reflected in this study. The responsibility for developing an improved referral pathway lies with the physiotherapy service, in consultation with the CPC team and the IT department. It may be possible to develop computer generated prompts, linked to the online recording of the PCPSS for symptoms such as pain and fatigue.

The development of SPC physiotherapy services, should be cognisant of the fears of both the individual and the person making the referral. It is important that SPC physiotherapy services should be developed to provide a wide range of interventions that meet the needs and the interests of the individuals. Engagement with the wider SPC team as physiotherapy services expand may lead to an increased number of appropriate referrals.

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7. Appendices

7.1. Appendix 1: Data Extraction Tool

DOB: _____ DOD: _____ Place of death: _____
 Male/Female Initial Ax: _____ Date no longer under care of CPC: _____

Referred to	Community / SFH	Date	Offered & Declined
Physio Yes / No			
OT Yes / No			
MLD Yes / No			

Reason referred To SFH Physio
 Mobility
 Respiratory
 Neurological
 Musculoskeletal
 Other: _____

		At time of Physio referral:
Primary Diagnosis	Breast Cancer Prostate Cancer Lung Cancer Colo-rectal Pancreatic Upper GI Gynaecological Urological (excluding prostate) Brain Head & Neck Other: _____	Within 4 weeks prior to referral to physio Recent Fall Yes/No Recent hospitalisation Yes/No Recent infection Yes/No Other Issues:
Metastatic Disease	Bone Mets Yes / No <ul style="list-style-type: none"> • Lumbar Spine • Pelvis • Femur • T-Spine / Ribs • Other _____ 	New Bone Mets Yes / No <ul style="list-style-type: none"> • Lumbar Spine • Pelvis • Femur • T-Spine / Ribs • Other _____
Locally Advanced Yes / No	Brain Mets Yes / No Lung Mets Yes / No Liver Mets Yes / No Lymph Node involve Yes / No Peritoneal mets Yes / No	New Brain Mets Yes / No New Lung Mets Yes / No New Liver Mets Yes / No New Lymph Nodes Yes / No New Peritoneal mets Yes / No
Distant mets Yes / No		
Medications:		Changes:

Previous Treatment	Surgery Chemotherapy Radiotherapy (sites) • • • • • Hormone Therapy Other: _____	Yes / No Yes / No Yes / No Yes / No	
Ongoing Treatment	Chemotherapy Radiotherapy (sites) • • • • • Hormone Therapy Other: _____	Yes / No Yes / No	Chemotherapy New/ongoing/Stop Further Radiotherapy (sites) • • • • • Hormone Therapy New/ongoing/Stop Other: _____
Co – morbidities			
Phase	Stable Unstable Deteriorating Actively Dying		Stable Unstable Deteriorating Actively Dying
PPS Score			
Pain Score			
Symptoms & severity score			
Functional status as commented			
Social Support	Lives alone Lives with family Home care package Nursing Home resident		Lives alone Lives with family Home care package Nursing home resident
Comments referencing physio:			

Physio specific data extraction

Reason for referral	Mobility Respiratory Neurological Musculoskeletal Other:
Symptoms identified at initial physio assessment	Functional decline Dyspnoea Fatigue Pain Other
Other rehabilitative needs identified through physio intervention & actions taken	
No. of sessions patient attended	
No. of Cancelled appointments & reasons why	
Reason for no further physio appointments	Too unwell to continue to attend Admission to hospital / hospice Symptom/issue resolved, discharged from physio Patient declined to attend Independent with self-management strategies Other
If discharged was patient re-referred for new symptom / deterioration in symptom	

7.2. Appendix 2: Palliative Care Phase

Start	End
Stable	
<p>Patient problems and symptoms are adequately controlled by established plan of care and</p> <ul style="list-style-type: none"> • Further interventions to maintain symptom control and quality of life have been planned <p>And</p> <ul style="list-style-type: none"> • Family / carer situation is relatively stable and no new issues are apparent 	<p>The needs of the patient and or family / carer increase, requiring changes to the existing plan of care</p>
Unstable	
<p>An urgent change in the plan of care or emergency treatment is required because</p> <ul style="list-style-type: none"> • Patient experiences a new problem that was not anticipated in the existing plan of care <p>And / or</p> <ul style="list-style-type: none"> • Patient experiences a rapid increase in the severity of a current problem <p>And / or</p> <ul style="list-style-type: none"> • Family / carers circumstances change suddenly impacting on patients care 	<ul style="list-style-type: none"> • The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean the symptom / crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. the patient is stable or deteriorating) <p>And / or</p> <ul style="list-style-type: none"> • Death is likely within days (i.e. the patient is now terminal)
Deteriorating	
<p>The care plan is addressing anticipated needs but requires periodic review because</p> <ul style="list-style-type: none"> • Patients overall functional status is declining • Patients experience a gradual worsening of existing problems <p>And / or</p> <ul style="list-style-type: none"> • Patient experiences a new but anticipated problem <p>And / or</p> <ul style="list-style-type: none"> • Family / carers experience a gradual worsening distress that impacts on patient care 	<ul style="list-style-type: none"> • Patients condition plateaus (i.e. the patient is now stable) or • An urgent change in the care plan or emergency treatment <p>and / or</p> <ul style="list-style-type: none"> • Family / carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. the patient is now unstable) <p>or</p> <ul style="list-style-type: none"> • Death is likely within days (i.e. the patient is now terminal)

Appendix 2: Palliative Care Phase (continued)

Start	End
Terminal	
Death is likely within days	<ul style="list-style-type: none"> • Patient dies or • Patient condition changes and death is no longer likely within days (i.e. the patient is now stable or deteriorating)
Bereavement	
<ul style="list-style-type: none"> • The patient has died • Bereavement support provided to family/carers is documented in the deceased patients clinical record 	<ul style="list-style-type: none"> • Case closure <p>Note, if counselling is provided to a family member or carer, they become a client in their own right</p>

7.3. Appendix 3: Palliative Performance Scale

PPS Level	Ambulation	Activity and evidence of disease	Self-care	Intake	Conscious level
100%	Full	Normal activity No evidence of disease	Full	Normal	Full
90%	Full	Normal activity Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable for normal job /work Some evidence of disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby / housework Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50%	Mainly Sit / Lie	Unable to do any work Extensive disease	Considerable assistance necessary	Normal or reduced	Full or confusion
40%	Mainly Sit /Lie	As above	Mainly assistance	Normal or reduced	Full or drowsy or confusion
30%	Totally bed bound	As Above	Total care	Reduced	Full or drowsy or confusion
20%	As Above	As Above	Total care	Minimal sips	Full or drowsy or confusion
10%	As Above	As Above	Total care	Mouthcare only	Drowsy or coma
0%	Death				

7.4. Appendix 4: Palliative Care Problem Severity Score

Clinician Rated:

For the following domains, assess the severity of the problem as:

0 = absent, 1 = mild, 2 = moderate, 3 = severe

Pain	
Other Symptom	
Psychosocial / Spiritual Distress	
Family / Carer Problem	

7.5. Appendix 5: Data Dictionary

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
A	Study_ID	Study ID Number	Number assigned chronologically	Qualitative	Discrete	Nominal	Enter Number
B	DOB	Date of Birth	Self-explanatory	Qualitative	Discrete	N/A	Enter in date format (dd/mm/yyyy)
C	DOD	Date of Death	Self-explanatory	Qualitative	Discrete	N/A	Enter in date format (dd/mm/yyyy)
D	POD	Place of Death	Where patient died	Qualitative	Discrete	Nominal	1=Home, 2=Hospital, 3=Nursing home, 4=hospice, 9=unknown
E	DIAx	Date of Initial Ax	Self-explanatory	Qualitative	Discrete	N/A	Enter in date format (dd/mm/yyyy)
F	DNCPC	Date no longer under care of CPC	Self-explanatory	Qualitative	Discrete	N/A	Enter in date format (dd/mm/yyyy)
G	Sex	Gender	Gender of patient	Qualitative	Discrete	Nominal	1=male, 2=female, 9=unknown
H	SFHP	Referred to SFH physiotherapy	Self-explanatory	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
I	CommP	Referred to Community Physio	Self-explanatory	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
J	Reason_P	Reason for referral to Physio	Self-explanatory	Qualitative	Discrete	Nominal	1=mobility, 2=respiratory, 3=neurological, 4=Musculoskeletal, 5=other, 9=unknown 99=not referred
K	SFHOT	Referred to SFH OT	Self-explanatory	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
L	COT	Referred to Community OT	Self-explanatory	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
M	Reason_O	Reason for referral to OT	Self-explanatory	Qualitative	Discrete	Nominal	1=seating Ax, 2=Functional Ax, 3= Equipment Ax & Provision 4=Anxiety Management, 5=Pressure care, 6=Other, 9=unknown, 99=not referred
N	SFHMLD	Referred to SFH MLD	Self-explanatory	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
O	Diag	Primary Diagnosis	Self-explanatory	Qualitative	Discrete	Nominal	1=Breast, 2=Prostate, 3=lung, 4=Colorectal, 5=Pancreatic, 6=Upper GI, 7=Gynaecological, 8=Urological excluding Prostate, 9=Brain, 10=Head & Neck, 11=other
P	L_Adv	Locally Advanced	Self-explanatory	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
Q	D-Mets	Distant Metastatic Disease	Self-explanatory	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
R	Bo_Met	Bone Mets	Presence of bone mets	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
S	N_B_Met	Number of sites of bone mets	Number of different sites of bone mets	Quantitative	Discrete	Interval	Enter total no. of bone mets
T	Br_Met	Brain Mets	Presence of Brain mets	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
U	Lu_Met	Lung Mets	Presence of Lung Mets	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
V	Lv_Met	Liver Mets	Presence of Liver mets	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
W	Ly_Met	Lymph node	Lymph node involvement	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
X	P_Met	Peritoneal Mets	Metastatic disease in the peritoneum	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
Y	O_Mets	Other Mets	Other metastatic disease	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
Z	LO_Mets	Location of other mets	Location of other mets	Qualitative	Discrete	Nominal	99=none
AA	Opioid	Opioid medications	Patient taking opioid medication	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AB	L_Opioid		List of opioid meds				
AC	Adj_An	Adjunctive Analgesia	Patient taking adjunctive analgesia	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AD	L_Adj		List of adjunctive analgesia				
AE	A_Emet	Anti-emetics	Patients taking anti-emetic medication	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AF	L_A_Em		List of anti-emetics				

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
AG	Anx	Anxiolytics	Patients taking anxiolytics	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AH	L_Anx		List of anxiolytics				
AI	A_Conv	Anti-convulsant	Patients taking anticonvulsant	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AJ	L_A_Conv		List of anticonvulsant				
AK	Ster	Steroids	Patients taking steroid medication	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AL	L_Ster		List of Steroid medication				
AM	Med_Rel	Other relevant meds	Patients taking other relative medication	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AN	L-Meds		List other relevant meds				
AO	Prev_S	Previous Surgery	Patient had surgery for removal of tumor	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AP	Prev_C	Previous Chemo	Patient completed previous chemo	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
AQ	Prev_R	Previous Radiotherapy	Patient complete previous radiotherapy	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AR	PR_Site	Previous radiotherapy sites	List previous radiotherapy sites				0=none
AS	Prev_H	Previous Hormone Rx	Patient on previous hormone therapy	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AT	Prev_O	Previous other Rx	Patient completed other disease modifying treatment	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AU	L_Oth		List alternative Rx				
AV	O_Chemo	Ongoing Chemo	Patient currently having Chemo	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AW	O_Radio	Ongoing radiotherapy	Patient currently undergoing radioTx	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
AX	OR_Sites		List sites of ongoing radioTx				
AY	O_Horm	Ongoing hormone Tx	Patient currently having hormone Tx	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
AZ	O_Other	Ongoing other Tx	Patient receiving other disease modifying Tx	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
BA	Cardiac	Chronic Cardiac Condition	Patient has chronic Cardiac Condition	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
BB	L-Cardiac		List of cardiac conditions				
BC	Resp	Chronic Respiratory Condition	Patient has chronic respiratory condition	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
BD	L-Resp		List respiratory conditions				
BE	MSK	Chronic Musculoskeletal condition	Patient has chronic MSK condition	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
BF	L_MSKE		List Chronic MSK conditions				
BG	Other	Other relevant Medical Conditions	If patient has other notable health conditions	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
BH	L_MedC		List other medical conditions				

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
BI	Phase_I	Phase of illness	Phase of illness	Qualitative	Discrete	Ordinal	1=stable, 2=unstable, 3=deteriorating, 4=dying, 9=unknown
BJ	PPS_I	Palliative Performance Score	Palliative performance score percentage	Quantitative	Discrete	Interval	Enter %
BK	Pain_I	Initial pain score	Pain score at initial Ax	Qualitative	Discrete	Ordinal	0=none, 1=mild, 2=moderated, 3=severe, 9=unknown
BL	Sym1_I	1 st symptom at initial Ax	First non-pain Symptom at initial Ax	Qualitative	Discrete	Nominal	1=Decreased mobility, 2=respiratory symptoms, 3=Upper GI dysfunction, 4=Lower GI dysfunction, 5=Neurological symptoms, 6=Cognitive Issues, 7=Fatigue, 8=Weakness, 9=Mood, 10=Urinary Symptoms, 11=Sleep Problems, 12=Odema, 13=Other 99=none recorded

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
BM	Sym2_I	2 nd symptom at initial Ax	Second non-pain symptom at initial Ax	Qualitative	Discrete	Nominal	1=Decreased mobility 2=respiratory symptoms, 3=Upper GI dysfunction, 4=Lower GI dysfunction, 5=Neurological symptoms, 6=Cognitive Issues 7=Fatigue, 8=Weakness, 9=Mood, 10=Urinary Symptoms, 11=Sleep Problems, 12=Odema, 13=Other 99=none recorded
BN	Sym_Scl	Symptom Severity Score Initial Ax	Non-pain symptom severity score	Qualitative	Discrete	Ordinal	0=none, 1=mild, 2=moderate, 3=severe, 9=unknown
BO	Fxn_I	Functional status initial Ax	Functional status as documented at initial Ax	Qualitative			Comments recorded verbatim
BP	SocS_I	Social Supports Initial Ax	Social Supports at initial Ax	Qualitative	Discrete	Nominal	1=Lives alone, 2=lives with family, 3=lives alone with HCP, 4=lives with family & HCP, 5=nursing home resident, 99=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
BQ	Comm	Comments referencing physio	Comments relating to physio throughout chart	Qualitative			
BR	PRefD	Physio referral date	Date referred to SFH physio	Qualitative	Discrete	N/A	Enter date format (dd/mm/yyyy)
BS	Fall	Recent fall	Documentation of a fall in the 4 weeks prior to referral to physio	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
BT	Hosp	Recent hospitalisation	Documentation of hospitalisation 4 weeks prior to referral to physio	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
BU	Inf	Recent infection	Documentation of an infection in the 4 weeks prior to referral to physio	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
BV	Rel_4	Relative information	Any other relevant information in the 4 weeks prior to referral to physio	Qualitative	Discrete	Nominal	0=no relevant information, 1=increasing hemiparesis, 2=severe anaemia, 9=unknown
BW	New_Bo	New bone mets	New bone mets since initial Ax	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
BX	NNew_B o	Number of new bone met sites	Number of new sites of diagnosed bone mets	Quantitative	Discrete	Interval	Enter number
BY	New_Br	New brain mets	New brain mets since initial Ax	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
BZ	New_Lu	New lung mets	New lung mets Dx since initial Ax	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
CA	New_Lv	New liver mets	New liver mets Dx since initial Ax	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
CB	New_Ly	New lymph node	New lymph node disease Dx since initial Ax	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
CC	New_P	New peritoneal mets	New peritoneal mets Dx since initial Ax	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
CD	New_O	New other mets	Any other new mets Dx since initial Ax	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
CE	C_Opioid	Change in opioid med	Change in opioid medication since initial Ax	Qualitative	Discrete	Nominal	1=started opioids, 2=increased dose, 3=decreased dose, 4=unchanged dose, 5=not taking 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
CF	C_Adj	Change in adjunctive analgesia	Change in adjunctive analgesia since initial Ax	Qualitative	Discrete	Nominal	1=started adjunctive analgesia, 2=increased dose, 3=decreased dose, 4=unchanged dose, 5=not taking 9=unknown
CG	C_emet	Change in antiemetic's	Change in antiemetic's	Qualitative	Discrete	Nominal	1=started anti-emetic, 2=increased dose, 3=decreased dose, 4=unchanged dose, 5=not taking 9=unknown
CH	C_Anx	Change in anxiolytics	Changed anxiolytics since initial Ax	Qualitative	Discrete	Nominal	1=started anxiolytics 2=increased dose, 3=decreased dose, 4=unchanged dose, 5=not taking 9=unknown
CI	C_Conv	Change in anticonvulsant	Change in anticonvulsant since initial Ax	Qualitative	Discrete	Nominal	1=started anti-convulsant, 2=increased dose, 3=decreased dose, 4=unchanged dose, 5=not taking 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
CJ	C_Ster	Change in steroids	Change in steroids since initial Ax	Qualitative	Discrete	Nominal	1=started steroids 2=increased dose, 3=decreased dose, 4=unchanged dose, 5=not taking 9=unknown
CK	C_other	Change in other relevant medication	Change in other relevant medication	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
CL	C_Chemo	Change in Chemo	Change in Chemo status	Qualitative	Discrete	Nominal	1=Started new chemo, 2=maintained on prev. regime, 3=stopped, 4=not on chemo 9=unknown
CM	N_Rad	Receiving radiotherapy	Having further radiotherapy Tx	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown
CN	C_Horm	Change in Hormone	Change in hormone Tx	Qualitative	Discrete	Nominal	1=Started hormone Tx, 2=maintained on prev. hormone Tx, 3=hormone Tx stopped, 4=not on hormone Tx, 9=unknown
CO	N_Oth	Started other disease modifying Tx	Started other disease modifying Tx	Qualitative	Discrete	Nominal	1=yes, 2=no, 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
CP	Phase_P	Phase of illness at time of referral to physio	Phase of illness at time of referral to physio	Qualitative	Discrete	Ordinal	1=stable, 2=unstable, 3=deteriorating, 4=dying, 9=unknown
CQ	PPS_P	Palliative Performance Score % at referral to physio	Palliative performance score percentage at time of referral to physio	Quantitative	Discrete	Interval	Enter %
CR	Pain_P	Pain score at time of referral to physio	Pain score at time of referral to physio	Qualitative	Discrete	Ordinal	0=none, 1=mild, 2=moderated, 3=severe
CS	Sym1_P	1 st symptom time of referral to physio	First non-pain Symptom at time of referral to physio	Qualitative	Discrete	Nominal	1=Decreased mobility, 2=respiratory symptoms, 3=Upper GI dysfunction, 4=Lower GI dysfunction, 5=Neurological symptoms, 6=Cognitive Issues, 7=Fatigue, 8=Weakness, 9=Mood, 10=Urinary Symptoms, 11=Sleep Problems, 12=Odema, 13=Other 99=none recorded

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
CT	Sym2_P	2 nd symptom at time of referral to physio	Second non-pain symptom at time of referral to physio	Qualitative	Discrete	Nominal	1=Decreased mobility, 2=respiratory symptoms, 3=Upper GI dysfunction, 4=Lower GI dysfunction, 5=Neurological symptoms, 6=Cognitive Issues, 7=Fatigue, 8=Weakness, 9=Mood, 10=Urinary Symptoms, 11=Sleep Problems, 12=Odema, 13=Other 99=none recorded
CU	Sym_Sc_P	Symptom Severity Score at time of referral to physio	Non-pain symptom severity score at time of referral to physio	Qualitative	Discrete	Ordinal	0=none, 1=mild, 2=moderate, 3=severe
CV	Fxn_P	Functional status at time of referral to physio	Functional status as documented at time of referral to physio	Qualitative			Comments recorded verbatim

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
CW	SocS_P	Social Supports at time of referral to physio	Social Supports at time of referral to physio	Qualitative	Discrete	Nominal	1=Lives alone, 2=lives with family, 3=lives alone with HCP, 4=lives with family & HCP, 5=nursing home resident, 99=unknown
CX	Reason	Reason for referral	Reason for referral to physiotherapy	Qualitative	Discrete	Nominal	1=mobility, 2=respiratory, 3=neurological, 4=Musculoskeletal, 5=other, 9=unknown
CY	Sym_ID1	1 st Symptoms identified	First symptom identified at initial physiotherapy Ax	Qualitative	Discrete	Nominal	1=Functional decline, 2=Dyspnoea, 3=fatigue, 4=pain, 5=other, 9=unknown
CZ	Sym_ID2	2 nd Symptom identified	second symptom identified at initial physiotherapy Ax	Qualitative	Discrete	Nominal	1=Functional decline, 2=Dyspnoea, 3=fatigue, 4=pain, 5=other, 9=unknown
DA	Sym_ID3	3 rd Symptom identified	3 rd symptom identified at initial physiotherapy Ax	Qualitative	Discrete	Nominal	1=Functional decline, 2=Dyspnoea, 3=fatigue, 4=pain, 5=other, 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
DB	Rehab	Other rehab needs identified	If other rehab needs were identified at initial physiotherapy Ax	Qualitative	Discrete	Nominal	0=none, 1=referred to SFH OT, 2=referred to SFH MLD, 3=referred to community services, 4= referred to both SFH & Community services 9=unknown
DC	Attend	No. of physiotherapy appointments attended	Number of physiotherapy appointments attended	Quantitative	Discrete	Interval	Enter number
DD	Cancel	No. of cancelled physiotherapy appointments	Number of cancelled physiotherapy appointments	Quantitative	Discrete	Interval	Enter number
DE	R_Canc	Reason for cancelled appointments	Reason for cancelled physiotherapy appointments	Qualitative	Discrete	Nominal	1=unwell, 2=in hospital, 3=preference, 4=combination, 9=unknown

Col	Abbrev	Full name of Variable	Definition of Variable	Type of Variable		Level of Measurement	Coding Option
				Qual /Quant	Disc / Cont		
DF	R_DC	Reason for discontinuing physiotherapy	Reason for discontinuing physiotherapy	Qualitative	Discrete	Nominal	1=too unwell to attend, 2=admitted to hospital/hospice, 3=symptom resolved, 4=patient declined further appointment, 5=independent with self-management strategies, 6=other, 9=unknown
DG	Re_Ref	Re-referral to physiotherapy		Qualitative	Discrete	Nominal	1=appropriate re-referral, 2=not referred despite clearly documented evidence in chart 3=no clinical need for re-referral document in chart, 9=unknown

7.6. Appendix 6: SFH Research Ethics Permission October 2016

St. Francis Hospice Dublin

(Under the care of the Daughters of Charity of St. Vincent de Paul)

ST. FRANCIS HOSPICE RAHENY, STATION ROAD, RAHENY, DUBLIN 5. TELEPHONE (01) 832 7535 FAX: (01) 832 7635
ST. FRANCIS HOSPICE BLANCHARDSTOWN, BLANCHARDSTOWN, DUBLIN 15. TELEPHONE: (01) 829 4000 FAX: (01) 829 4099
E-MAIL: info@sfh.ie WEBSITE: www.stfrancishospice.ie

Ms. Fiona Cahill
Senior Physiotherapist
St. Francis Hospice Blanchardstown
Blanchardstown
Dublin 15

25th October, 2016

Dear Ms. Cahill

RE: Research Proposal: A retrospective cross-sectional review of Community Palliative Care Patients to describe the profile of patients attending Specialist Palliative Care Outpatient Physiotherapy: an exploratory study

I refer to your research proposal entitled above which was considered by the Research Ethics Committee at its meeting on 19th October, 2016.

As Chairperson of the Committee, I am pleased to advise that the decision of the Research Ethics Committee is that this research proposal is approved subject to the following modifications:

Title: the wording **Patient Files** should be included in the title.

Section J, p. 22 should read either SFH or Trinity College Dublin. Either is correct but needs to be consistent.

I would draw your attention to the requirement to complete and return the enclosed Exit Form within one month of completion of the research study. A paper and an electronic copy of the final report on the study will be required on its completion.

In conclusion, I would like to take this opportunity to wish you well with your research.

Yours sincerely,

Tom McMahon
Chairperson
Research Ethics Committee

Encl.

Directors: Mr. Justice Peter Kelly (Chairman), Dr. John Cooney, Prof. Peter Daly, Ms. Mary Hayes, Ms. Ita Gibney, Sr. Bernadette MacMahon, Sr. Annette McKenna, Mr. Thomas McMahon, Mr. James Flynn, Dr. Carol-Ann Casey, Mr. Patrick Kenny, Sr. Bridget Callaghan, Mr. Joseph Pitcher, Fr. Philip Baxter, Mr. Padraig O'Dea.

Registered Number 153874 Charity Number 10568

Information given to St. Francis Hospice may be kept on computer for administrative purposes. This information will not be disclosed to any third party.

7.7. Appendix 7: TCD Research Ethics Permission November 2016

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Ms. Fiona Cahill
St. Francis Hospice,
Blanchardstown,
Dublin 15,
D15 DE98

Ref: 161103

Title of Study: A retrospective cross-sectional review of Community Palliative Care patients to describe the profile of patients attending Specialist Palliative Care outpatient physiotherapy: An exploratory Study.

Dear Ms. Cahill,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held on 29th November 2016, we are pleased to inform you that the above project has been approved without further audit.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Prof. Brian O'Connell'.

Prof. Brian O'Connell
Chairperson
Faculty Research Ethics Committee

Bainne na nEolaochtaí Sláinte
Fóiginneachas Ceirice,
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie

7.8. Appendix 8: Letter from SFH Medical Director re permission to access medical charts

St. Francis Hospice Dublin

(Under the care of the Daughters of Charity of St. Vincent de Paul)

ST. FRANCIS HOSPICE RAHENY, STATION ROAD, RAHENY, DUBLIN 5, D05 E392, TELEPHONE: (01) 832 7535 FAX: (01) 832 7635
ST. FRANCIS HOSPICE BLANCHARDSTOWN, BLANCHARDSTOWN, DUBLIN 15, D15 DE98, TELEPHONE: (01) 829 4000 FAX: (01) 829 4099
E-MAIL: info@sfh.ie WEBSITE: www.stfrancishospice.ie

Fiona Cahill
Physiotherapist
St. Francis Hospice Dublin
Raheny
Dublin 5

25 October 2016

RE: Request for Access to St. Francis Hospice Patient Records

Dear Fiona

Further to your recent request you have permission to review medical records of current and deceased patients for the purpose of your research.

Yours sincerely,

Dr. Regina McQuillan
Palliative Medicine Consultant
Medical Council Registered Number: 09943

Directors: Mr. Justice Peter Kelly (Chairman), Dr. John Cooney, Prof. Peter Daly, Ms. Mary Hayes, Ms. Ita Gibney,
Sr. Bernadette MacMahon, Sr. Annette McKeena, Mr. Thomas McMahon, Mr. James Flynn, Dr. Carol Ann Casey,
Mr. Patrick Kenny, Sr. Bridget Callaghan, Mr. Joseph Pitcher, Fr. Philip Baxter, Mr. Padraig O'Dea.

Registered Number 153874

Charity Number 10568

7.9. Appendix 9: Questions guiding focus group interviews

Can you explain the role of community palliative care (CPC)?

Who is usually involved in CPC (members of a typical CPC team)?

Can you describe the typical profile of patients referred to the community palliative care team?

Are there any patterns in relation to patients' diagnosis, symptoms, social supports etc who are under the care of the CPC team?

What usually happens during an initial CPC team visit?

What usually happens during follow-up visits?

What role do you see SPC physiotherapy playing for community based patients?

Is there a particular stage in a person's illness that physiotherapy has a role? / Do you see a role for physiotherapy in specialist palliative care?

Do you see any differences between SPC physiotherapy and community physiotherapy?

Do you see any barriers to referring individuals to physiotherapy?

7.10. Appendix 10: Letter of Invitation

Letter was printed on headed paper

Dear _____

You are invited to participate in a focus group to establish your views of specialist palliative care physiotherapy in an outpatient setting. I am conducting this study as part of a MSc in Clinical Medicine through Trinity College Dublin.

The aim of this aspect of the study is to further examine how members of the community palliative care team identify the need for specialist palliative care outpatient physiotherapy, what their understanding is of the role of physiotherapy and to identify barriers to referral. I hope that this study will inform future developments within the physiotherapy department which in turn will improve the service that is available for patients.

Focus groups will be held in both SFH Raheny and Blanchardstown at a convenient time within rostered working hours and will be facilitated by a member of Trinity College Dublin academic staff. It is envisaged that these will take between 30 – 60 minutes. The interviews will be recorded and the audio files will be transcribed. Information shared will be treated in a strictly confidential manner. You will have the opportunity to review and amend your contribution once the files are transcribed before analysis will take place. Participation is voluntary and you are free to withdraw from the study at any time without prejudice.

This study has been approved by a Research Ethics Committee of St Francis Hospice and Trinity College Dublin.

If you are interested in participating in this study or have any questions regarding this, please contact me in Blanchardstown ext 2105 or via email fcahill@sfh.ie by xxxxx date.

Many Thanks

Fiona Cahill MISCP
Senior Physiotherapist

7.11. Appendix 11: Participant Information Leaflet

Title of Study: *An exploration of the beliefs of community palliative care team members with regards to specialist palliative care outpatient physiotherapy*

Introduction: Palliative care patients have many rehabilitative needs related to multiple factors including deconditioning, fatigue, complications from treatments, anxiety, depression and pre-existing co-morbidities. Physiotherapy has been shown to improve physical function in patients with advanced cancer through appropriate exercise interventions as demonstrated in a variety of studies. Improvements in symptom management have been found through physiotherapy interventions.

The aim of this aspect of the study is to examine how members of the community palliative care team identify the need for specialist palliative care outpatient physiotherapy, what their understanding of the role of physiotherapy is and to identify barriers to referral. It is anticipated that by analysing the content of these focus groups it may help to further develop the physiotherapy department at a local level and may highlight learning needs or further areas of research nationally.

Procedure: You have been invited to participate in a focus group interview as part of this study as you are working directly with patients in the community palliative care setting. The focus group interviews will be scheduled during rostered working hours and will take place in both SFH Raheny and Blanchardstown. It is anticipated that the interviews will last between 30 to 60 minutes. The interviews will be audio recorded. You will be asked to sign a consent form prior to the interviews. You will have the opportunity to review and amend your contribution prior to analysis of the interviews.

Benefits and Risks: The anticipated benefits from participating in this study will be that your views will contribute to the content of the focus group interviews. The analysis of these may inform future developments within the physiotherapy department which in turn will improve the service that is available for your patients. There are no anticipated risks from participating in this study.

Confidentiality: Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the study group.

Voluntary Participation: If you decide to volunteer to participate in this study, you may withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not give up any benefits that you had before entering the study.

Stopping the Study: You understand that you may withdraw your participation in this study at any time. Your participation in the study may also cease if the study comes to an end, or if the investigator considers that your continuation in the study is not in your best interest.

Data Retention: Data in relation to this study will be retained for 5 years and will be destroyed after this time period. The data retained will not be used for any other purpose without obtaining specific permission from participants to do so.

Permission: This study has been granted ethical approval from St. Francis Hospice Research Ethics Committee and Trinity College Dublin School of Medicine Research Ethics Committee.

Further Information: You can get more information or answers to your questions about the study, your participation in the study, and your rights from Fiona Cahill (fcahill@sfh.ie 01 8294000, ext 2105).

7.12. Appendix 12: Date for potential interview letter

Letter was printed on headed paper

14th February 2018

RE: Invitation to focus group interviews to establish views of specialist palliative care physiotherapy in an outpatient setting

Dear CPC Colleague,

Further to the letter of invitation to participate in focus group interviews dated January 31st, I wish to advise you that the date that the interview facilitators have indicated their availability is Monday March 5th February at psychosocial time (approx. 11.30am) in SFH Raheny.

It is envisaged that the interviews will take between 30 – 60 minutes to complete.

If you are interested in participating and can attend on the proposed date, please inform me via email (fcahill@sfh.ie) or via phone (ext 2105 Blanchardstown).

Kind Regards

Fiona Cahill MISCP

7.13. Appendix 13: Participant Consent Form

Study title: An exploration of the beliefs of community palliative care team members with regards to specialist palliative care outpatient physiotherapy

I have read and understood the invitation to participate in this study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	Yes ☐	No ☐
Storage and future use of information: I give my permission for an audio recording of the focus group be made. I am aware that this will be transcribed and I will have the opportunity to review and amend my contribution. I give my permission for the transcriptions to be stored electronically and analysed for the purpose of scientific research as approved by a Research Ethics Committee of St Francis Hospice and Trinity College Dublin.	Yes ☐	No ☐
Withdrawal from the study I have been informed of my right to withdraw from this study at any time without prejudice.	Yes ☐	No ☐

 Participant Name (Block Capitals) | Participant Signature | Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study in a way that they could understand. I have invited them to ask questions on any aspect of the study that concerned them.

 Block Capitals | Signature | Date

7.14. Appendix 14: Initial List of Codes Generated

1	SPC as a speciality
2	Holistic approach to patient care
3	Team work in SPC
4	Issues requiring SPC input
5	Physio as part of the CPCT
6	Physio in respiratory management
7	Expertise of SPC physio
8	Physical benefits of SPC physio
9	Physio as a stepping stone to SPC services
11	Reasons for referral to SPC physio
22	SPC physio service provision
33	Patients focused on physio
44	CPC perception of benefit of SPC physio
55	Physio and confidence in patients
66	Physio and safety / falls
77	Independence
88	Mobility/strength/aids
99	Perceptions of community physio service
111	What SPC represents
222	Physio as a positive thing
333	Emotional wellbeing
444	Physio and Hope
555	Blanket referral to OPD
666	Community physio as a primary link
777	Impact of Health and safety on referral to physio
888	Waiting time for community service
999	Experience of the SPC physio
1111	Accessibility and availability of SPC physio
2222	Psychological benefit of SPC physio
3333	Control
4444	Reasons for not referring to physio
5555	SPC in the community
6666	Understanding of the breadth of the role of physio in SPC

7777	Patients being able for physio
8888	Timing of referral to SPC services
9999	Refer if potential for improvement
11111	Quality of life
22222	Patients' goals
33333	Experience of OPD
44444	Communication with the team
55555	Medication use in SPC
66666	Physio as an expert resource
77777	Staff promoting referrals to OPD to patients

7.15. Appendix 15: Initial List of Themes Generated

7.16. Appendix 16: Final list of Themes Generated

7.17. Appendix 17: SFH Research Ethics Permission October 2017

St. Francis Hospice Dublin

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E-MAIL: info@sfh.ie WEBSITE: www.stfrancishospice.ie

Ms. Fiona Cahill
Senior Physiotherapist
St. Francis Hospice Blanchardstown
Blanchardstown
Dublin 15

27th October, 2017

Dear Ms. Cahill

RE: Research Proposal: An exploration of the beliefs of community palliative care team members with regards to specialist palliative care outpatient physiotherapy

I refer to your research proposal entitled above which was considered by the Research Ethics Committee at its meeting on 18th October, 2017.

As Chairperson of the Committee, I am pleased to advise that the decision of the Research Ethics Committee is that this research proposal is approved.

I would draw your attention to the requirement to complete and return the enclosed Exit Form within one month of completion of the research study. A paper and an electronic copy of the final report on the study will be required on its completion.

In conclusion, I would like to take this opportunity to wish you well with your research.

Yours sincerely,

Tom McMahon
Chairperson
Research Ethics Committee

Encl.

Directors: Mr. Justice Peter Kelly (Chairman), Dr. John Cooney, Prof. Peter Daly, Ms. Mary Hayes, Ms. Ita Gibney, Sr. Bernadette MacMahon, Sr. Annette McKenna, Mr. Thomas McMahon, Mr. James Flynn, Fr. Michael Burgess, Dr. Carol-Ann Casey, Mr. Patrick Kenny, Sr. Bridget Callaghan, Mr. Joseph Pitcher.

Registered Number 153874 Charity Number 10568

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7.18. Appendix 18: TDC Research Ethics Permission January 2018

Fiona Cahill

Subject: FW: TCD REC WebApp: The status of 'An exploration of the beliefs of community palliative care team members with regards to specialist palliative care outpatient physiotherapy' (350) has been updated by the Committee

From: <rec-app-help@tchpc.tcd.ie>

Date: Thu 25 Jan 2018 at 18:18

Subject: TCD REC WebApp: The status of 'An exploration of the beliefs of community palliative care team members with regards to specialist palliative care outpatient physiotherapy' (350) has been updated by the Committee

To: <fcahill@tcd.ie>

The status of 'An exploration of the beliefs of community palliative care team members with regards to specialist palliative care outpatient physiotherapy' has been updated by the Committee.

Title: 'An exploration of the beliefs of community palliative care team members with regards to specialist palliative care outpatient physiotherapy'

Applicant Name: Fiona Cahill

Submitted by: Fiona Cahill

Academic Supervisor: Emer Guinan

Application Number: 20171101

Result of the REC Meeting: Approved

The Feedback from the Committee is as follows:

25th January 2018

Re: Application 20171101

Dear Fiona Cahill,

Your revised application has been reviewed by the School of Medicine Research Ethics Committee and we are pleased to inform you that the above project has been approved.

Applicants must submit an annual report for ongoing projects and an end of project report upon completion of the study. You will find these forms on the School of Medicine Research Ethics website.

An electronic, signed, approval letter can be provided upon request.

Yours sincerely,

Dr. Laure Marignol

Chairperson

School of Medicine Research Ethics Committee

The application can be viewed here:

https://webhost.tchpc.tcd.ie/research_ethics/?q=node/350

If amendments are required, please use the following link to edit the application and upload the changes:

https://webhost.tchpc.tcd.ie/research_ethics/?q=node/350/edit