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INSTITIÚID TEICNEOLAÍOCHTA PHORT LÁIRGE

An Exercise Intervention for Cancer Fatigue

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Abstract

Cancer related fatigue (CrF) is a debilitating side effect reported by cancer survivors, often lasting years following treatment. Although some evidence exists of a beneficial effect of exercise on CrF, there are critical shortcomings in the literature. Previous exercise rehabilitation studies did not specifically target fatigued cancer survivors. Most studies also lacked an appropriate control condition to isolate the effects of exercise *per se*.

This thesis is comprised of three studies. The first study, an efficacy study, compared the effects of a 10-wk exercise intervention to a health education intervention on fatigue, fitness and psychological health outcomes in post-treatment cancer survivors with documented fatigue. The 37 post-treatment cancer survivors (33 females, 20 severe fatigue, 11 moderate fatigue, 30 breast cancer, aged 55±2 y, 2.3±0.3 y since treatment; mean±SEM) were allocated to an exercise group (EXG, n=19) or health education comparison group (HEG, n=18). The intervention effect on FACT-F determined fatigue was significantly greater ($p<0.05$) in EXG compared to HEG. The net change in fatigue was of considerable magnitude (Cohen's d = 1.38, 4 times the FACT-F clinical important difference). The EXG also increased ($p<0.05$) cognitive function, global quality of life, fitness scores and significantly reduced ($p<0.05$) insomnia and fear of physical activity. The intervention effect on fatigue in EXG was largely achieved by wk 4 and changes were all sustained to 26 wk. There was 100% retention rate at 10-wk in both experimental groups and no adverse events reported.

The second study, a qualitative exploratory study, explored survivors' perceptions and experiences of CrF, management of this fatigue, and experiences of the 10-week exercise programme. Two focus groups and four individual interviews were held with 14 programme participants. The results provide a deeper understanding of the quantitative results observed in the efficacy study. Results suggest that CrF not only affects cancer survivors physically, it affects them mentally, socially and financially. Barriers, facilitators, preferences, and motives to exercise in fatigued survivors are also elucidated. It was concluded that a tailored exercise programme designed specifically to the needs of cancer survivors can have a multitude of physical, psychological, social and educational benefits. The combination of elements in the exercise programme was identified as fundamental and access to such a programme should be a routine part of cancer care.

The third study, a qualitative feasibility study, examined the factors influencing the subsequent implementation of the exercise rehabilitation programme in a community setting. Semi-structured individual interviews (n=15) were undertaken with survivors who agreed and declined to participate in the programme, programme delivery agents, and cancer healthcare professionals. Implementation was examined using Fixsen's Active Implementation Frameworks with Glasgow's 'Reach, Effectiveness, Adoption, Implementation, Maintenance Framework'. Implementation appears to be most successful where an enabled environment is created, a collaborative multidisciplinary team are involved, champions exist in recruitment settings and an overall programme leader exists to co-ordinate. Barriers and challenges to programme scale up outside of a major urban centre included accessibility to the target population and financial support from relevant agencies. Future cost effectiveness research needs to be undertaken if exercise programmes are to be incorporated into routine cancer care.

Statement of originality and ownership of work

Department of Health, Sport and Exercise Science

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I confirm that all the work submitted in this dissertation is my own work, not copied from any other person's work (published or unpublished) and that it has not previously been submitted for assessment on any other course, in any other institution.

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"Rock bottom became the solid foundation on which I rebuilt my life". JK Rowling

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%1RM:	Percentage one repetition maximum
%HRR:	Percentage heart rate reserve
%MHR:	Percentage heart rate maximum
%VO_2 max:	Percentage maximal oxygen uptake
6MWT:	6-minute walk test
A/P/S:	Active/Palliative/Survivors
ACSM:	American College of Sports Medicine
ADL:	Activities of daily living
AHA:	American Heart Association
ATS:	American Thoracic Society
BDNF:	Brain-derived neurotrophic factor
BFI:	Brief Fatigue Inventory
BMI:	Body mass index
BP	Blood pressure
CBPR:	Community-based participatory research
CDC:	Center for Disease Control and Prevention
CFFL:	Cancer Foundation for Life
cfPWV:	carotid-femoral pulse wave velocity
CI:	Confidence interval
CID:	Clinically important difference
CrF:	Cancer-related fatigue

CRP:	C-reactive protein
CV:	Cardio vascular
DCU:	Dublin City University
EORTC QLQ C30:	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30
EX:	Exercise
EXG:	Exercise group
F PAX-B:	Fear of Physical Activity Exercise Scale-Breast Cancer
FACIT-F:	Functional Assessment of Chronic Illness Therapy-Fact scale
FACT-An:	Functional Assessment of Cancer Therapy-Anaemia
FACT-F:	Functional Assessment of Cancer Therapy-Fatigue
FITT:	Frequency Intensity Time Type
FQ:	Fatigue Questionnaire
FSI:	Fatigue Symptom Inventory
FSS:	Fatigue Severity Scale
HE:	Health Education
HEG:	Health education group
HPA:	Hypothalamic-pituitary-adrenal
HR max:	Heart rate maximum
HR	Heart rate
HSE:	Health Service Executive
IL-10:	Interleukin-10
IL-1A:	Interleukin-1 alpha

IL-1B:	Interleukin-1 beta
IL-1ra:	Interleukin-1 receptor antagonist
IL-6:	Interleukin-6
IPAQ:	International Physical Activity Questionnaire
IPAQ-LF:	International Physical Activity Questionnaire-Long form
IPAQ-SF:	International Physical Activity Questionnaire-Short form
ISI:	Insomnia Severity Index
LASA:	Linear Analogue Self-Assessment
MAF:	Multidimensional Assessment of Fatigue
MCID:	Minimum clinically important difference
MET:	Metabolic equivalent of task
MFI-20:	Multidimensional Fatigue Inventory
MFSI-30:	Multidimensional Fatigue Symptom Inventory
MVPA:	Moderate to vigorous physical activity
NCCN:	National Comprehensive Cancer Network
NCRI:	National Cancer Registry Ireland
NIRN:	National Implementation Research Network
PA:	Physical activity
PFS-R:	Piper Fatigue Scale revised
PHCS:	Perceived Health Competence Scale
POMS:	Profile of Mood States
POMS-F:	Profile of Mood States-fatigue
PWV:	Pulse wave velocity

PWV:	Pulse wave velocity
QOL:	Quality of life
R:	Recommendations
RE-AIM:	Reach, Effectiveness, Adoption, Implementation, and Maintenance
REM:	Rapid eye movements
RM:	Repetition maximum
RPE:	Borg Rating of Perceived Exertion
RPE:	Rate of perceived exertion
RTW:	Return to work
SCFS:	Schwartz Cancer Fatigue Scale
SD:	Standard deviation
SE:	Standard error
SMD:	Standard mean difference
TILDA:	The Irish Longitudinal Study of Ageing
TNFα:	Tumour necrosis factor alpha
TOI-F:	Trial Outcome Index-Fatigue
UHW:	University Hospital Waterford
VASF:	Visual Analogue Scale for Fatigue
WES:	Weighted effect size
WHO:	World Health Organisation
WIT:	Waterford Institute of Technology

CHAPTER 1.
INTRODUCTION

Chapter 1 Introduction to Thesis

1.1 Background

More and more people are living with and beyond cancer. At the end of 2013, there were approximately 124,000 individuals still alive having had a cancer diagnoses in the previous 20 years (1994 – 2013) (National Cancer Registry Ireland (NCRI), 2016). Cancer-related fatigue (CrF) is one of the most debilitating side effects of cancer and its treatment, and can persist for years (Bower et al., 2000). An intervention for fatigue that can be effective is exercise: a meta-analysis of nine aerobic trials (Meneses-Echávez et al., 2015) found that supervised exercise was more effective than conventional care in improving fatigue in breast cancer survivors (standard mean difference (SMD) −0.51; 95% confidence interval (CI) −0.81 to −0.21). A Cochrane review (Cramp & Byron-Daniel, 2012) that assessed the trials by cancer type and by timing in relation to treatment revealed similar small to moderate standard mean differences favouring exercise over no-exercise controls. The analysis included 10 trials undertaken following (rather than during) anti-cancer treatment (SMD −0.44, 95% CI −0.79 to −0.09). Comparisons of individual fatigue studies are hampered by the variety of instruments used to measure CrF. There are also other methodological shortcomings in the literature, in that most studies did not screen for a specific fatigue score for inclusion, and fatigue was not necessarily the primary outcome measured. Hence, our understanding of the role of exercise in reducing CrF is poor. To date, few studies have used a suitable control condition, with the majority adopting a “usual care” group without reference to investigator attention or peer support. Studies need to include appropriate comparison groups to control for the real chance of such effects (Knols et al., 2005). It is also critical that studies include follow-up for participants beyond the typical 10–12-week intervention period to determine the medium-term effects on physical activity (PA), fitness, fatigue, and other quality-of-life indicators. Study 1, the main study in this thesis, involved a quasi-experimental approach to determine the efficacy of a 10 week exercise intervention on CrF, QOL, cognitive functioning, sleep and physical fitness in individuals with documented fatigue. The changes in an exercise intervention group were compared to those from a non-exercise health education intervention. A secondary aim of this study was to determine the sustainability of changes for an additional 16 weeks post-intervention.

While it is essential to obtain quantitative data regarding the effectiveness of exercise on CrF, it is also important to allow participants the chance to have their voices heard and to discuss what cannot be measured quantitatively. Therefore, there is a need to capture the individual experiences of participants in an exercise programme tailored for cancer survivors with documented fatigue to provide an understanding as to what is meaningful (Creswell, 2013) for fatigued cancer survivors. In Study 2, a qualitative study, the aim was to explore three elements: fatigued cancer survivors' perceptions and experiences of CrF; their views on how this fatigue was managed and treated; and how they felt about their participation in the 10-week exercise programme.

It has been suggested that it takes several years to translate research to practice (Balas & Boren, 2000; Westfall, Mold, & Fagnan, 2007). One of the top research questions related to PA and cancer survivorship is how best to transfer physical activity interventions into clinical and community oncology practice (Courneya, Rogers, Campbell, Vallance, & Friedenreich, 2015). Knowing the answers to this question is vital for advances in the area of PA and cancer survivorship. It is also essential to improve the lives of the thousands of individuals diagnosed with cancer annually who have to deal with the after effects of cancer and its treatment. Identification of the factors influencing implementation of such programmes may shed some light on how we can best translate PA research into practice in a community setting. The majority of exercise and PA intervention studies for cancer survivors to date have been designed as randomised controlled trials. Their translation into practice is often obstructed, with many results unused, and implementation of such programmes in practice is still challenging (Glasgow, Green, Taylor, & Stange, 2012; Green & Glasgow, 2006; Rothwell, 2005). This may be because interventions are often developed and tested in unrealistic settings and are complex in nature, and are therefore impractical for implementation in a real-world community setting. The interventions are typically tested using methodologies designed to guarantee high internal validity, with less focus on issues associated with external validity (Glasgow, Klesges, Dzewaltowski, & Bull, 2004). Furthermore, studies often fail to consider the sustainability of an intervention once the research is over, and strategies for the translation of intervention programmes into cancer care are limited. More focus is needed on implementing such research studies in a real-world community setting to examine impacts on public health at the population level. The MedEx MoveOn programme at Waterford Institute of Technology (WIT) is a community-based exercise rehabilitation programme, to help mitigate the adverse effects of cancer and its treatment and, improve the quality of life and physical, psychological, and psychosocial well-being of individuals who have completed their treatment for cancer. The MedEx MoveOn programme evolved out of Study 1, commencing upon completion of this efficacy study. We strived to translate with fidelity the intervention developed and evaluated in Study 1, into the MedEx MoveOn programme. Participants are referred to the programme by anyone in the cancer care continuum (oncologist, nurse, GP, Solas cancer care support centre) but interested participants can also self-enrol. Study 3, a feasibility study, examined the factors influencing the initial implementation stage of MedEx MoveOn in the community setting. It was evaluated using the Active Implementation Frameworks, the RE-AIM framework, and qualitative methodology.

1.2 Outline of Thesis Structure

Chapter 2 critically analyses the most significant literature in the area of exercise and cancer. It is divided into four sections: cancer and CrF; exercise interventions for CrF; qualitative research in the area of exercise and cancer; and implementation and translational research and the factors that influence and affect transfer of findings from a research setting into practice.

Chapters 3–5 are the study chapters. Each chapter includes the methods, results, discussion, study strengths/limitations, and conclusions applicable to that study.

In Chapter 3, the effects of a 10-week exercise intervention compared to a health education intervention on fatigue, psychological health outcomes, and physical fitness in post-treatment cancer survivors with documented fatigue is presented.

Chapter 4 explores the perceptions of fatigued cancer survivors and their experiences of CrF; their views on how this fatigue was managed and treated; and how they felt about their participation in the 10-week exercise programme in Study 1. Unlike Chapter 3, these data were collected qualitatively, as much of the data to date examining exercise in the survivorship stage are quantitative.

Chapter 5 describes an in-depth qualitative study carried out with participants, non-participants, and key stakeholders to examine the factors influencing the initial implementation stage of the exercise intervention as the MedEx MoveOn programme.

Chapter 6 is the final chapter of the thesis. It makes recommendation for health care practice and further research based on an integrated analysis of the findings of Chapters 3 – 5.

CHAPTER 2.

LITERATURE REVIEW

Chapter 2 Literature Review

2.1 Introduction

This section sets the context for the thesis by reviewing and analysing the literature to date. The literature review is split into four sections. Section 1 examines cancer and cancer-related fatigue (CrF), while Section 2 examines the literature on exercise interventions for CrF. Qualitative research in the area of exercise and cancer is addressed in Section 3, while Section 4 examines implementation and translational research and the factors that influence and affect the transfer of findings from a research setting into practice.

Section 1 Cancer and cancer-related fatigue

2.1.1 Cancer in Ireland

Cancer is the second most common cause of death in Ireland, after diseases of the circulatory system (Eurostats, 2015). The most common types of cancer are breast, prostate, and colorectal cancers, skin melanoma, non-Hodgkins lymphoma, and lung cancer. Excluding non-melanoma skin cancers, prostate and female breast cancers are the most commonly diagnosed invasive cancers in Ireland (NCRI, 2016).

The lifetime risk of developing an invasive cancer up to the age of 75 years is approximately 1 in 3 for males and 1 in 4 for females, and the projected lifetime risk of dying from cancer is approximately 1 in 10 for females and 1 in 8 for males (NCRI, 2016).

The 5-year net survival rate for most cancers in Ireland has improved significantly overall, increasing from 44% for those diagnosed between 1994 and 1998 to 61% for individuals diagnosed between 2009 and 2013 (NCRI, 2016). The 5-year survival has improved from 50% to 63% for colorectal cancer, from 9% to 18% for lung cancer, from 72% to 81% for female breast cancer, and from 66% to 92% for prostate cancer over the same 20-year span (NCRI, 2016).

2.1.2 Cancer-related fatigue

One of the most common and debilitating side effects of cancer and its treatment is CrF. CrF can be defined as “a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning” (National

Comprehensive Cancer Network (NCCN), 2014, p. 1012). It has been described in the literature as a multidimensional construct having physical, cognitive and emotional factors (Reuter & Harter, 2004; Barsevick et al., 2013) and involving both peripheral and central aspects (Dantzer, Heijnen, Kavelaars, Laye, & Capuron, 2014). Peripheral fatigue occurs in the muscles and neuromuscular junctions, whereas central fatigue can be both physical and motivational and originates in the brain. While other symptoms such as vomiting, pain, and nausea are reported as shorter-term side effects, fatigue can be long-lasting and may persist for many years (Bower et al., 2000; Bennett, Goldstein, Friedlander, Hickie, & Lloyd, 2007). The diagnostic criteria for CrF are presented in Box 2.1.1.

Box 2.1.1: Diagnostic criteria for cancer-related fatigue (Bennett et al., 2007)

Symptoms present every day or nearly every day during the same 2-week period in the past month:

- Significant fatigue, diminished energy, or increased need to rest that is disproportionate to a recent change in activity level

And at least five of the following symptoms:

- Generalised weakness or limb heaviness
- Diminished concentration or attention
- Decreased motivation or interest in engaging in usual activities
- Insomnia or hypersomnia
- Sleep is unrefreshing or non-restorative
- Perceived need to struggle to overcome inactivity
- Marked emotional reactivity (e.g., sadness, frustration, or irritability) to feeling fatigued
- Difficulty completing daily tasks attributed to feeling fatigued
- Perceived problems with short-term memory
- Post-exertional malaise lasting several hours

2.1.3 Prevalence of CrF in survivorship

The evidence for fatigue among survivors across a range of cancers is strong. CrF persists for more than one-third of cancer patients following completion of their treatment (Hofman et al., 2007). In a meta-analysis involving 12,327 breast cancer survivors, an estimated one in four suffered from severe CrF (Abrahams et al., 2016). Bower et al. (2006) examined fatigue at 5–10 years after diagnosis. They found that 34% of breast cancer survivors had continuing problems with fatigue, with 21% reporting fatigue at both assessment time points (1–5 and 5–10 years after diagnosis). This highlights the persistence of CrF. Prior research undertaken in Waterford Institute of Technology showed that fatigue is a very significant problem for women with breast cancer and persists into survivorship (Murphy, 2009). The literature confirms this finding for a range of cancers, including colorectal (Thong et al. 2013) and prostate cancer (Langston et al. 2013). In a survey of breast, prostate, and colorectal cancer survivors, an estimated one-third (n = 1294) reported clinically relevant CrF levels present up to 6 years following treatment, which was also associated with greater levels of disability (Jones et al., 2016). However, because CrF is often undiagnosed, its prevalence may actually be underestimated.

2.1.4 Impact and management of CrF

Cancer survivors often report never returning to their pre-diagnosis energy level, which in turn diminishes their overall quality of life (QOL; Gledhill, 2005). CrF can have a severe impact on many aspects of health, including physical, emotional, social, cognitive, and psychological functioning, and thus affects QOL. CrF is regarded as the most problematic side effects of cancer and has the greatest impact on a survivor’s daily life (Curt et al., 2000). It has been ranked as having the greatest negative impact on activities of daily living (ADL) and QOL, being identified as more problematic than other cancer-related symptoms including pain, depression, and nausea (Curt et al., 2000; Stone et al., 2000). Almost 90% of post-treatment cancer patients have suggested that fatigue affects their ability to perform ADL, with more than three-quarters of cancer survivors changing their employment status because of CrF and more than one-third experiencing daily fatigue (Curt et al., 2000). One-third of all cancer survivors had not returned to employment by 18 months after their diagnosis (Mehnert, 2011). Moreover, cancer survivors are 1.4 times more likely to be unemployed than healthy individuals (De Boer, Taskila, Ojajrvi, Van Dijk, & Verbeek, 2009). Research suggests that it takes longer for individuals who suffer from CrF to return to work (Pryce, Munir, & Haslam, 2007; Spelten et al., 2003). Fatigue has also been suggested as the main reason why some cancer survivors stop working (Buckwalter, Karnell, Smith, Christensen, & Funk, 2007).

The literature mentioned above has not only highlighted the scale of the problem in terms of prevalence but has also emphasised the impact CrF has on a survivor's QOL. Hence, there is a need to develop an intervention to help with the management and treatment of this side effect that hampers individuals from returning to a normal life. However, health professionals must be aware of the chronic nature of CrF and the need for diagnosis and assessment of the problem. Unfortunately, assessment and management of CrF have not been incorporated into routine medical practice; this deficiency needs to be addressed, as CrF may also predict shorter overall cancer survival (Bower, 2014). Surprisingly, only 50% of post-treatment cancer patients have discussed treatment choices with their oncologist, with only one-third of oncologists recommending any CrF treatment (Stone et al., 2000). Despite the prevalence and harmful impact of CrF, it is still often undertreated and health care professionals often do not understand the extent of the distress and functional impairment such a disabling side effect can have on patients (Mitchell, 2010; Nekhlyudov et al., 2013). As CrF is often seen as an inevitable part of cancer and its treatment, clinicians and patients may not see the need to manage it (Mitchell, 2010). This may be because of a lack of information and knowledge about the mechanisms that cause the symptoms and the multiple factors that may influence CrF, including demographic, medical, psychosocial, behavioural, and biological factors.

2.1.5 Possible causes and correlates of CrF

The cause CrF is difficult to identify but, it is a multidimensional construct comprising multiple physical, biological, psychological, and contextual factors and their interactions (Berger et al., 2015; Neefjes, van der Vorst, Blauwhoff-Buskermolen, & Verheul, 2013). Many biological processes have been suggested to play a part in the development of CrF, such as anaemia, inflammation (Dantzer, Meagher, & Cleeland, 2012), dysfunction of the hypothalamic-pituitary-adrenal (HPA) axis (Fagundes et al., 2011), circadian rhythm dysfunction (Berger et al., 2010), and skeletal muscle loss (Courneya, 2003). Factors contributing to the development and persistence of CrF both during and after treatment may include the cancer itself, the treatment and consequent comorbidities, adverse effects of medication, nutritional problems, deconditioning, mood disturbances, pain, higher body mass index (BMI), and sleep dysfunction (Mitchell, 2010). Bower et al. (2000) found that patients who were single and those on lower incomes had higher levels of fatigue. This suggests that the social and emotional support of a partner might influence the experience of fatigue symptoms.

2.1.5.1 Cognitive function and sleep

Cognitive function appears to be a correlate of fatigue. A common feature of post-chemotherapy cognitive dysfunction, commonly known as “chemobrain” (Berger, Shuster, & Von Roenn, 2013), is its relationship to fatigue (Alexander, Minton, Andrews, & Stone, 2009). In a study among 150 disease-free survivors of breast carcinoma, severely fatigued survivors reported more concentration impairment and memory issues than those who were not severely fatigued and those with no history of breast carcinoma. In addition, the severely fatigued survivors reported slower speeds for information processing than those who were not severely fatigued and the control subjects. Similarly, in a study of 291 patients with colorectal cancer, Vardy et al. (2014) found an association between fatigue and cognitive symptoms ($r = 0.43–0.71$) both during and after treatment.

Reports over the past number of years have shown a putative relationship between cancer related sleep problems and CrF. Studies have shown that sleep disturbance is, 1. positively associated with fatigue, 2. worse in fatigued individuals compared to non-fatigued individuals and, 3. a significant predictor of fatigue (K. O. Anderson et al., 2003; Bower et al., 2000; Broeckel, Jacobsen, Horton, Balducci, & Lyman, 1998; Redeker, Lev, & Ruggiero, 2000).

2.1.5.2 Inflammation

The mechanism that has attracted the most experimental attention and support to date is dysregulation of proinflammatory cytokines. Research has suggested an association between circulating inflammatory cytokine levels and fatigue (Brenu et al., 2012; Fletcher, Zeng, Barnes, & Kilmas, 2009). A review of 18 clinical trials to assess the link between proinflammatory cytokines and CrF revealed a significant positive correlation between fatigue and IL-6 ($r=0.12$, $p=0.004$; Schubert, Hong, Natarajan, Mills, & Dimsdale, 2007). The anti-inflammatory effect of IL-6 involves downregulation of the proinflammatory cytokine tumour necrosis factor-α (TNF-α) (Starkie, Ostrowski, Jauffred, Febbraio, & Pedersen, 2003) and upregulation of the anti-inflammatory cytokines IL-1RA and IL-10 (Peterson & Pederson, 2006; Steensberg, Fischer, Keller, Moller, & Pedersen, 2003). IL-10 then inhibits the production of IL-1A, IL-1B, and TNF-α (Pedersen, 2007; Pretolani, 1999).

Current understanding of the process underlying the effects of inflammation on CrF is limited. Cancer cells produce proteins known as cytokines that promote tumour growth, causing the immune system to induce the production of additional cytokines (Kurzrock, 2001). Behavioural factors such as physical inactivity have also been associated with higher levels of cytokines in cancer patients (Bower & Lamkin, 2013). Comparison of fatigued individuals with a history of breast cancer and survivors of breast cancer revealed alterations in Il-6, IL-1RA, C-reactive protein (CRP), neopterin, and soluble tumour necrosis factor receptor-II (Bower, Ganz, Aziz, & Fahey, 2002; Evans & Lambert, 2007; Bower et al., 2009).

Alexander, Minton, Andrews, and Stone (2009) found significant elevation of CRP in breast cancer survivors with documented fatigue (n = 60) compared to non-fatigued controls (n = 104). Similarly, higher levels of fatigue were associated with higher CRP levels among a cohort of 299 disease-free cancer survivors (Orre et al., 2011). Higher levels of CRP in cancer survivors, have been linked to a higher risk of being fatigued (Alfano et al., 2012). Alexander et al. (2009) found significant raised CRP in breast cancer survivors compared to non-fatigued controls. Average CRP was 2.74 mg/dL in the non-fatigued group versus 3.91 mg/dL among fatigued controls, signifying low-grade inflammation.

After controlling for age, menopausal status, use of antidepressants, medical comorbidities, and BMI, elevated CRP was linked to a higher chance of being classed as fatigued in a study of 633 breast cancer survivors (Alfano et al., 2012). Similarly, Orre et al. (2011) found a positive link between CRP and fatigue that remained significant after controlling for same factors as well as sleep disturbance and self-rated help. In an earlier study, Orre et al. (2009) found an association between fatigue and higher levels of circulating IL-1RA and CRP among long-term testicular cancer survivors. This evidence suggests that low-grade inflammation may play a part in the pathogenesis of fatigue in cancer survivors with differing cancers.

Higher leukocyte levels have also been associated with fatigue in breast cancer survivors (Alexander et al., 2009; Landmark-Høyvik et al., 2009).

2.1.5.3 Cortisol and hypothalamic pituitary adrenal (HPA) axis functioning

The glucocorticoid hormone cortisol is released by the adrenal glands under the control of the pituitary glands. Cortisol plays a vital role in metabolic function and has been associated with CrF. Irregular patterns of cortisol secretion, usually distinguished as higher nocturnal cortisol, have been observed in a variety of cancer populations (Abercombie et al., 2004; Jehn et al., 2010, Palesh et al., 2008). Abnormal cortisol rhythms have also been linked to CrF (Bower et al., 2005). In analyses at an individual level, Bower et al. (2005) found that fatigued breast cancer survivors display altered daytime cortisol slopes, with raised evening cortisol levels. A study by Weinrib et al. (2010) also suggested possible HPA involvement in CrF. Higher levels of evening cortisol and lower cortisol variability were associated with fatigue, depression, and physical dysfunction in a cohort of ovarian cancer patients, although this was before the patients had undergone surgery. The stress of impending surgery may have had an impact on the cortisol levels secreted, as stress is a stimulus that can influence cortisol secretion.

2.1.5.4 Brain-derived neurotrophic factor

Brain-derived neurotrophic factor (BDNF) is a neurotrophin produced in nerve cells and distributed throughout the central nervous system, mainly in the prefrontal cortex and hippocampus (Binder & Scharfman, 2004; Zhang et al., 2012). Studies have demonstrated that serum BDNF is correlated with brain-tissue BDNF in adult animals (Sartorius et al., 2009). A number of studies investigating the potential role of BDNF in cognitive disorders such as Alzheimer’s disease, cognitive impairment, and schizophrenia found that lower serum BDNF levels were associated with these conditions (Shimada et al., 2014; Teixeira, Barbosa, Diniz, & Kummer, 2010; Zhang et al., 2012). On the contrary, higher BDNF levels were correlated with better cognition among healthy older individuals (Gunstad et al., 2008). Similar findings have been observed for cancer patients. A recent longitudinal study found that BDNF serum levels were associated with self-perceived concentration deficits and cognitive impairments in post-chemotherapy patients with early-stage breast cancer (Ng et al., 2017). As well as having a role in cognitive function, BDNF may also be involved in CrF. Saligan, Lukkahatai, Holder, Walitt, and Machado-Vieira (2016) suggested that decreasing BDNF serum levels during external beam radiation therapy in a cohort of patients with non-metastatic prostate cancer (n = 47) exacerbated CrF. A greater understanding of the role of BDNF may further our knowledge of the aetiology of CrF and its relationship with other impairments such as cognitive dysfunction experienced in cancer cohorts.

2.1.5.5 Impaired vascular function

Impaired vascular function may also be related to fatigue, as observed in individuals with chronic fatigue syndrome (non-cancer causes), which is related to higher concentrations of the aforementioned inflammatory markers along with impaired vascular function (Spence et al., 2008). Both chemotherapy and radiotherapy appear to have a negative impact on the cardiorespiratory system (Dimeo, 2002). Chaosuwannakit et al. (2010) found that pulse wave velocity (PWV) increased in study participants who were receiving cancer therapy. This increase was associated with a threefold higher risk of a future CV event, which is comparable to a 10–20-year increase in age-associated CV decline. More recently, Drafts et al. (2013) investigated the effects of 6 months of a low to moderate dose of anthracycline-based chemotherapy in 53 men and women with breast cancer, leukaemia, or lymphoma. They found that aortic PWV increased from 6.7 ± 0.5 to 10.1 ± 1 m/s, confirming the results of Chaosuwannakit et al. (2010). Meta-analysis evidence from 17 longitudinal studies (n = 15,877, mean follow-up 7.7 years) suggests that for every 1 m/s increase in carotid–femoral PWV the risk of future cardiovascular (CV) incidents and mortality and all-cause mortality increases by 15% (Vlachopoulos, Aznaouridi, & Stefanadis, 2010). CV issues have been suggested as one of the chief correlates of long-term fatigue among breast cancer survivors (Bower et al., 2006).

2.1.6 Summary

The pathophysiology of CrF is poorly understood (Bower et al., 2009). Hence, it is often undiagnosed and unmanaged, which in turn has a negative impact on adherence to treatment and patient outcomes. Effective treatment of CrF should start with identification of the causative factors. Understanding these causes and their correlates in individuals is not without challenges, as each person may experience many causes of fatigue concurrently because of its complexity. The insufficient understanding of the biology underlying CrF is seriously impeding the development of adequate and effective treatments for the condition.

2.1.7 Measurement of fatigue

A range of tools are available for measuring CrF (Table 2.1.1; 2.1.2) and reflect the range of CrF definitions. Fatigue is generally measured on a scale, with tools divided into unidimensional scales (Table 2.1.1), which cover only one element of fatigue such as physical fatigue, and multidimensional scales (Table 2.2.2), which assess the multidimensional nature of fatigue.

A systematic review by Minton and Stone (2009) identified 14 scales in use at that time. The authors recommended the 13-item Functional Assessment of Cancer Therapy–Fatigue (FACT-F) or the three-item fatigue subscale of the European Organisation for Research and Treatment of Cancer (EORTC QLQ C30). An advantage of the FACT-F tool is validation of the clinical significance of a score change (Cella, Eton, Lai, Peterman, & Merkel, 2002). The minimum clinically important difference for FACT-F is a score change of 3.0 points (Cella, Eton, et al., 2002). Although it is a unidimensional measure of fatigue, measuring physical function, FACT-F also measures the social impact of CrF, as reported by Minton and Stone (2009), and has been identified as a multidimensional measure of fatigue by other authors.

Table 2.1.1: Unidimensional tools for measuring cancer-related fatigue

Scale name	No. of items	Scale type	Population used in original validation study	Internal consistency	Dimensions of fatigue covered	Test and retest reliability	Responsiveness to change	No. of participants in original validation study	Cohort studies (active/palliative/ survivors)
Brief Fatigue Inventory (BFI)	9	Numerical	Mixed cancer	0.96	Physical functioning	–	Not completed	305	A/P/S
EORTC QLQ C30	3	Likert	Lung, bone marrow transplant, metastatic	0.80–0.85	Physical functioning	–	On basis performance status deterioration	366	A/P/S
Fatigue Severity Scale (FFS)	9	Numerical	Chronic illness	0.96	Physical functioning	Subset 87 patients, 3/52 later measurement, error 4.7 units	Not completed	227	A/P
Functional Assessment of Cancer Therapy Fatigue (FACT F)	13	Numerical	Mixed cancer on treatment	0.95	Physical functioning	r = 0.90 (3–7 days later)	Minimum clinically important difference (MCID) derived (3 points)	50	A/P/S
Profile of Mood States (POMS F)	7	Likert	Mixed work population and psychiatric patients	0.90–0.94	Physical functioning	r = 0.66 (12–16 weeks later)	MCID derived (5.6 points)	695	A/P/S

Table 2.1.2: Multidimensional tools for measuring cancer-related fatigue

Scale name	**No. of items**	**Scale type**	**Population used in original validation study**	**Internal consistency**	**Dimensions of fatigue covered**	**Test and retest reliability**	**Responsiveness to change**	**No. of participants in original validation study**	**Cohort studies (active/palliative/ survivors)**
Chalder Fatigue Scale (also known as the Fatigue Questionnaire, FQ)	11	Likert	General practice	0.88–0.90	Physical and mental	Not completed	Not completed	374	A/P/S
Fatigue Symptom Inventory (FSI)	13	Numerical	Breast cancer on treatment	0.94	Physical and mental	Range of values: patients, r = 0.35–0.75; controls, r = 0.10–0.74	Distinguished between pre- and post-treatment fatigue levels	270	A/S
Lee fatigue scale (or Visual Analogue Scale for Fatigue, VASF)	18	Visual analogue scale	Sleep disorder patients	0.91–0.96	Physical and mental	Not completed	Limited ability to detect changes over treatment period	122	A
Multidimensional Assessment of Fatigue (MAF)	16	Numerical	Arthritis patients	0.93	Distress, interference, severity, and cognitive	Not completed	Not completed	50	A
Multidimensional Fatigue Inventory (MFI-20)	20	Likert	Mixed cancer	0.84	Cognitive, physical, and emotional	Not completed	Change monitored over course of radiotherapy	111	A/P/S

Multidimensional Fatigue Symptom Inventory short form (MFSI-30)	30	Likert	Breast cancer	0.87–0.96	Cognitive, physical, and mental	Three occasions, r > 0.50	Not completed	275	A/S (breast only)
Revised Piper Fatigue Scale (PFS-R)	22	Likert	Breast	0.97	Temporal, intensity, cognitive, affective and sensory	r = 0.98	Not completed	382	A/S (breast only)
Schwartz Cancer Fatigue Scale	28	Likert	Mixed cancer	0.96	Physical, emotional, cognitive	Not completed	MCID calculated on treatment population (5 points)	166	A
Wu Cancer Fatigue Scale	9	Likert	Breast	0.91	Physical and emotional	Not completed	Not completed	82	A (breast only)

2.1.8 Treatment for CrF

Although there is no gold standard treatment currently in use for CrF (Ollie Minton et al., 2013), four treatment types are recommended for management of CrF: exercise; psychological; exercise and psychological; and pharmaceutical. Pharmaceutical treatments used include, hematopoietic growth factors, progestational steroids, methylphenidate (a psychostimulant) and, paroxetine (an anti-depressant) (Ollie Minton, Richardson, Sharpe, Hotopf, & Stone, 2008). A recent meta-analysis of 113 studies, that included 11525 participants revealed that the greatest improvements in CrF both during and after treatment were in studies that used exercise, with significant moderate effects observed (weighted effect size (WES) 0.30, 95% CI 0.25–0.36; $p < 0.001$). Psychological interventions had similar effects (WES 0.27, 95% CI 0.21–0.33; $p < 0.001$), as did exercise + psychological interventions (WES 0.26, 95% CI 0.13–0.38; $p < 0.001$). However, the pharmaceutical interventions did not improve CrF during and after primary treatment (WES 0.09, 95% CI 0.00–0.19; $p = 0.05$) (Mustian et al., 2017).

Section 2 Exercise and cancer-related fatigue

2.2. PA levels among cancer survivors

While it is well known that exercise has many cancer-specific benefits and there is evidence that exercise is an effective strategy for managing and treating CrF, many cancer survivors suffering from CrF are sedentary. In fact, at least one-third of individuals with cancer reduce their PA levels following diagnosis (Blanchard et al., 2003). A study carried out in the USA suggested that almost 70% of cancer patients were not meeting US PA guidelines (Blanchard, Courneya, & Stein, 2008). Moreover, it is estimated only 20–30% of cancer patients after treatment do not meet their PA guidelines (Courneya, Karvinen, & Vallance, 2007; Pinto & Ciccolo, 2011). It has also been posited that while behaviours such as diet and smoking improve following a cancer diagnosis, exercise usually declines (Blanchard et al, 2003). Perhaps this is because of lack of knowledge about guidelines for PA among cancer survivors and a fear of doing more harm than good by exercising.

2.2.1 Safety of exercise after treatment

Research suggests that exercise is safe both during and after cancer treatment (Speck, Courneya, Masse, Duval, & Schmitz, 2011). However, when implementing an exercise intervention, the wide range of contraindications for exercise among cancer survivors must be acknowledged. Specific precautions should be taken while working with survivors suffering from side effects such as anaemia, compromised immune function, neuropathy, ataxia, and lymphedema (McNeely, Peddle, Parliament, & Courneya, 2006). The development of programmes that are specific to the individual and within the individual’s capabilities is imperative, and the participant should be made aware that the pros for exercise outweigh the cons. PA studies have reported improvements in lymphedema (Schmitz, 2010; Chang & Cormier, 2013). A review carried out by Dennet, Peiris, Shields, Prendergast, and Taylor (2016) revealed that among 22 trials reporting an adverse event, only 19 of the 1888 participants in the exercise group experienced an adverse effect, which ranged from dizziness, fatigue, and bone, knee, and chest pain to dyspnoea and myocardial infarction. This suggests that exercise can be safe and that may help in improving other side effects and comorbidities following treatment.

2.2.2 PA guidelines for cancer survivors

In 2009, a roundtable discussion consisting of clinical and research experts in the field of exercise and cancer was organised by the American College of Sports Medicine (ACSM) to develop an exercise prescription specific to cancer survivors (Schmitz et al., 2010). The conclusion was that cancer survivors should follow the same exercise prescription as the age-appropriate guidelines from the US Department of Health Services, American Heart Association (AHA) and ACSM, as summarised in Table 2.2.1. These guidelines are still in place according to the most recent American Cancer Society (ACS) update in 2012 (Rock et al., 2012). As well as these guidelines, The Clinical Oncology Society of Australia released a position statement calling for exercise to be prescribed as part of routine cancer care and for cancer patients to be referred to exercise specialists with experience in cancer care (Cormie et al., 2018).

Table 2.2.1: Summary of physical activity guidelines for cancer survivors (Haskell et al., 2007; Pinto & Ciccolo, 2011, Speck, Courneya, Masse, Duval, & Schmitz, 2011; Brown et al., 2003).

Year	Institute	Recommendations
2003/2006	American Cancer Society	• Follow guidelines for cancer prevention (at least 30 minutes of moderate-vigorous physical activity at least 5 days per week above usual activities, 45–60 minutes of intentional PA is preferred • Daily and regular PA may be the preferred goal and therefore any steps to move from a sedentary to an active lifestyle should be encouraged
2010	American College of Sports Medicine	• Avoid inactivity and return to normal activity as soon as possible after diagnosis or treatment • Aerobic activity: • Perform 150 min/week of moderate-vigorous activity or 75 min/week of vigorous-intensity activity or an equivalent combination • Activity should be done in bouts of at least 10 minutes in duration and spread throughout the day

2.2.3 Exercise interventions for CrF

Exercise is now generally accepted as a primary intervention for the management of CrF (NCCN, 2013). However, the volume of research on exercise and CrF is not extensive. This section presents a review of recent literature on exercise interventions that have reported CrF findings. A literature search revealed 16 studies that were deemed suitable for inclusion in the review. For inclusion in the review, studies were required to: (1) include post-treatment cancer patients; (2) include fatigue as either a primary or a secondary outcome; and (3) use exercise as an intervention. The studies included are summarised in Table 2.2.2. There were features in the studies reviewed that were of particular interest to this research that previous investigators did not focus on, such as the control condition in the study, the fatigue inclusion criteria, and the tool used to measure CrF, which may add value to the existing body of knowledge.

2.2.3.1 Participant characteristics

Among the studies included in the review, nine were conducted solely among breast cancer survivors, one in prostate cancer survivors, one in head and neck cancer survivors, one in colorectal cancer survivors, and the remaining four among survivors of various types of cancer. The mean participant age ranged from 39 to 73 years and the mean time since treatment ranged from 9 days to 5 years.

Table 2.2.2: Summary of studies included in review: participant characteristics

Reference	Sample	Gender	Mean age, years (SD)	Cancer type	Time since treatment
Broderick, 2013	43	M & F	Exercise group 52.3 (8.3) Usual care group 51.2 (10.3)	Breast, colon, lymphoma, oesophageal, gynaecological	2–6 months since chemotherapy completion
Burnham & Wilcox, 2002	21	M & F	Moderate intensity group 50.7 (8.2) Low intensity group 54.2 (8.1) Control group 56.0 (10.1)	Breast, colon, lung	Minimum 2 months
Cantarero Villanueva, 2013	68	F	Aquatic exercise group 47 (8) Usual care group 49 (7)	Breast	Finished oncology treatment except hormonal therapy in previous 18 months
Cormie et al., 2013	20	M	Exercise group 73.1(7.5) Usual care group 71.2(6.9)	Prostate (had bone metastatic disease secondary to prostate cancer)	Not stated
Courneya et al., 2003	53	F	Exercise group 59 (5) Control group 58 (6)	Breast	Not stated
Daley et al., 2007	108	F	Exercise therapy group 51.6 (8.8) Exercise placebo group 50.6 (8.7) Usual care group 51.1 (8.6)	Breast	Mean 7.5 months after treatment
Dimeo ,Thomas, Raabe-Menssen, Propper & Mathias, 2004	72	M & F	Aerobic exercise group 55.1(10) Relaxation training group 60 (9.5)	Lung or gastrointestinal tumours	Mean 120 days after surgery
Ergun, Eyigor, Karaca, Kisim & Uslu, 2013	60	F	Supervised exercise group 49.7(8.3) Home exercise group 55.1 (6.9) Education group 50.3 (10.4)	Breast	Not stated
McNeeely et al., 2008	52	M & F	Progressive resistance exercise training 53 (range 32–76) Therapeutic exercise protocol 57 (range 43–76)	Head and neck	2–180 months
Milne, Wallam, & Gordon, 2008	58	F	Immediate exercise group 55.2 (8.4) Delayed exercise group 55.1 (8.0)	Breast	Within 2 years of completing adjuvant therapy

Pinto, Clark, Maruyama, & Feder, 2003	24	F	Overall group 52.5 (6.8)	Breast	3 years
Pinto, Frierson, Truzno, & Marcus, 2005	86	F	Physical activity intervention 53.4 (9.0) Contact control 52.9 (10.4)	Breast	Up to 5 years
Pinto, Papandonatos, Goldstein, Marcus, & Farrell, 2013	46	M & F	Physical activity intervention 59.5 (11.2) Control group 55.6 (8.2)	Colorectal	≤5 years since treatment completion
Saarto et al., 2012	500	F	Exercise group 52.3 (range 36–68) Control group 52.4 (range 35–68)	Breast	At least 6 months after treatment
Thorsen et al., 2005	111	M & F	Intervention group 39.0 (8.4) Control group 39.1 (8.6)	Breast, gynaecological, lymphoma, testicular	At least 1 month after chemotherapy
Yuen & Sword, 2007	29	F	Aerobic exercise group 53.1 (13.5) Resistance group 53.7 (11.3) Control group 55.0 (13.4)	Breast	9 days to 35 months

2.2.3.2 Intervention characteristics

The majority of exercise interventions were supervised and centre-based, while the remainder were unsupervised and home-based. Fourteen of the studies incorporated an aerobic exercise arm and six included a resistance exercise arm. The session duration varied from 10 minutes to 60 minutes, with sessions undertaken from one to five times per week over a period that ranged from 3 to 52 weeks. Most studies were of at least 12 weeks in duration. Intensity was calculated using a variety of methods, including percentage heart rate reserve (%HRR), rate of perceived exertion (RPE), percentage maximal oxygen uptake (% VO_{2max}), percentage heart rate maximum (%MHR), and percentage one repetition maximum (%1RM). The intensity of the interventions was primarily moderate, with only one trial incorporating low to moderate intensity. Interventions that were centre-based tended to be supervised. Conversely, home-based programmes were unsupervised.

2.2.3.3 Control group

Another important feature of the studies reviewed is the control condition used, which was typically a “usual care” group. This control group does not receive the exercise intervention, but also does not receive the peer support, positive health focus, and investigator attention that come with being part of a dedicated cancer survivor group. Ten studies in the review had no contact with the usual care group during the intervention period, with participants only attending for testing before and after the intervention (Broderick et al., 2013; Burnham & Wilcox, 2002a; Cantarero-Villanueva et al., 2013; Cormie et al., 2013; Courneya et al., 2003; Daley, Crank, Saxton, et al., 2007; Pinto, Clark, Maruyama, & Feder, 2003; Saarto et al., 2012; Thorsen et al., 2005; Yuen & Sword, 2007). However, control participants in four studies that incorporated a usual care group were offered the exercise intervention after the intervention period (Broderick et al., 2013; Burnham & Wilcox, 2002a; Cormie et al., 2013; Courneya et al., 2003). Although researchers have emphasised the need for comparison groups that involve peer support, a positive health focus, and investigator attention (Institute of Medicine (US) Committee, 2008), only two studies in the review incorporated a comparison group that involved matched investigator attention and peer support (Dimeo, Thomas, Raabe-Menssen, Pröpper, & Mathias, 2004; McNeely et al., 2008). However, two other studies did incorporate a contact control group that received a weekly phone call to monitor symptoms and ensure the same frequency of contact as for the intervention group (Pinto, Frierson, Rabin, Trunzo, & Marcus, 2005a; Pinto, Papandonatos, Goldstein, Marcus, & Farrell, 2013). Other investigators opted for a delayed exercise intervention (Milne, Wallman, Gordon, & Courneya, 2008a). To maintain study interest, those in the delayed exercise group received calls in weeks 3, 6, 9, and 12, while those in the immediate exercise group received calls in weeks 15, 18, 21, and 24. However, the aim of the calls was to maintain study interest rather than to provide investigator attention or peer support. The delayed exercise group was asked not to take part in exercise during weeks 1–12. On the contrary, those in the immediate exercise group were not given any specific exercise instructions to adhere to during weeks 13–24 (Milne et al., 2008a).

Table 2.2.3: Summary of studies included in review: description of the exercise programmes used

Reference	F.I.T.T. principles of training	Exercise intervention location	Supervision	Control group
Broderick, 2013	2 x p/w, 8 weeks, 21–42 min, aerobic, group, individual	Centre- and home-based	Supervised	Usual care: instructed to maintain habitual levels of activity; individualised exercise prescription provided on study completion
Burnham & Wilcox, 2002	3 x p/w, 10 weeks, 40–60% HRR moderate, 25–40% HRR low, 14–32 min, aerobic; treadmill, stationary bike, stair climbing	Centre-based	Supervised	Usual care: no intervention but offered exercise intervention after completion of the intervention period
Cantarero Villanueva, 2013	3 x p/w, 8 weeks, moderate RPE, 60 min, aerobic and resistance; aquatic	Centre-based	Supervised	Usual care: followed oncologist recommendation for maintaining a healthy lifestyle
Cormie et al., 2013	2 x p/w, 12 weeks, 12–18RM, 45 min, resistance	Centre-based	Supervised	Usual care: no intervention but offered exercise intervention after completion of the intervention period
Courneya et al., 2003	3 x p/w, 15 weeks,70–75% max oxygen consumption, 15–35 min, aerobic; cardiovascular programme on cycle ergometer	Centre-based	Supervised	Usual care: no intervention but offered exercise intervention after completion of the intervention period
Daley et al., 2007	3 x p/w, 8 weeks, 65–85% age-adjusted HRmax, RPE 12–13, 50 min, aerobic	Centre-based	Supervised	Exercise placebo: performed light body conditioning or stretching instead of aerobic exercise, no CBT or behaviour change techniques (below 40% HRR) Usual care: continued lives as usual
Dimeo, Thomas, Raabe-Menssen, Propper, & Mathias, 2004	5 x p/w, 5 weeks, 80% HRmax or RPE 13–14, 30 min, aerobic 3 x p/w, 3 weeks, progressive relaxation group, 45 min, relaxation	Not stated	Not stated	Comparison study; aerobic compared to relaxation, no control group
Ergun, Eyigor, Karaca, Kisim, & Uslu, 2013	3 x p/w, 45 min aerobic and resistance + 3 x p/w, 30 min, brisk walking	Centre- and home-based	Supervised at centre, unsupervised at home	Control group: home-based brisk walking, 30 min/day 3 days/week + education programme, education-only group

McNeeely et al., 2008	2 x p/w (3rd session optional), 25–30% 1 RM and slowly progressing to 60–70% 1 RM by week 12, 12 weeks, resistance	Centre- and home-based	Supervised at centre, unsupervised at home	Comparison study, compared PRET programme to standardised therapeutic exercise protocol; no control group
Milne, Wallam & Gordon, 2008	3 x p/w, 25 min; cardiovascular, resistance, 2 x 10-15 reps, 12 weeks, aerobic; cycle and rowing ergometer, mini trampoline, step up blocks	Centre-based	Supervised	Delayed exercise group: telephone calls received in weeks 3, 6, 9, and 12 to maintain study interest; began the programme weeks 13–24
Pinto, Clark, Maruyama & Feder, 2003	3 x p/w,12 weeks, 60–70% HRmax, 40 min, aerobic	Centre- and home-based	Supervised at centre, unsupervised at home	Waitlist group: no intervention but offered exercise intervention after completion of the intervention period
Pinto, Frierson, Truzno & Marcus, 2005	2–5 x p/w, 12 weeks, 55–65% HRmax, 10–30 min, home-based activities	Home-based	Unsupervised	Contact control: weekly phone call to monitor symptoms and ensure the same contact frequency as for the intervention group; after final follow-up assessment, received the PA tip sheets
Pinto, Papandonatos, Goldstein, Marcus & Farrell, 2013	3-5 x p/w, 12 weeks, 65–75% MHR, 10–30 min, aerobic	Home-based	Phone based	Contact control: instructed not to begin a structured exercise program, weekly phone call to monitor symptoms and ensure the same contact frequency as for the intervention group; received the same colorectal cancer survivorship tip sheets as the PA group; after the final follow-up assessment, received the PA tip sheets
Saarto et al., 2012	1 x p/w group + 2–3 x p/w home, 52 weeks, RPE 14–16, 86–92% HRmax, 76–85% VO_2max, 40–50 min, aerobic	Centre- and home-based	Supervised at centre, unsupervised at home	Control group: encouraged to maintain previous level of PA and exercise habits throughout the study minus any supervised or home training programs
Thorsen et al., 2005	2 x p/w, 14 weeks, 60–70% HRmax, RPE 13–15, 30 min, aerobic	Home-based	Supervised (contacted fortnightly) and unsupervised	Control group: did not receive a personalised training program, told be as physically active as before study

Yuen & Sword., 2007	3 x p/w, 12 weeks, 8–12 RM resistance, RPE 10–13, 20–40 min, aerobic and resistance	Home-based	Unsupervised	Usual care: advised to continue their normal activities but did not receive any form of exercise-related training or follow-up phone monitoring.

Abbreviations: F.I.T.T. = Frequency, Intensity, Time, Type, HRmax = heart rate maximum, HRR = heart rate reserve, p/w = per week, MHR = maximum heart rate, RPE = rate of perceived exertion, RM = repetition maximum.

2.2.3.4 Fatigue measurements

The literature review revealed that 12 different instruments were used to measure CrF. The use of such a wide variety of tools hampers comparisons between individual fatigue studies (Table 2.2.4). Fatigue reduction was the primary outcome of the intervention in only five studies (Cantarero-Villanueva et al., 2013; Dimeo, Thomas, Raabe-Menssen, Pröpper, & Mathias, 2004; Pinto et al., 2003; Saarto et al., 2012; Yuen & Sword, 2007). Of these five, only two required a specific fatigue score for inclusion in the study (Cantarero-Villanueva et al., 2013; Yuen & Sword, 2007), even though all 16 studies reported fatigue findings (Table 2.2.4).

2.2.3.5 Follow-up assessments in studies

Follow-up assessment of long-term outcomes was poor in the majority of studies, with 10 failing to assess outcomes beyond the end of the intervention period (Burnham & Wilcox, 2002a; Cormie et al., 2013; Courneya et al., 2003; Dimeo et al., 2004; Ergun, Eyigor, Karaca, Kisim, & Uslu, 2013; McNeely et al., 2008; Pinto et al., 2003; Saarto et al., 2012; Thorsen et al., 2005; Yuen & Sword, 2007). Of the six studies that did include follow-up, the duration varied. One study followed the participants for 3 months (Broderick et al., 2013), one for 6 months (Cantarero-Villanueva et al., 2013), two for 24 weeks (Daley et al., 2007; Milne et al., 2008a), one for 6 months and 9 months (Pinto et al., 2005a), and one for 12 months (Pinto, Papandonatos, & Goldstein, 2013). In two studies, participants in the exercise group had maintained the positive fatigue changes observed at follow-up (Broderick et al., 2013; Cantarero-Villanueva et al., 2013). The immediate exercise group in the study by Milne et al. (2008a) maintained the change in fatigue at 24-week follow-up, while the delayed exercise group did not. Although Pinto et al. (2005) included 6-month and 9-month follow-up, no follow-up results were reported in their article. No change in fatigue was observed at follow-up in the studies carried out by Pinto et al. (2013) and Daley et al. (2007).

2.2.3.6 Changes in fatigue

Of the studies that showed a positive change in fatigue, four were carried out among breast cancer cohorts (Cantarero-Villanueva et al., 2013; Courneya et al., 2003; 2003; Milne et al., 2008a; Pinto, Frierson, Rabin, Trunzo, & Marcus, 2005b). The remaining study was carried out among lung and gastrointestinal cancer patients (Dimeo et al., 2004). Various fatigue measurement tools produced significant results even though, the

FACT-F and EORTC are suggested as the best validated fatigue instruments (Minton & Stone, 2009). These instruments were used in just two studies that produced positive changes in fatigue (Courneya et al., 2003; Dimeo et al., 2004). All studies reporting a positive change in fatigue incorporated some element of aerobic exercise, with two studies combining aerobic and resistance (Cantarero-Villanueva et al., 2013; Milne et al., 2008a). Three of the studies reporting positive changes in fatigue were centre based and supervised (Cantarero-Villanueva et al., 2013; Kerry S Courneya et al., 2003; Milne et al., 2008a), one was homebased and unsupervised (Pinto et al., 2005b) and, one study did not report this data (Dimeo et al., 2004). All studies reporting a significant change in fatigue, exercised for at least 3 times per week. Sessions lasted an average of 30 minutes and most used a moderate intensity.

From the literature reviewed, mean SMD improvements for CrF ranged from -1.40 to -0.00. This is similar to recent meta-analysis who have reported mean SMD improvements for CrF ranged from −1.05 to −0.01 (Kelley & Kelley, 2017). Of the studies reporting a positive change in fatigue in our literature review, SMD improvements in CrF ranged from 0.63 (Pinto et al., 2005b) to 1.4 (Cantarero-Villanueva et al., 2013). Comparison between individual fatigue studies is difficult and hampered by the variety of instruments used to measure cancer-related fatigue.

Of the studies reporting a significant change in fatigue, four did not require a specific fatigue score as a study inclusion criterion (Courneya et al., 2003; Dimeo et al., 2004; Milne et al., 2008a; Pinto et al., 2005b). Inclusion of participants with low fatigue levels does not allow a great opportunity for improvement. One study that included only participants with moderate to high levels of fatigue (Cantarero-Villanueva et al., 2013) reported a large effect size (d = 0.87) that could be explained by a fatigue inclusion criterion that allows for a greater scope for improvement.

While there was a significant decrease in fatigue after the intervention that favoured the exercise group in five studies (Cantarero-Villanueva et al., 2013; Courneya et al., 2003; Dimeo et al., 2004; Milne, et al., 2008a; Pinto et al., 2005), 11 studies did not observe any change in fatigue (Burnham & Wilcox, 2002; Broderick et al., 2013; Cormie et al., 2013; Daley, Crank, Saxton, et al., 2007; Ergun et al., 2013; McNeely et al., 2008; Pinto et al., 2003; Pinto, Papandonatos, Goldstein, et al., 2013; Saarto et al., 2012; Thorsen et al., 2005; Yuen & Sword, 2007). There are many reasons why some studies did not observe any change in fatigue. In the study carried out by Broderick et al. (2013), participants did not observe a decrease in fatigue after the intervention, but did observe a decrease at 3-month follow-up. The participants in this study were in the early survivorship phase of their recovery and the early fatiguing effects of starting an exercise intervention could have concealed any preliminary changes in fatigue. However, by the 3-month follow-up time they may have observed evidence of habituation to exercise (Broderick et al., 2013). Cormie et al. (2013) suggested that the small number of participants in their study might have restricted the power to detect significant changes in outcomes such as fatigue. The small sample size and high dropout rate in the study by Pinto et al. (2003) was suggested as factors that severely affected the power to detect significant differences in fatigue. The short duration of 8 weeks may explain why Daley et al. (2007) did not observe any decrease in fatigue in their study. Ergun et al. (2013) suggested that participants with relatively low baseline fatigue scores before the intervention may have been the cause of the failure to observe a decrease in fatigue, as there was not much scope for improvement. Low baseline fatigue scores may also explain the non-significant decrease in fatigue observed by McNeely et al. (2008). In addition to a small sample size, Pinto et al. (2013) reported that participants in their study were high functioning, which may have contributed to ceiling effects that affected the ability to detect any changes in outcomes such as fatigue. Although the sample size was large in the study by Saarto et al. (2012), they included participants who were actively engaging in exercise, and only a quarter of the participants were sedentary. Again, this may have contributed to a ceiling effect in the ability to detect intervention changes, with participants who are already active and leading a healthy lifestyle less likely to benefit from the intervention (Saarto et al., 2012).

2.2.3.7 Study limitations

A number of limitations can be identified in the existing literature that is likely influencing the results reported. First, recruitment of a small sample size was an issue in many studies (Broderick et al., 2013; Cormie et al., 2013; Courneya et al., 2003; Ergun et al., 2013; Pinto et al., 2003, 2005; Pinto, Papandonatos, Goldstein, et al., 2013; Yuen & Sword, 2007). A small sample size restricts the power to detect changes in outcomes, and is a limitation in many of the studies reviewed. Second, studies reporting CrF findings rarely include a fatigue cutoff score as an inclusion criterion (Broderick et al., 2013; Burnham & Wilcox, 2002a; Cormie et al., 2013; Courneya et al., 2003; Daley, Crank, Saxton, et al., 2007; Dimeo et al., 2004; Ergun et al., 2013; McNeely et al., 2008; Milne et al., 2008a; Pinto et al., 2005, 2003; Pinto, Papandonatos, Goldstein, et al., 2013; Saarto et al., 2012; Thorsen et al., 2005). Use of a fatigue threshold for inclusion would reduce the likelihood of including high-functioning participants who reported low baseline fatigue levels. Inclusion of participants with low baseline fatigue does not leave much scope for improvement in the condition, contributing to a ceiling effect; including only participants who report high fatigue levels provides greater scope for improvement. Third, only a few studies included follow-up in their design (Broderick et al., 2013; Cantarero-Villanueva et al., 2013; Daley, Crank, Saxton, et al., 2007; Milne et al., 2008a; Pinto et al., 2005; Pinto, Papandonatos, Goldstein, et al., 2013). It is critical that studies follow participants beyond the typical 12-week intervention period to determine the medium-term effects on PA, fitness, fatigue, and other QOL indicators. Fourth, few studies used a suitable control condition, with many incorporating a "usual care" group without considering investigator attention or peer support. This approach is hardly addressed in the literature, with studies failing to incorporate group-based control conditions or comparison groups in their design. Studies need to include appropriate comparison groups to control for the real chance of such effects (Knols et al., 2005), which is a limitation in many of the studies reviewed. Other limitations noted were a short intervention length (Milne et al., 2008a), so a longer intervention may have been needed to see a change in outcomes. Inclusion of only breast cancer survivors (Ergun et al., 2013) or a homogeneous group (Pinto et al., 2005a) or a high proportion of females (Broderick et al., 2013) reduces the generalisability of the results.

Table 2.2.4: Summary of primary and secondary outcomes measured, fatigue tools used, fatigue thresholds for inclusion, main fatigue results, and study limitations identified by the study authors and in the review

Reference	Primary Outcome	Secondary Outcome	Fatigue Measurement tool used	Was a fatigue score needed for inclusion in study	Main fatigue results	Study limitations
Broderick, 2013	Aerobic fitness	Physical activity, waist circumference, fatigue and quality of life	FACIT-F TOI-F	NO	No change in fatigue from pre to post in either group. Decrease in fatigue from pre to 3-month follow up in the exercise group.	No minimum fatigue score needed for inclusion, small sample size, high proportion of females,
Burnham & Wilcox, 2002	To improve physiological & psychological function	Evaluate the differential effects of low-moderate exercise on physiological and psychological function	LASA	NO	No change (SMD -0.61, 95% CI -1.62 to 0.39) in fatigue from pre to post in the exercise group.	No follow up, no minimum fatigue score needed for inclusion.
Cantarero Villanueva, 2013	Fatigue	mood stat, and abdominal and leg strength	PFS	YES (>3 in total score)	Decrease (SMD -1.40, 95% CI -0.87 to -1.93) in fatigue in the exercise group, effects maintained at 6 months.	Only breast cancer, difficult to measure HR and muscle function during water based exercise, intention to treat not included, no follow up.
Cormie et al., 2013.	Safety and efficacy	Patient-reported outcomes, Body composition, Physical function and physical activity levels	MFI	NO	No between group differences for fatigue	No minimum fatigue score needed for inclusion, small sample size, participants high functioning, no follow up.
Courneya et al., 2003	Changes in peak oxygen consumption and overall QOL	Changes in happiness, self-esteem, fatigue and various subscales of overall QOL	FACT-F	NO	Decrease (SMD -0.77, 95% CI -1.34 to -0.20) in fatigue from pre to post in the exercise group	No minimum fatigue score needed for inclusion, no follow up, 14% recruitment rate, small sample size, short intervention, sig difference at baseline in fatigue scores
Daley et al., 2007	Differences in QoL as measured by the Functional	Fatigue, depression, self-perception, physical activity,	PFS	NO	No change (SMD -0.48, 95% CI, -0.97 to 0.01) in	No minimum fatigue score needed for inclusion, intervention contamination.

	Assessment of Cancer Therapy–General (FACT-G)	aerobic fitness, body composition			fatigue post intervention or at follow up	
Dimeo ,Thomas, Raabe-Menssen, Propper & Mathias, 2004	Fatigue and physical performance	None stated	EORTC QOL-C30	NO	Decrease in fatigue in both the aerobic exercise group and relaxation training group. The decreases in the aerobic group was not greater that then relaxation training.	No minimum fatigue score needed for inclusion, no follow up, no control group without therapy for fatigue.
Ergun, Eyigor, Karaca, Kisim & Uslu, 2013	Effects of exercise programmes of moderate intensity on angiogenesis and apoptosis-related molecules	Fatigue, depression and quality of life	BFI	NO	No change in fatigue in any group	No minimum fatigue score needed for inclusion, no follow up, small sample size, breast cancer only cohort, post treatment only
McNeeely et al., 2008	Reduce upper extremity pain and dysfunction	Upper extremity strength and endurance, range of motion, fatigue, and quality of life	FACT-An	NO	No change (SMD -0.23, 95% CI -0.78 to 0.31) in fatigue in exercise group or control group	No minimum fatigue score needed for inclusion, no follow up, treatments for both groups administered by first author, range of time since surgery,
Milne, Wallam & Gordon, 2008	QOL	Fatigue, social physique anxiety, and physical fitness	SCFS	NO	Immediate exercise group decreased fatigue from pre to week 6 (SMD -1.35, 95% CI -1.92 to -0.78) and, week 12 to week 18 Delayed exercise group decreased from week 12 to week 18 Immediate exercise group only maintained decrease at 24 week follow up	No minimum fatigue score needed for inclusion, 61.3% adherence rate, short length of intervention
Pinto, Clark, Maruyama & Feder, 2003	Psychological Distress (inc.	Physical Fitness	POMS	NO	No change (SMD -0.28, 95% CI -1.08 to 0.53) in	No minimum fatigue score needed for inclusion, no follow up, small sample size,

	fatigue) and Body Distress				fatigue in exercise group or control group	difficulty with retention of control group, study did not allow research to separate the effects from the exercise from nonspecific aspects of group support as no group based control condition was used
Pinto, Frierson, Truzno & Marcus, 2005	Can sedentary post treatment cancer patients adopt a homebased moderate intensity PA programme	Body composition, activity levels, 1-mile walk, motivational readiness for exercise, mood, fatigue, body esteem	POMS	NO	Decrease (SMD -0.63, 95% CI -1.06 to -0.20) in fatigue from pre to post in the exercise group No follow up results reported in article	No minimum fatigue score needed for inclusion, high exclusionary rate, homogeneous group.
Pinto, Papandonatos, Goldstein, Marcus & Farrell, 2013	Effect on self-reported PA and fitness	Progression in stages of motivational readiness for PA, fatigue, self-reported physical functioning, and QOL	FACT-F	NO	No change (SMD 0.05, 95% CI -0.53 to 0.63) in fatigue in exercise group or control group at any time points	No minimum fatigue score needed for inclusion, sample size
Saarto et al., 2012	QOL, fatigue, depression & menopausal symptoms	Effects on physical fitness	FACIT-F	NO	No change (SMD 0.00, 95% CI -0.18 to 0.18) in fatigue in exercise group or control group	No minimum fatigue score needed for inclusion, considerable motivation of the control condition, selected participants that mainly active-contributes to ceiling effect, past exercise predictor of exercise contamination, low adherence to the supervised exercise training.
Thorsen et al., 2005	Cardio respiratory fitness	HRQOL, Mental distress, Activity level, Adherence to exercise	EORTC QOL-C30	NO	Decrease in fatigue in the control group No change (SMD 0.37, 95% CI -0.02) to in exercise group	No minimum fatigue score needed for inclusion, no follow up,
Yuen & Sword., 2007	Fatigue and Functional Capacity	None stated	PFS	YES (experiencing at least a moderate	No change (SMD -0.61, 95% CI -1.69 to 0.47) in fatigue from pre to post in the exercise group	No follow up, small sample size, exercise intervention was self-directed, no measure on quantity of quality of sleep

				amount of fatigue, at least 4 on 11 point scale)		incorporated with impact on fatigue, Control group not asked to keep track of their exercise,

Abbreviations: BFI = Brief Fatigue Inventory, EORTC QLQ- C30 = European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire C30 version, FACIT-F Functional Assessment of Chronic Illness Therapy – Fatigue scale, FACT = Functional Assessment of Cancer Therapy, FACT-An = Functional Assessment of Cancer Therapy – Anaemia, FACT-F = Functional Assessment of Cancer Therapy – Fatigue, LASA = Linear Analogue Self-Assessment, MFI = Multi-dimensional Fatigue Inventory, PFS = Piper Fatigue Scale, POMS = Profile of Moods States, SCFS= Schwartz Cancer Fatigue Scale, TOI-F= Trial Outcome Index-Fatigue

2.2.4 Summary

The literature review demonstrated that the evidence supports the efficacy of exercise for reducing CrF with the majority of studies having a small to moderate effect, which is a common feature of the literature to date. A recent meta-analysis of 42 studies (Dennett, Peiris, Shields, Prendergast, & Taylor, 2016), carried out on 3816 cancer survivors reported moderate intensity aerobic exercise was safe and effective for reducing CrF (SMD, 0.32, 95% CI 0.22 to 0.40). Similar results were reported by Tian, Lu, Lin, & Hu (2015) who reported exercise to be more effective than conventional care in improving fatigue in cancer survivors (SMD, -0.22, 95% CI -0.39 to -0.04). A previous Cochrane review (Cramp and Byron-Daniel, 2012) that isolated the trials by cancer type and by timing of in relation to treatment, reported similar small to moderate standard mean differences favouring exercise over no exercise control. This analysis included 10 trials undertaken following (rather than during) anti-cancer treatment (SMD, -0.44, 95% CI -0.79 to -0.09). The main aim of any treatment intervention is to alleviate the burden and factors that may worsen side effects such as CrF. However, a number of questions regarding exercise and CrF remain to be addressed, as the review revealed a number of gaps and shortcomings. From the studies reviewed it is evident that there is a lack of a proper control condition in which control subjects experience the same degree of group support and investigator attention as the intervention group. Thus, a recommendation arising from the review is that exercise interventions should be compared to a comparison condition that includes group supports, a positive health focus, and investigator attention, which is lacking in the scientific literature so far.

Very few previous studies have exclusively focused on CrF as a primary outcome. Moreover, although research has highlighted exercise as effective in reducing CrF, studies rarely included a specific level of baseline fatigue as an inclusion criterion. There is a need to develop an exercise rehabilitation intervention that specifically targets persistent fatigue, one of the most disabling side effects of cancer and its treatment. The majority of programmes are fully supervised, so there is a need to develop and evaluate community-based “real life” approaches to exercise treatment. Exercise interventions should be both feasible and sustainable: increasing exercise knowledge and exercise self-efficacy, and reducing perceived barriers and erroneous perceptions of illness will help to achieve this. Interventions should build exercise self-efficacy to support sustainable long-term exercise behaviours.

Although many studies have been conducted, sufficient data on CrF are still lacking, with few studies including any follow-up. Therefore, it is impossible to assess if the initial intervention effects were maintained in these studies. Incorporation of follow-up is essential to identify whether or not an intervention is sustainable and if any improvements are maintained in the long term. Likewise, there is a lack of evidence on the factors influencing individual success and the characteristics of a successful intervention programme.

2.2.5 Mechanisms by which exercise may alleviate cancer related fatigue

2.2.5.1 Introduction

Just as the biological mechanisms responsible for cancer-related fatigue are poorly understood, the biological mechanisms by which exercise may alleviate fatigue are similarly poorly understood. Changes in biological factors including inflammation, fitness and psychobehavioural factors have all been proposed as potential mediators of the beneficial effects of exercise, in a model by Al-Majid & Gray (2009).

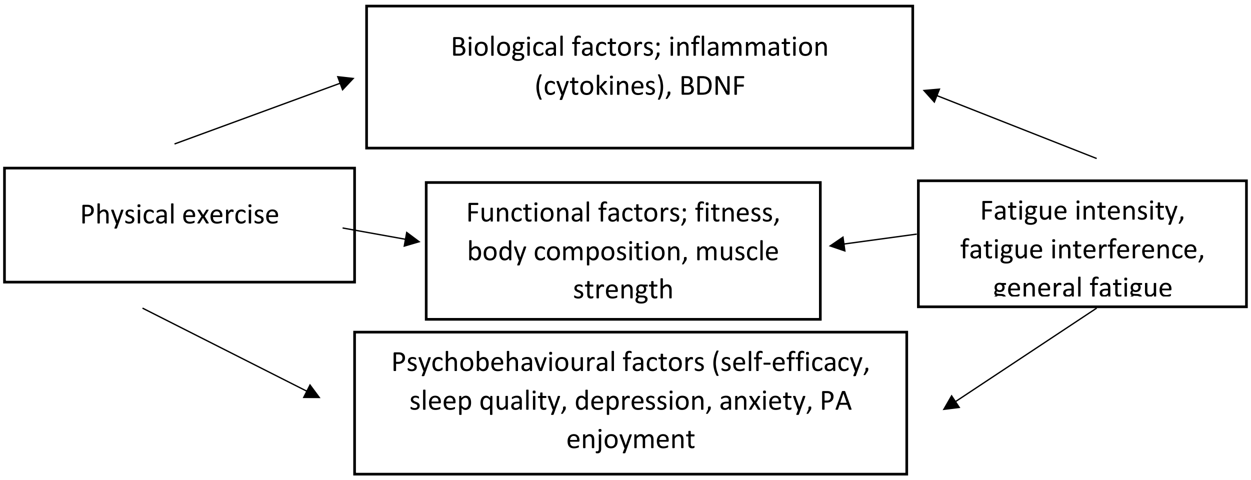


Figure 2.2.1: Hypothesised mediators of exercise effects on cancer related fatigue among breast cancer survivors. Adapted from (Al-Majid & Gray, 2009)

2.2.5.2 Biological

2.2.5.2.1 Anti-inflammatory effects

Inflammation remains one of the principal biological mediators of cancer fatigue and the evidence in this regard has been presented previously. In healthy individuals, exercise has been shown to increase anti-inflammatory cytokines such as IL-10 and reduce pro-inflammatory cytokines such as TNF-α and C-reactive protein (CRP) (Gleeson et al., 2011; Peterson & Pederson, 2005; Plaisanace & Grandjean, 2006). In chronic disease cohorts, the majority of studies have been undertaken in cardiovascular disease cohorts. Results have shown reductions in IL-1, IL-6 and TNF-α and increases in IL-10 following a 12-week moderate intensity aerobic intervention (Goldhammer et al., 2005). Fairey et al., (2005) reported a reduction in CRP approaching statistical significance among post-menopausal breast cancer survivors after 15 weeks of aerobic exercise training. This study did not measure fatigue however so it is not possible to say whether or not any reduction in inflammation would transfer to enhancements in fatigue. The results of a study by Jones et al. (2013), are equally inconclusive. In this study, no effect of exercise was evident for CRP, TNF-α IL-6, though an effect on IL-6 was evident in the participants with the greatest adherence to exercise. Once again, fatigue was not documented. In their systematic review and meta-analysis of the small number of available trials (between 2 and 5 depending on marker or interest), there was no significant exercise effect on IL-6, IL-8, IL-10 or CRP (Dennett et al., 2016). Thus, despite plausibility, the evidence linking the reduction in fatigue post-training to changes in inflammatory factors is not strong.

2.2.5.2.2 BDNF and brain function

The putative role of BDNF in brain function has already been reviewed with implications for cognitive function, dementia, mental health disorders, mood and chronic fatigue. A specific role in cancer-related fatigue has also been identified in prostate cancer patients (Salligan et al., 2016). It is clear however that fatigue overlaps with other dimension of BDNF-relevant brain processes including cognitive function and depression. Animal studies investigating exercise-induced changes in brain levels of BDNF and human studies of serum BDNF are in their infancy. In a recent study (Pietrelli et al., 2018, Neurobiol Learn Mem) lifelong aerobic exercise has been shown to positively affect BDNF pathways, improve cognitive function and protect the brain against the deleterious effects of aging. In a small review of human studies, exercise training did not influence serum BDNF in individuals with major depressive disorder (Kurebayashi & Otaki, 2018). At present, we are unable to provide an evidence-based link for an effect of exercise on brain or serum BDNF that accounts for the exercise effects on fatigue in cancer survivors. However, a plausible mechanism is likely to receive greater research attention in the years to come.

2.5.2.3 Training induced changes in physical fitness and body composition

It has been postulated that physical activity could help alleviate cancer related fatigue by improving functional capacity, hence making it easier to carry out activities of daily living (Cramp & Byron-Daniel, 2012). While there is evidence to suggest cardiorespiratory fitness is impaired following treatment, evidence also highlights aerobic training improves cardiorespiratory fitness among survivors (Schmitz, 2010; Klassen et al., 2010). Functional changes associated with cancer related fatigue include physical functioning reductions, which decreases individual's ability to carry out simple activities of daily living (Brown. McMilliam & Milroy, 2005; Segal et al., 2001). Improvements in cardiorespiratory fitness and muscle mass may help to reduce the effort needed to carry out both endurance and strength tasks, reducing fatigue among cancer survivors participating in exercise interventions (McMillian & Newhouse, 2011; Courneya et al., 2003; Al-Maji & Gray, 2009).

Following treatment, sacropenia affects both physical function and mobility (Villaseñor et al., 2012). Reductions in muscle strength and muscle mass contribute to functional impairment (Muscaritoli, Bossola, Aversa, Bellantone & Fanelli, 2006), decreased performance (Simons et al., (1998) and contribute excessive fatigue and tiredness (Argiles, Busquets, Garcia-Martinez & Lopez-Soriano, 2005). However, exercise may benefit same because of its potential positive effects on muscle mass and strength (Argilés, Busquets, López-Soriano, Costelli, & Penna, 2012).

Exercise can also decrease fat mass, which is also important, as high BMI is associated with persistent fatigue among breast cancer survivors (Reinertsen et al., 2010). By reducing BMI it may also help tackle chronic inflammation through reduced release of pro-inflammatory adipokines from visceral fat (Gleeson et al., 2001). Studies to date however that have controlled for BMI have found that exercise improves fatigue independently of body composition changes (Bower, 2014; Courneya et al., 2003).

2.5.2.4 Psychological benefits

2.5.2.4.1 Self-efficacy

The psychological benefits of exercise may help reduce the burden and symptoms of fatigue. Researchers have posited that self-efficacy facilitates the link between increased PA and reduced fatigue levels among breast cancer survivors (McAuley, White, Rogers, Motl, & Courneya, 2010; Philips & McAuley, 2013). Learning new skills, gaining new information, meeting new people, and achieving physical fitness goals can all help improve confidence and self-efficacy (McAuley & Blissmer, 2000) thus reducing isolation, loneliness, low confidence and low self-efficacy, all relevant to cancer related fatigue. Through participation in exercise, participants develop a sense of mastery which has been shown to promote positive psychological states and restore a sense of hope (Asmundson et al., 2013). Cancer patients may disengage from life roles and social activities due to ongoing fatigue. Previous research has suggested the social benefits of exercising with others who share the same background, such as enhances feelings of self-confidence and sense of positivity (Midtgaard, Rorth, Stelter, & Adamsen, 2006).

2.5.2.4.2 Improved sleep

Psychobehavioral aspects of cancer related fatigue include psychological distress and sleep disturbance (Payne, 2002; Ramsey, Berry, Moinpour, Giedzinska & Andersen, 2002). Cancer patients often suffer from insomnia with the prevalence ranging from 18% to 68% (Zhou, Partridge, Syrjala, Michaud, & Recklitis, 2016). Chronic insomnia has been reported to cause fatigue, cognitive dysfunction as well as psychological issues such as depression and an increased risk of suicide (Otte et al., 2016). Exercise has been shown to improve sleep quality and reduce pain and mood disturbances (Hartescu, Morgan, & Stevinson, 2015) all of which may help alleviate fatigue. Exercise has been shown to improve sleep quality by having a direct impact on circadian rhythms which results in an increase in total sleep time and deep sleep as well as reducing sleep onset latency and rapid eye movements (REM) (Fairbrother et al., 2014).

Section 3 Qualitative exercise research

2.3 Introduction

As discussed in Section 1 of this chapter, an increasing number of individuals are living with and beyond cancer; however, many have unmet needs and struggle with the consequences of their treatment. There is a growing body of quantitative evidence highlighting the positive effects of exercise on the side effects of cancer treatments, including CrF. By contrast, there has been a very limited focus on qualitative data in terms of the subjective experiences of participants in cancer-specific exercise programmes. It is vital to listen to and value the voices of cancer survivors, so qualitative research has an important role (Parry, 2007; Unruh & Elvin, 2004).

2.3.1 Importance of qualitative research in cancer rehabilitation

Qualitative research, via data collection methods such as focus groups, individual interviews, and observation, allows in-depth exploration of cancer survivors' experiences of participating in an exercise intervention, along with their perspectives on the impact of PA on their fatigue levels, physical and psychological functioning, and overall quality of life. Such qualitative data can thus provide an understanding as to what is meaningful for cancer survivors (Creswell, 2013).

While quantitative data are essential, they do not capture the effect of contextual aspects (Hansen, Tjørnhøj-Thomsen, & Johansen, 2011) such as human interactions, the physical environment and atmosphere, and the individual carrying out the intervention. Exploring the social aspects experienced by participants in their natural setting (Malterud, 2001) is important and helps investigators gain a broader insight into the contextual factors of exercise interventions for cancer survivors, which is vital for the development and implementation of future programmes. This section identifies and discusses qualitative research on the experiences of cancer survivors involved in exercise-based cancer rehabilitation.

A literature search was undertaken with the following inclusion criteria: sample including adults ≥18 years; post-treatment cancer patients only; exercise used as an intervention; and qualitative findings presented separately from any quantitative results. Fourteen studies met all these criteria (Appendix 26).

2.3.2 Characteristics of the studies included

The majority of participants in the 14 studies were female (95.5%). Interventions were mainly group-based and lasted for between 6 and 76 weeks. Nine of the studies included only patients with breast cancer, four studies included individuals with mixed cancers, and one study included only patients with colorectal cancer. The data collection methods used included focus groups (5/14) and semi-structured individual interviews (9/14). The sample size ranged from seven to 83 participants. A range of analysis methods was applied, including thematic, phenomenological, systematic text condensation, and triangulation; one study did not report the analysis method used (Spence, Heesch, & Brown, 2011a).

2.3.3 Key themes identified

Each of the study findings was analysed using a thematic approach. Themes included benefits or improvements; barriers, facilitators, preferences, and motivators in the context of exercise/PA participation; experience of the programme; value of an exercise programme for cancer survivors; and improvements that could be made to the programme. Appendix 27 outlines the most popular themes and subthemes as outlined above, along with supporting quotations from the original studies.

2.3.4 Benefits and improvements

Across the studies reviewed, participants reflected on physical, psychological, and social benefits. Physical benefits included less fatigue and improvements in physical function and pain (Groeneveld et al., 2013; Luoma et al., 2014; Parry, 2008). Most participants experienced psychological improvements, including feeling a sense of normality once again, regaining their self-confidence, being conscious of an enhanced emotional state, and becoming more self-assured (Korstjens et al., 2008; Luoma et al., 2014; Parry, 2008; Spence, Heesch, & Brown, 2011b; Wurz et al., 2015). Participants reported that the sense of mastery over their disease gained through participation in the exercise programme enhanced their psychological health. They identified this as being a consequence of their increase in physical function and meeting other patients (Luoma et al., 2014). For many the exercise programme facilitated their social wellbeing. Participation in the programme enhanced their sense of social connection to other cancer survivors who had been through and understood the same cancer experience. Participants felt a huge sense of camaraderie, and the programme provided them with an opportunity to make new friends. The peer social support they received brought comfort to participants and offered an opportunity to share information with others with first-hand experience (Luoma et al., 2014; Sabiston et al., 2007). Participants in one study suggested that their return to work was possible because of the physical fitness and energy they gained from the exercise programme.

Social support was a theme that repeatedly emerged in the studies reviewed. Participants felt that the cancer-specific exercise programmes included individuals who had an unconditional understanding of the cancer experience (Sabiston et al., 2007). Participants were able to share first-hand information about their experiences, which provided them with comfort when dealing with fear of the unknown (Sabiston et al., 2007). It could be argued this happens in most cancer support groups; however, participants felt that exercise programmes are different from others in that the focus is not on how terrible cancer is or on the treatment phase, and it involves an actual activity (Sabiston et al., 2007), which may distract individuals from their cancer. Others noted that it gave them an opportunity to help others (Sabiston et al., 2007), which enhanced their sense of giving back to the community.

2.3.5 Barriers to participation in PA/exercise

Identification of barriers to exercise among cancer survivors can help in implementing strategies to improve adherence to exercise behaviours and thus enhance the rollout of effective programmes. Although cancer survivors face similar barriers to those in the general population (Clark et al., 2007), they also encounter unique barriers that are specific to their disease and treatment side effects (Courneya et al., 2005; Courneya et al., 2008; Blaney, Lowe-Strong, Rankin, Campbell, Allen & Gracey, 2010).

For some, individual barriers to participation in exercise included change in their appearance, along with feelings of fear and isolation (Groeneveld et al., 2013; Luoma et al., 2014; Parry, 2008). Participants reported that they feared they would overdo it, increasing their risk of injury. Situational barriers included the time of day for the intervention and life roles, for example returning to work (Wurz et al., 2015). Restricting classes to morning times may pose problems for cancer survivors who have returned to work. This factor should be taken into consideration when developing and implementing exercise programmes targeted at cancer cohorts. Some mentioned their fatigue as a barrier (Sander et al., 2012). Others suggested that their social support was a barrier to participation in exercise and PA. They felt that their family would not let them undertake certain activities and acknowledged the fact they should be allowed to do so (Sander et al., 2012).

2.3.6 Exercise preferences

Cancer survivors felt it was essential to exercise in the company of other cancer survivors with similar experiences, as this allowed individuals to share their experiences and worries and enhanced humour within the group (Korstjens et al., 2008). In addition, most participants highlighted the importance of programme supervision by a skilled professional instructor. This meant that participants not only felt safe but also obtained motivational support from the exercise professional, which helped to increase their exercise self-efficacy and confidence (Luoma et al., 2014). Participants suggested that if the programme were unsupervised they would not have taken part (Spence et al., 2011b). They also reported a preference for the programme to commence straight after treatment, as they sensed motivation is still high at this stage of the cancer continuum (Spence et al., 2011b).

2.3.7 Motivators to exercise

There are many reasons why a cancer survivor may or may not decide to exercise. One key factor in a person’s decision is their individual motivation. Participants identified a range of motives for exercising, including the individual carrying out the exercise intervention and, having a structured cancer-specific group (Frensham et al., 2014; Luoma et al., 2014).

The presence of others who had been through the same ordeal meant that participants felt a sense of belonging that motivated them to exercise (Wurz et al., 2015). Individuals emphasised that the specificity of the programme allowed them the chance to gain a sense of normality. The programme was seen as something that they could take control of and do for themselves, and some even viewed it as their medicine, all of which motivated them to exercise (Wurz et al., 2015). Participants gained a huge sense of achievement, which contributed to their personal fulfilment and enhanced their motivation to participate. Additional exercise motivators were achieving goals (Frensham et al., 2014), the positive affirmation that participating in exercise/PA could help in saving their lives (Midtgaard et al., 2011), and reducing the fear of cancer recurrence (Midtgaard et al., 2011).

2.3.8 Experience of the programme

Many experiences of the programme were described by participants. Being part of an exercise programme provided them with an opportunity to obtain and share information (Sabiston et al., 2007). Others experienced comfort in knowing that there were others in the same situation (Sabiston et al., 2007). Participants also stated that their exercise programme was unique among other treatment and rehabilitation groups in that it did not focus on the illness, but rather on moving on from cancer and getting on with their life (Sabiston et al., 2007). Other participants reported feeling a sense of relief that the programme was supervised by professionals (Groeneveld et al., 2013).

2.3.9 Recommendations for programme improvements

Participants in the studies included in the review identified many improvements to programmes that could be made. These suggestions are important, as they could be useful when developing and implementing similar interventions for a vulnerable population such as cancer survivors. Participants mentioned inclusion of a psychologist and psychiatrist in the programme (Korstjens et al., 2008), which suggests that a multidisciplinary team is the best strategy. Others reported that they would like additional coaching on life after cancer (Korstjens et al., 2008). Some individuals suggested programmes with a variety of exercise types to suit different people and alternative methods of delivery during bad weather (Spence et al., 2011b). These options could enhance motivation to exercise and aid with adherence to the programme. Finally, participants suggested the option of an unsupervised programme that still ensured participant safety when individuals are unable to attend supervised sessions (Spence et al., 2011b). This indicates that addition of a home-based option would be beneficial for those who cannot make the supervised exercise session.

2.3.10 Summary

Although participants identified many barriers to participation in an exercise programme following treatment for cancer, they also reported many physical, social, and psychological improvements and benefits from being part of an exercise programme specifically designed for post-treatment cancer survivors. They valued being part of a group comprising individuals who had shared similar experiences and the utilisation of skilled exercise professionals. In addition, participants enjoyed the feeling that exercise groups are different from other groups; they felt that the focus was not on the disease, but rather on moving on from their illness. Participants also highlighted that they do not feel that their health care providers listening to their post-treatment needs.

Although there is accumulating evidence on the efficacy of exercise rehabilitation in cancer survivorship, the full impact cannot be accurately understood without taking into account personal experience of exercise interventions. Despite the value of such knowledge, there seems to be a paucity of studies exploring fatigued cancer survivors' experiences of participating in an exercise programme. The Clinical Oncology Society of Australia issued a position statement acknowledging the importance of exercise in cancer care, so collecting qualitative data may help in optimising the development, implementation, and sustainability of exercise programmes to cater for the ever-increasing number of cancer survivors. This may help to reduce the burden of CrF and improve the quality of life and health outcomes for cancer survivors following cancer treatment.

Qualitative research on exercise and cancer, although sparse, has provided important information regarding survivors’ barriers to, preferences for, and facilitators and motivators of exercise. A more thorough understanding of the personal experience of fatigued cancer survivors of fatigue and these exercise factors warrants further investigation. In addition, greater insight into the experience of fatigued cancer survivors participating in an exercise intervention specific to CrF requires further research.

Section 4

2.4 Introduction

In April 2017, the MedEx Move On programme was launched at Waterford Institute of Technology (WIT). Progress during the initial implementation process in WIT was investigated in a feasibility study via implementation science. The science of dissemination and implementation seeks to address the gap between what should happen, according to the evidence, and what actually happens in real life by evaluating ways of integrating interventions into real-world settings to improve health and prevent disease. The feasibility study can inform the ongoing MedEx MoveOn implementation as well as the future MedEx Chronic Illness Rehabilitation Programme. In the following sections, I present an overview of the MedEx programme, a synopsis of implementation science and frameworks, and a review of implementation challenges.

Cancer survivorship is improving worldwide for many reasons, including greater uptake of cancer screening, early detection of cancer, improvements in cancer treatments, and better nutrition and living conditions for an aging population (American Cancer Society, 2014; Parry, Kent, Mariotto, Alfano, & Rowland, 2011). All these factors are contributing to an increase in cancer survivor numbers. Despite an increase in survival, many individuals still live with the side effects of cancer and its treatment (Aziz & Rowland, 2003; Mantyh, 2006) which often persist for years following treatment. However, such side effects are not necessarily unmanageable (Kirshbaum, 2007; McNeely et al., 2006; Redd, Montgomery, & DuHamel, 2001). Exercise has been widely investigated as a strategy to help alleviate and treat such side effects (Ballard-Barbash et al., 2012; Brown et al., 2011b; Cramp & Byron-Daniel, 2012; Dennett et al., 2016). This research, along with the study outlined in Chapter 3, has demonstrated the efficacy of exercise for post-treatment cancer patients. However, these studies focused mainly on the efficacy of PA or exercise and paid little attention to how such interventions might translate into practice. It is essential that findings from effective survivor research are translated into practice and implemented in a variety of settings, including community, health care, and occupational settings. Evidence-based guidelines recommend the implementation of cancer rehabilitation programmes to enhance PA uptake into the cancer care continuum. However, PA uptake is low (Stevinson & Fox, 2006; Courneya et al., 2003; Segal 2001).

The majority of exercise and PA intervention studies for cancer survivors to date have been designed as randomised controlled trials. Their translation into practice is often obstructed, with many results unused, and implementation of such programmes in practice is still challenging (Glasgow, Green, Taylor, & Stange, 2012; Green & Glasgow, 2006; Rothwell, 2005). This may be because interventions are often developed and tested in unrealistic settings and are complex in nature, and are therefore impractical for implementation in a real-world community setting. The interventions are typically tested using methodologies designed to guarantee high internal validity, with less focus on issues associated with external validity (Glasgow, Klesges, Dzewaltowski, & Bull, 2004). Furthermore, studies often fail to consider the sustainability of an intervention once the research is over, and strategies for the translation of intervention programmes into cancer care are limited. More focus is needed on implementing such research studies in a real-world community setting to examine impacts on public health at the population level.

2.4.1 Translational Science Process

The National Cancer Institute defined translational research covering the complete cancer research spectrum as follows: “Translational research uses knowledge of human biology to develop and test the feasibility of cancer-relevant interventions in humans OR determines the biological basis for observations made in individuals with cancer or in populations at risk for cancer. The term ‘interventions’ is used in its broadest sense to include molecular assays, imaging techniques, drugs, biological agents, and/or other methodologies applicable to the prevention, early detection, diagnosis, prognosis, and/or treatment of cancer” (National Institute of Health, 2014). The translational research process as described by Philips et al. (2014) is made up of five phases that facilitate translation of research evidence to a population health impact, as illustrated in Figure 2.4.1. Each phase is important and informs the next; each phase answers a different question, leading to new visions, understandings, and discoveries. This in turn provides knowledge for every phase to improve the translation of science into practice.

The process begins at T0, the discovery of an opportunity for tackling a health problem. The first phase of the process is T1, in which the opportunity is translated to humans and applied to health, which includes clinical interventions and their initial testing. In the T2 phase, new therapies are tested in a controlled setting, which in turn informs evidence-based guidelines. The majority of studies on exercise and cancer to date have remained in phase T0–T2 of the translation research process, and have examined the effects of exercise on specific health- and disease-associated outcomes (Khoury et al., 2010; Khoury et al., 2007). It is essential that research on this issue progresses beyond the T2 phase and includes actions to translate relevant findings into practice and policy. Since its development, the Khoury model has been updated and now includes drivers of translation research (Lam, Spitz, Schully, & Khoury, 2013). Collaboration, technology, multilevel analysis, and the combination of knowledge gained have all been identified as drivers (Lam et al., 2013). In the T3 phase, translation to practice occurs and interventions are implemented and disseminated in real-world settings. In the final T4 phase (translation to populations), health outcomes at a population level in real-world settings are evaluated, along with the impact on public health. The translational research process is non-linear, with each phase informing all the other phases. To accelerate the process, collaboration and coordination are essential among all key stakeholders and researchers across all phases.

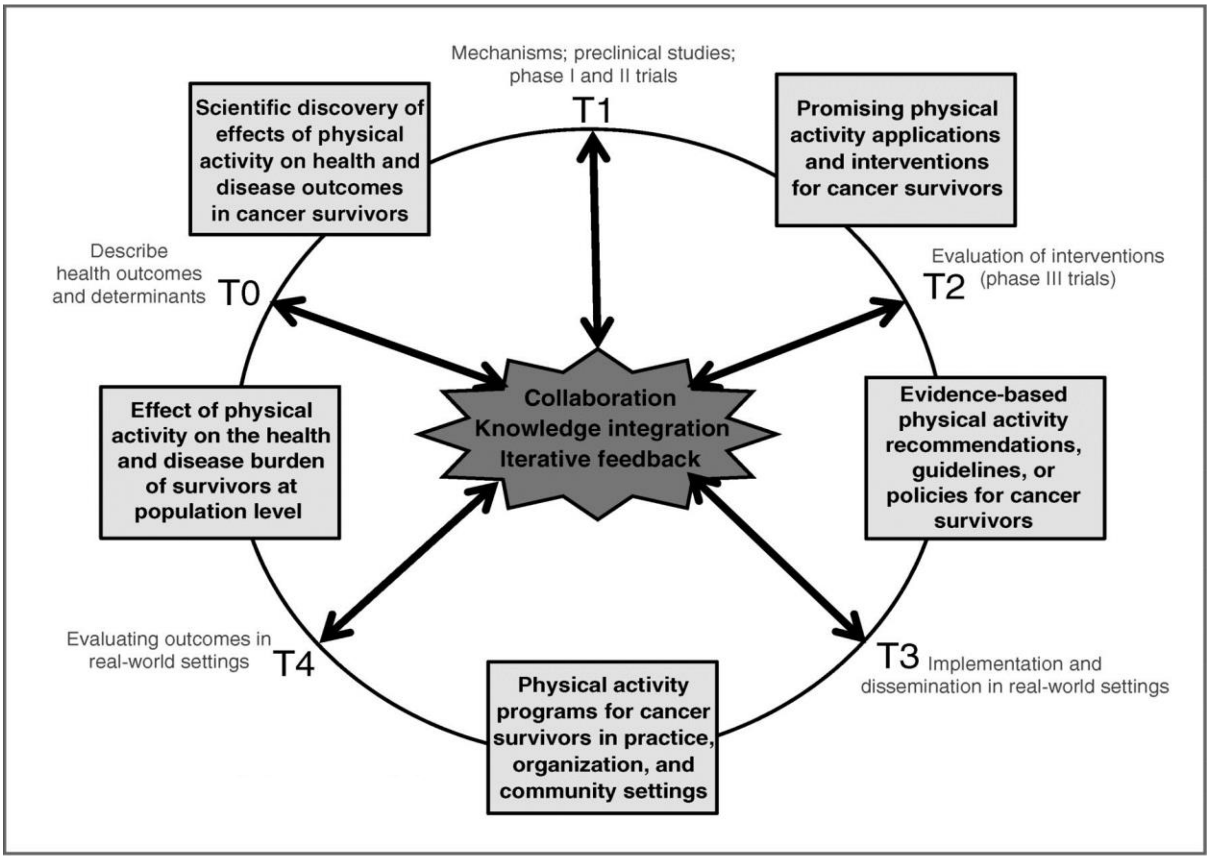


Figure 2.4.1: The translational science process for physical activity and cancer survivorship (Phillips, Alfano, Perna, & Glasgow, 2014).

2.4.2 Implementation science

Efficacy studies deal with how well an intervention works under thorough and controlled clinical investigation in an ideal setting. Effectiveness is concerned with the usefulness of an intervention under conditions of actual practice in real-world settings. Numerous efficacious exercise interventions exist for rehabilitation of cancer patients after their treatment (Brown et al., 2011a; Cramp & Byron-Daniel, 2012; Dennett et al., 2016; Tian, Lu, Lin, & Hu, 2016). However, cancer survivors at a population level cannot benefit from interventions that they do not receive. This is where implementation science can help in navigating the pathway from research to practice, and could be a key tool in addressing such gaps. Implementation is defined as “a specific set of activities designed to put into practice an activity or program of known dimensions” (Duda et al., 2012, p. 2). Implementation science is the examination of elements that affect the successful use of research findings and evidence-based practices in real-life practice settings (Fixsen, Blasé, Van Dyke, & Metz, 2015). A lack of attention to the implementation process represents a huge gap between research evidence gathered and actions taken to implement the evidence into practice in real-world settings. Implementation science research examines factors (at individual and health-system levels) that create barriers to attaining population health benefits and explores alternative methods for delivering and practicing health care (FI Centre, 2013). Frameworks to guide this research take into account factors that influence the implementation of exercise programmes into cancer care practice.

2.4.3 Active implementation frameworks

Active implementation frameworks can help in building implementation capacity at multiple levels within health and other systems. Such frameworks can help in implementing and sustaining evidence-based practices to improve patient outcomes and provide meaningful change. In their review of the literature, Fixsen, Naoom, Blasé, Friedman, & Wallace (2005) identified common factors that influence effective implementation for human services in real-world settings.

Active implementation frameworks constructed by Fixsen “provide guidance for purposeful and effective action in complex human services environments” (Fixsen, Blasé, & Metz, 2016, p. 5). Active implementation frameworks identify and accept the challenges and obstacles to implementation and focus on improvement phases. Fixsen acknowledges that, just as implementation teams solve problems, they should expect that problems are the norm. Full implementation is a process that usually takes between 2 and 4 years (National Implementation Research Network, 2013).

Implementation of an innovation in a system often requires change at many levels and is not a single event, but rather a process. Implementation stages guide the team through a purposeful approach to managing system change, building capacity, and sustaining the new programme or practice. The implementation phases can be used to analyse what is working and what is not working but can be improved, so that via experience and the use of best practices, a research finding can become institutionalised and sustainable within the organisation (Fixsen et al., 2005).

2.4.3.1 Usable interventions

If a programme or practice cannot be clearly defined, then its implementation will be difficult or even impossible. Taking into account the essential criteria of a usable intervention can ensure fidelity when it is being implemented.

2.4.3.2 Implementation drivers

Specific activities can help in driving the success of programmes and practices, such as the way in which staff training on new skills is planned and routine assessment of the fidelity of the programme implementation. Trained staff need to implement a programme that is embedded in a supportive environment. Three types of implementation driver exist (Balas & Boren, 2000): competency drivers, organisation drivers, and leadership drivers (Figure 2.4.2). When used together, these drivers can ensure high fidelity and sustainable implementation of a programme.

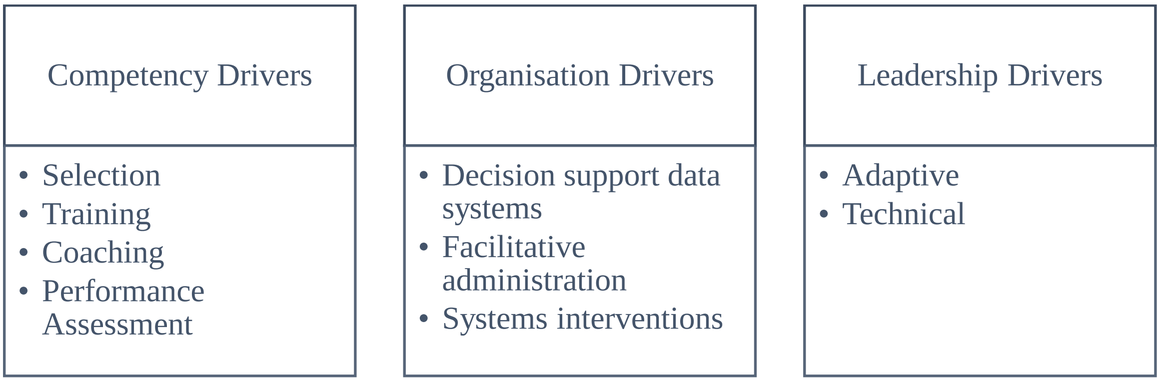


Figure 2.4.2: Implementation driver types and their features.

2.4.4 Factors that affect the translation of research into practice

2.4.4.1 Collaboration amongst key stakeholders

Many factors can limit the dissemination and implementation of exercise and cancer survivor research into real-world settings. Chubb (2012) described the factors that lead to success as having “a key part to play in improving our lives and in justifying taxpayer dollars [spent on research]”. Previous studies have focused mainly on discovery and there is often inadequate collaboration and communication between researchers and key stakeholders (Glasgow et al., 2012; Khoury, Gwinn, & Ioannidis, 2010). To date, the majority of studies on exercise in cancer survivorship have not included stakeholders such as oncologists, survivors, community organisations, nurses, administrators, and families (Wolin, Colditz, & Proctor, 2011). There is a need for coordination and collaboration among researchers, patients and their families, public health professionals, and policy makers if research evidence is to be translated into care.

Coordinated management of research collaborations that involve affiliations with significant stakeholders, decision makers, and targeted cohorts (Glasgow & Emmons, 2007; Wallerstein & Duran, 2010) is essential. Although the need for collaboration may seem obvious, there are many challenges that require collective cooperation among experts to address issues (Lam et al., 2013).

2.4.4.2 Failure to consider the community perspective

The majority of exercise and cancer studies to date are institutional or hospital-based and of limited duration. Failure to consider the community perspective in developing intervention strategies has been identified as a factor that can influence the translation of research into practice (Glasgow & Emmons, 2007). Community-based participatory research (CBPR) methods can help in enhancing the effectiveness of interventions (Israel, 2005; Minkler, Wallerstein, & Wilson, 2008). Such methods rely on collaborations between community partners who are actively involved in every aspect of the research process (Cornwall et al., 1995; Israel, Schulz, Parker, & Becker, 1998; Krieger et al., 2002; Laverack & Wallerstein, 2001). Achieving a shared understanding of the purpose of an intervention (Grazier, Trochim, Dilts, & Kirk, 2013) has also been identified as an important factor that can influence successful translation of research into practice. Ideally, community partners should have a shared interest in the research topic or health outcome, so that partners are engaged in data collection, intervention development, and evaluation

(Glasgow & Emmons, 2007). The principles of CBPR include the following (Israel et al., 1998):

1. Recognises community as a unit of identity;
2. Builds on strengths and resources within the community;
3. Facilitates collaborative partnerships in all phases of the research;
4. Integrates knowledge and action for the mutual benefit of all partners;
5. Fosters co-learning and empowering processes that address social inequalities;
6. Involves a cyclical and incremental process;
7. Addresses health from positive and ecological perspectives;
8. Disseminates findings and knowledge gained from all partners; and
9. Involves a long-term process and commitment to sustainability.

2.4.4.3 Target setting

In many cases, target settings that have the potential to adopt a PA programme for cancer survivors may not have the space, support, resources, staff hours, time to train staff, or expertise to implement the programme correctly (Basch, Sliepcevich, Gold, Duncan, & Kolbe, 1985). This can influence the translation of research into practice.

2.4.4.4 Research design

The research design has been identified as a factor that influences the dissemination and implementation of interventions. Attention to contextual factors can be either promoted or deflected by research design decisions (Shadish, Cook, & Campbell, 2002). Research design factors identified as having an influence on the translation of research into practice include the exclusion of individuals with comorbid chronic conditions; non-representative samples; homogeneous samples; failure to evaluate the cost, reach, or implementation; and inclusion of stakeholders (Glasgow & Emmons, 2007; Santa Mina et al., 2012).

2.4.4.5 Intervention characteristics

Many intervention characteristics that can influence the translation of research into real-world settings for cancer survivors have been identified. These include the high cost involved, the high level of expertise needed to deliver the intervention, programmes that are not adaptable to the needs of cancer survivors, and participants who are unwilling to travel to cancer centres (Alfano, Ganz, Rowland, & Hahn, 2012; Glasgow & Emmons, 2007; Irwin, 2009; Santa Mina et al., 2012).

2.4.4.6 Lack of reimbursement for exercise/PA programmes

Most rehabilitation services are either fully or partially covered through the majority of the insurance plans available. However, issues such as limited coverage schedules, caps on funding, and stringent rules for the continuation of therapy may mean that some cancer survivors do not receive their recommended therapy (Alfano, Ganz, et al., 2012). In addition, exercise/PA programmes for cancer survivors are not subsidised for medical cardholders. The lack of reimbursement available to cancer survivors, along with the complexity of benefit schedules, may contribute to the lack of use of cancer rehabilitation programmes (Alfano, Ganz, et al., 2012).

2.4.4.7 Health care factors

Even though there was initially some resistance to its incorporation into coronary care, exercise was finally included in the care of cardiac patients in the 1960s and is now regarded as essential in their post-treatment care (Balady et al., 2007; Certo, 1985; Thomas, Witt, Lopez-Jimenez, King, & Squires, 2005; Williams et al., 2006). Some 50 years later, a large body of evidence on exercise in relation to cancer has been accumulated. However, challenges to knowledge translation seem to persist in this field. Many reasons exist for the poor knowledge translation.

Some clinicians are under the impression that exercise might exacerbate patient symptoms such as fatigue and pain, and increase the risk of injury (Blanchard et al., 2004; Demark-Wahnefried, Peterson, McBride, Lipkus, & Clipp, 2000; Durak, Harris, & Ceriale, 2001). In a study by Jones & Courneya (2002), of the 42% of patients who had discussed exercise with their oncologist, only 14% were referred to a specialist for additional exercise counselling. Most oncologists do not have the knowledge, experience, expertise, or resources to devise individual exercise prescriptions for cancer survivors.

Other factors that might explain the poor translation are as follows:

1. Clinicians may believe that there is not enough evidence to support the benefits of exercise in cancer survivorship;
2. Space restrictions;

3. Clinical programmes may not have sufficient financial resources;
4. Lack of a referral pathway;
5. Lack of clinician experience, expertise, and knowledge in the area of exercise and cancer; and
6. Lack of discussion time with patients regarding the importance and relevance of exercise (Alibhai et al., 2017).

A study was carried out in Ireland to investigate current knowledge and practice regarding exercise and exercise prescription among physiotherapists and nurses working in oncology services. Participants in the study were members of the Irish Society of Chartered Physiotherapists in Oncology and Palliative Care and the Irish Association for Nurses in Oncology (O'Hanlon & Kennedy, 2014). The results revealed that only 16.4% of oncology nurses and 8% of physiotherapists had received undergraduate education on the use of exercise in cancer populations. Barriers to prescribing exercise to cancer patients included a lack of exercise guidelines for cancer patients, limited time, and staffing restrictions. Family and friends were also identified as problematic because of advice to avoid activity and to rest that they gave patients. However, 81% of oncology nurses and 95% of physiotherapists agreed or strongly agreed that there is a need to enhance exercise services. Suggested exercise services included supervised group programmes during and after treatment, community-based group exercise programmes, and group programmes for exercise counselling.

2.4.4.8 Focus on context and external validity

Results from effective community-based cancer-specific exercise interventions have been published (Cheifetz et al., 2014; Foley, Barnes, & Hasson, 2015; Kirkham et al., 2016; Knobf et al., 2014; Leach, Danyluk, Nishimura, & Culos-Reed, 2015; Noble et al., 2012; Rajotte et al., 2012). However, effective translation of this research into practice is lacking. Therefore, the extent to which community-based exercise programmes remain effective when moved from a clinical or controlled setting is less clear, and is one of the top ten research questions in the oncology exercise field (Courneya et al., 2015). Internal validity refers to the reliability of the experiment itself. It is the ability to create an association between a treatment (e.g. exercise) and the dependent variable (e.g. CrF). External validity is the extent to which results of an intervention (e.g. exercise programme for cancer survivors) can be generalised across populations, time, and settings. A better focus on context and external validity (Glasgow & Emmons, 2007; Schillinger, 2010) have been identified as factors that can influence translation of research to real-world settings. Reviews have concluded that external validity issues are less likely to be reported than internal validity factors (Glasgow et al., 2004; Oldenburg & Glanz, 2008).

A tool that is widely used in health promotion is the Reach, Efficacy/Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework (Glasgow, Vogt, & Boles, 1999). For the purposes of our study, RE-AIM represents a useful framework for considering issues of external validity. RE-AIM can assist the dissemination process by focusing on dimensions that facilitate translation from research to practice. The framework can not only help with process evaluation but can also be identify study design factors that can improve the impact of each phase of the translational process (T0–T4) in achieving translation of exercise to cancer survivorship. The framework can identify characteristics of interventions that can:

- Reach the target population that can benefit the most from the intervention;
- Be extensively adopted in various settings;
- Be consistently implemented by delivery agents and staff with moderate to high levels of training and expertise; and
- Produce sustainable effects with minimal negative impacts at a reasonable cost.

Each step of the framework is important: if each of the five dimensions is applied, the framework can be used to assess individual/group level outcomes (reach and effectiveness) as well as institutional level outcomes (adoption, implementation, and maintenance).

White, McAuley, Estabrooks, and Courneya (2009) adopted the RE-AIM framework to provide a quantitative approximation of the extent to which recent PA studies among breast cancer survivors had addressed issues related to internal and external validity. The investigators also recommended ways to improve the design and reporting of future programmes for better dissemination capacity. Features assessed to evaluate each RE-AIM component are outlined in Table 2.4.1.

Table 2.4.1: Features assessed for evaluation of each RE-AIM component (White, McAuley, Estabrooks, & Courneya, 2009)

Reach	**Efficacy/Effectiveness**	**Adoption**	**Implementation**	**Maintenance**
• Methods used to identify the target population • Identification of inclusion and exclusion criteria • Whether the sample size and participation rate (number participating/number eligible) were reported or could be calculated from the information provided • Whether the characteristics of both participants and non-participants were reported	• Measures and results for at least one follow-up period after the intervention • Use of intention-to-treat analyses • A quality-of-life outcome • Degree of participant attrition from the trial	• Description of the intervention location • Description of the staff who delivered the intervention • Method used to identify target delivery agents • Level of expertise of the delivery agent • Inclusion/exclusion criteria for settings • Adoption rate • Characteristics of adoption/nonadoption	• Intervention type and intensity level of the activity • Extent to which the protocol was delivered as intended • Measures of the cost of intervention implementation	• Assessment of individual behaviour at least 6 months after completion of the intervention • Current status of the programme • Measures of the cost of maintaining the intervention

Results from the study highlight that efficacy/effectiveness was the component of the RE-AIM framework most consistently reported across all studies (75%). Adoption was not as well reported, with only a mean of 17.1% reporting this component across all studies. Individual level implementation was reported in more than half of the studies. However, no studies reported information on the organisation/setting level of implementation, or the costs involved with implementing the programme. Maintenance was the component of the RE-AIM framework least often reported, with only 5.3% of trials including this information. As these studies were all carried out among breast cancer survivors, it is difficult to generalise the results to other cancer types. (White et al., 2009). For successful implementation of PA or exercise interventions designed for cancer survivors, process evaluation at the setting level is required (White et al., 2009).

2.4.5 Summary

From the literature reviewed in this section, it is clear that many factors influence the implementation and translation of exercise into cancer care in real-world settings. Although there are many centres of excellence in oncology in Ireland, few incorporate or adopt exercise programmes. As cancer survivorship continues to increase, it is essential that exercise be embedded in cancer care through the availability of cancer-specific exercise rehabilitation programmes. Understanding the factors that influence the implementation and translation of exercise interventions into cancer care is essential. Identification of key strategies through the use of frameworks such as RE-AIM and Active Implementation can aid in addressing the factors that limit the implementation of exercise in cancer survivorship, which in turn can accelerate the translation of research into practice to impact health at a population level. To the best of our knowledge, no study on an exercise programme specific to cancer survivors has been carried out in an Irish context outside of Dublin city, so further investigation is warranted. In addition, few studies to date have included key stakeholders. Therefore, obtaining information from these individuals is essential to provide a better understanding of the factors that can influence the implementation and translation of exercise interventions for cancer survivors.

CHAPTER 3.

Effects of a 10 week exercise intervention on cancer related fatigue, cognitive functioning and quality of life, sleep and physical fitness in survivors with fatigue compared to a health education intervention.

“If exercise could be packed into a pill, it would be the single most widely prescribed and beneficial medicine in the nation”.

Harvard Women’s Health Watch, Harvard Medical School

Chapter 3: Effects of a 10 week exercise intervention on cancer related fatigue, cognitive functioning and quality of life, sleep and physical fitness in survivors with fatigue compared to a health education intervention.

3:1 Introduction

3.1.1 Cancer incidence and survivorship

Cancer, one of the leading causes of mortality in the developed world, is a highly complex group of diseases that can attack any organ or system of the body and affects both men and women. The number of new cases of invasive cancers in Ireland is expected to increase by 84% for women and 107% for men by 2040 (National Cancer Registry Ireland (NCRI), 2015). Although an increase in diagnoses is predicted, an increase in survivorship is also expected. According to the Centers for Disease Control and Prevention (CDC, 2017) a cancer survivor is defined as anyone with a diagnosis of cancer from the time of their diagnosis for the remainder of their life. Of those diagnosed with an invasive cancer between 1994 and 2013, almost 124,000 individuals were still alive at the end of 2013 (NCRI, 2015). Advances in diagnostic tools allowing for faster detection and technological improvements in treatments have been recognised as the main reasons for the greater longevity seen in oncology patients (Schmitz et al., 2010; Siegel at al., 2012). Treatment for cancer may involve radiation, surgery, chemotherapy, immunotherapy, and hormones, which can not only destroy cancer cells but also sometimes damage healthy tissues and leave survivors with ongoing symptoms. With this increase in survivorship, there is a corresponding rise in rehabilitation and symptom management needs.

3.1.2 Cancer related fatigue

One of the most common and debilitating side effects of cancer and its treatment is CrF, often reported as being worse than pain, nausea, and vomiting (Ryan et al., 2007). This fatigue can have a severe impact on many aspects of health, including physical, emotional, social, cognitive and psychological functioning, and quality of life (QOL). CrF can persist for many years (Bower et al., 2000). Cancer survivors often report never returning to their pre-diagnosis energy level, which in turn diminishes their overall QOL (Gledhill, 2005). In a longitudinal investigation, more than one-fifth (21%) of breast cancer survivors reported having continuing problems with fatigue 5–10 years after their diagnosis (Bower et al., 2006). The evidence of fatigue in survivors across a range of cancers seems indisputable. Research undertaken by Murphy (2009) showed that fatigue is a very significant problem for women with breast cancer and persists into survivorship. Similar findings have been reported for a range of cancers, including breast (Kim et al., 2008), colorectal (Thong et al., 2013), and prostate cancer (Langston et al., 2013).

3.1.3 Exercise and CrF

One intervention that has attracted increasing attention owing to its putative positive impact on fatigue and its non-invasive nature is exercise. The effects of exercise on CrF have been assessed in a number of meta-analyses (McMillan & Newhouse, 2011; Meneses-Echávez, Ramírez-Vélez, & González-Jiménez, 2015; Tian, Lu, Lin, & Hu, 2016; Van Vulpen, Peeters, Velthuis, Van Der Wall, & May, 2016). They generally show a small to moderate effect size in favour of exercise over no exercise, with an effect size in terms of the standard mean difference (SMD) ranging from −0.22 to −0.51 (Meneses-Echávez et al., 2015; Tian et al., 2016). A Cochrane review by Cramp and Byron-Daniel (2012) evaluated the effect of supervised multimodal exercise on CrF both during and after cancer treatment. This concluded that exercise is a beneficial intervention for CrF. Thirty-eight studies involving 2656 patients were included in the review. Exercise was statistically more effective than the control condition for the management of CrF in studies conducted during and after treatment (SMD −0.27; 95% confidence interval (CI) −0.37 to −0.17). However, the greatest effect was observed among participants who were post-treatment cancer patients when the exercise intervention was undertaken (SMD −0.44, 95% CI −0.79 to −0.09).

While Cramp and Byron Daniel (2012) cite a number of studies demonstrating positive effects of exercise training, the literature cited has a number of shortcomings. Most of the studies did not screen for a specific fatigue score as an inclusion criterion and fatigue was not necessarily the primary outcome measure, with CrF sometimes only a secondary study endpoint. There is a need to develop an exercise intervention specifically targeting fatigue that is tested in a cohort for which all fatigue at baseline is documented. It is possible that the beneficial effect of exercise has been underestimated by only evaluating changes in heterogeneous cohorts.

The absence of an appropriate control condition is another limitation of the review by Cramp and Byron-Daniel (2012), with the majority of studies adopting a “usual care” or “waitlist” group, without reference to investigator attention or peer support. Such groups do not receive the exercise intervention but they also do not receive the peer support, positive health focus, and investigator attention that come with participation in a dedicated cancer survivor group. Given that effect sizes for the reduction in fatigue are only small to moderate, it is plausible that exercise may not be the dominant mediator. Studies need to include appropriate comparison groups to control for the chance of such effects (Knols et al., 2005).

Other important questions remain unanswered in the literature. A critical issue in intervention studies is follow-up for participants beyond the typical 10–12-wk intervention period to determine the medium-term effects on PA, fitness, fatigue, and other QOL indicators. The majority of studies to date failed to assess outcomes beyond the end of the intervention period. In those that did include follow-up, the duration varied. It is unclear if fatigue returns to pre-intervention levels when supervised exercise ceases. Appropriate follow-up of both fatigue and fitness and PA levels is needed when attempting to justify exercise-based rehabilitation for cancer survivors to providers of health services. Decision-makers need to know if reductions in fatigue are sustained in conjunction with changes in PA and fitness or even in the absence of ongoing changes in activity and fitness.

In addition, the mechanisms underpinning the effects of exercise on CrF are unclear. Inflammation is one mechanism that has been linked to the side effects of anti-cancer treatment. It is known that exercise reduces fatigue in survivors, yet few studies have simultaneously measured fatigue and inflammatory markers. One meta-analysis involving a small number of studies found no significant effect of exercise on IL-6, IL-8, IL-10 or CRP in cancer survivors (Dennett et al., 2016).

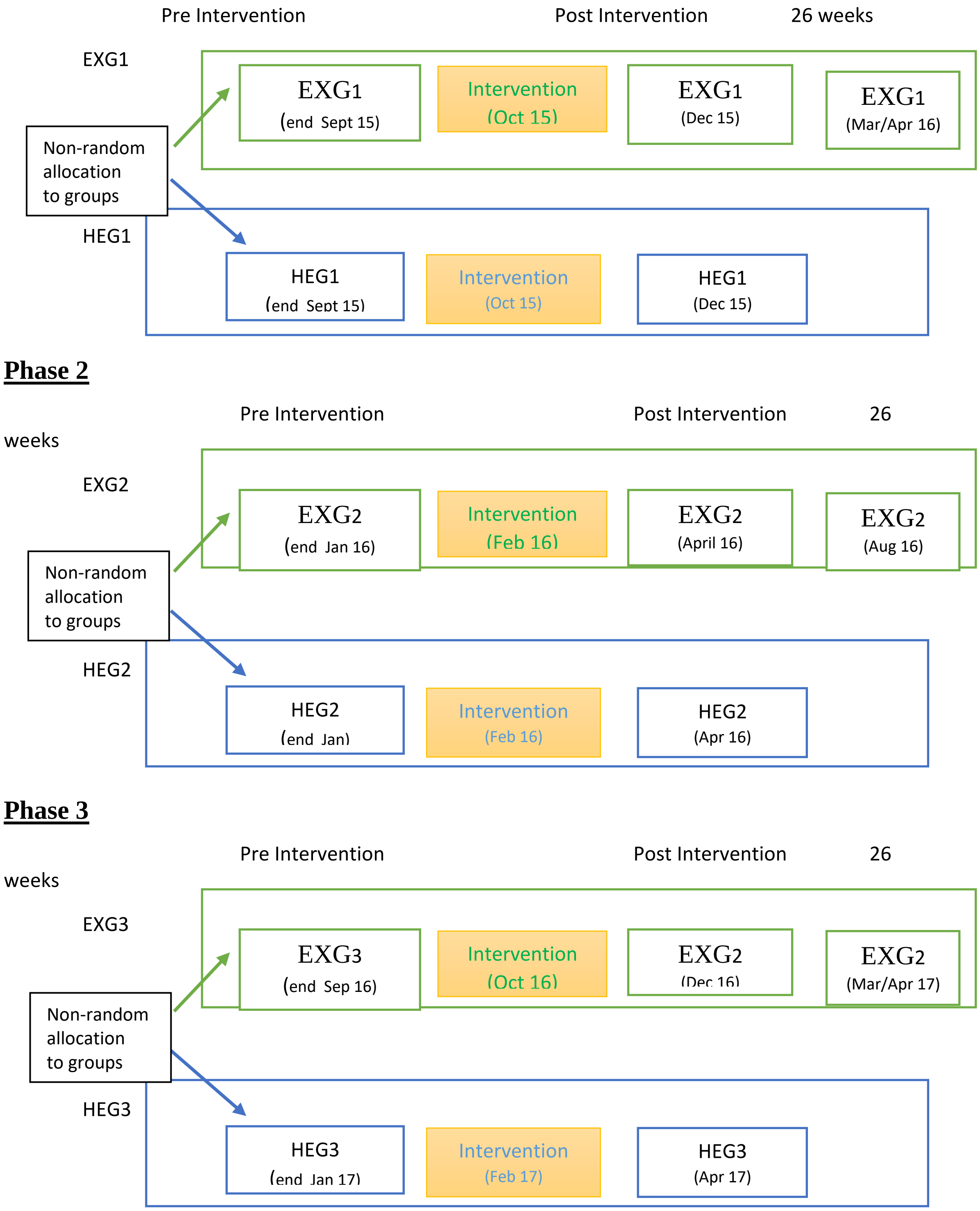
3.1.4 Study aims

The overall study aim was to determine the effect of a 10-week exercise intervention on CrF, other related psychological variables, physical fitness, and CRP in individuals with documented fatigue, and to determine the sustainability of any changes for an additional 16 weeks after the intervention. To elucidate the effects of exercise, a health education (HE) comparison group that received equal investigator attention and peer support was set up. The mechanisms underpinning CrF are unclear, so another aim was to determine the role of CRP and arterial stiffness as potential mediators of any intervention effect on CrF in cancer survivors suffering from fatigue after cancer treatment.

3.2 Methods

3.2.1 Study design

This study was a quasi-experimental trial to determine the efficacy of a 10-week progressive exercise intervention compared to a HE comparison treatment in reducing CrF in survivors with fatigue. There were three separate recruitment phases in the study, with classes for the exercise (EX) and HE participants taking place at two locations. Full randomisation was not possible as the numbers recruited to each of the three phases were small and these were split between two locations. All those presenting at a given location had to be allocated to either EX or HE to maintain a class structure. The allocation of volunteers to EX or HE was undertaken before baseline testing. At the end of the 10-week period, the EX group was followed up to 26 weeks and the HE participants could either leave the study or opt to attend the exercise classes. Thus, the efficacy of the intervention was determined in relation to a comparison group up to 10 weeks, but assessment of the maintenance of an exercise effect up to 26 weeks was determined in the absence of a comparison group (Figure 3.1).



EXG1 = Exercise group 1 phase 1
EXG2 = Exercise group 2 phase 2
EXG3 = Exercise group 3 phase 3

HEG1 = Health education group 1 phase 1
HEG2 = Health education group 2 phase 2
HEG3 = Health education group 3 phase 3

Figure 3.1: Quasi-experimental study design

3.2.2 Participants

This quasi-experimental study allocated 37 post-treatment cancer survivors (33 females, 30 breast cancer, aged 55 ± 2 years, body mass index (BMI) 28.5 ± 1.3 kg/m^2, time since treatment 2.3 ± 0.3 y; mean ± standard error of the mean) to an exercise group (EXG, n = 19) or HE comparison group (n = 18). Patients with all cancer types were eligible for participation in the study, and 152 individuals were assessed for eligibility. The inclusion criteria were age >18 years, a diagnosis of cancer, and at least 6 weeks but not more than 10 years since completion of surgery, radiotherapy, and chemotherapy (to allow for stabilisation of fatigue following treatment) except for ongoing hormonal therapy. In addition, participants were only included in the study if they were experiencing ongoing fatigue (FACT-F fatigue score <45). Participants were excluded from the study if they were unable to travel for testing and for the EX/HE sessions, if their general practitioner could not provide medical clearance for moderate-intensity exercise, if they had orthopaedic problems that limited their ability to participate in a moderate-intensity exercise programme, or if they were already undertaking >90 min/week of moderate-vigorous intensity exercise. There were no dropouts in the intervention stage, with only two participants lost to follow up at 26 weeks from the EX group.

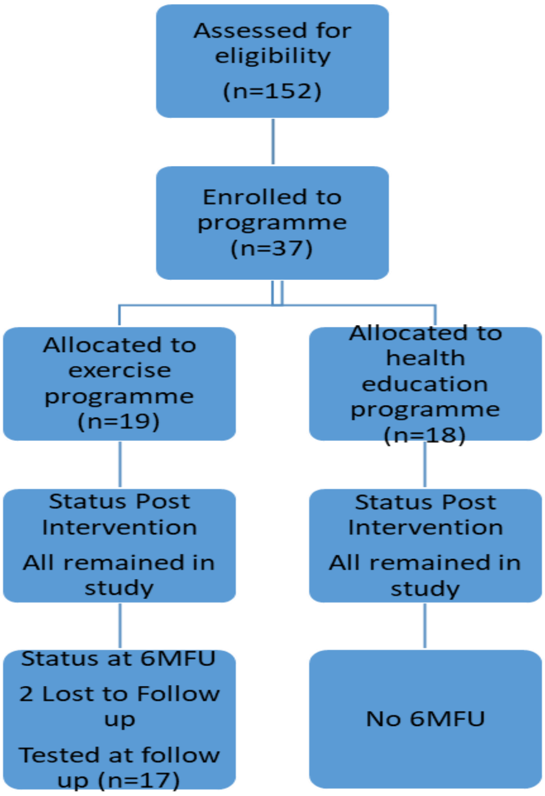


Figure 3.2: Sample selection, allocation and follow-up

3.2.3 Recruitment and ethics

3.2.3.1 Recruitment

Study recruitment began in June 2015 and concluded in January 2017. Participants were recruited from oncology review clinics at University Hospital Waterford (UHW) and via social media, social contacts, and radio and newspaper information pieces. Interventions and testing ended in April 2017. Potential eligible participants who met the inclusion criteria for the study were provided with a general information leaflet about the study (Appendix 4). The researcher was available to answer any questions from potential participants. Those interested in participating were assessed for fatigue using the FACT-F questionnaire (Appendix 10) and for leisure-time PA using the International Physical Activity Questionnaire (IPAQ) to confirm they met the study inclusion criteria. Following verbal consent, the researcher contacted those interested via telephone and arranged for them to attend the Sport & Exercise Department at WIT, where further information about the study was given and written consent was obtained (Appendix 5 &6). Participants were also provided with a medical clearance form (Appendix 24) to be completed by their general practitioner to confirm their suitability for participation in the exercise intervention.

3.2.3.2 Ethics and data protection

This study was approved by the WIT Research Ethics Committee and the Research Ethics Committee of the Health Services Executive, South East. The trial was registered with BioMed Central (ISRCTN 58635908). All participants were allocated a unique identifying code for the purpose of confidentiality. Questionnaires were stored in a locked cabinet in the Postgraduate Room in WIT. No data that could have identified the participant were held on computer files. Notwithstanding this, computers and computer files with study data were password-protected. Blood samples were collected from consenting patients using coded bottles and were stored in coded vials after processing.

3.2.3.3 Minimising risk

Exercise carries a low risk of adverse events for cancer survivors, some related to and some independent of the cancer and/or its treatment. A second trained individual was always in close proximity to the researcher for the 6-min walk test (6MWT) and a defibrillator was available. While overseeing exercise sessions, the researcher always carried a mobile phone if a landline was not available. Initial clearance for participation in the study and relevant medical background information for each patient were obtained from the relevant general practitioner. Participants were made aware of exercise risks in the informed consent process and were instructed to inform the research team or exercise leader of side effects or symptoms of concern. As all participants in the study had a cancer diagnosis and were experiencing fatigue, the researcher was sensitive at all times to emotional distress experienced, particularly during health-related discussions.

3.2.4 Interventions

3.2.4.1 Exercise intervention outline

3.2.4.1.1 Class location

Exercise classes took place at WIT and St. Joseph’s Primary School, Dungarvan, and were delivered by the lead investigator (P.S.). On wet days, circuits were performed indoors and included exercises such as sit to stand, aerobic exercises to music, and shuttle walks. These are all exercises that can be completed at home to ensure that exercise was continued on days other than intervention days even in the event of bad weather, which can be a barrier to exercise. Participants trained twice a week as a group in scheduled classes for the first 5 weeks, which was then reduced to once per week for the remaining 5 weeks to enhance the sustainability element of the intervention.

3.2.4.1.2 Class aim

The main aim of the supervised exercise intervention was to develop and enhance aerobic capacity and flexibility. A secondary aim was to motivate and educate subjects and offer them peer support. Social support was also implemented with a buddy system. An overview of the exercise programme is shown in Figure 3.3 and Appendix 28.

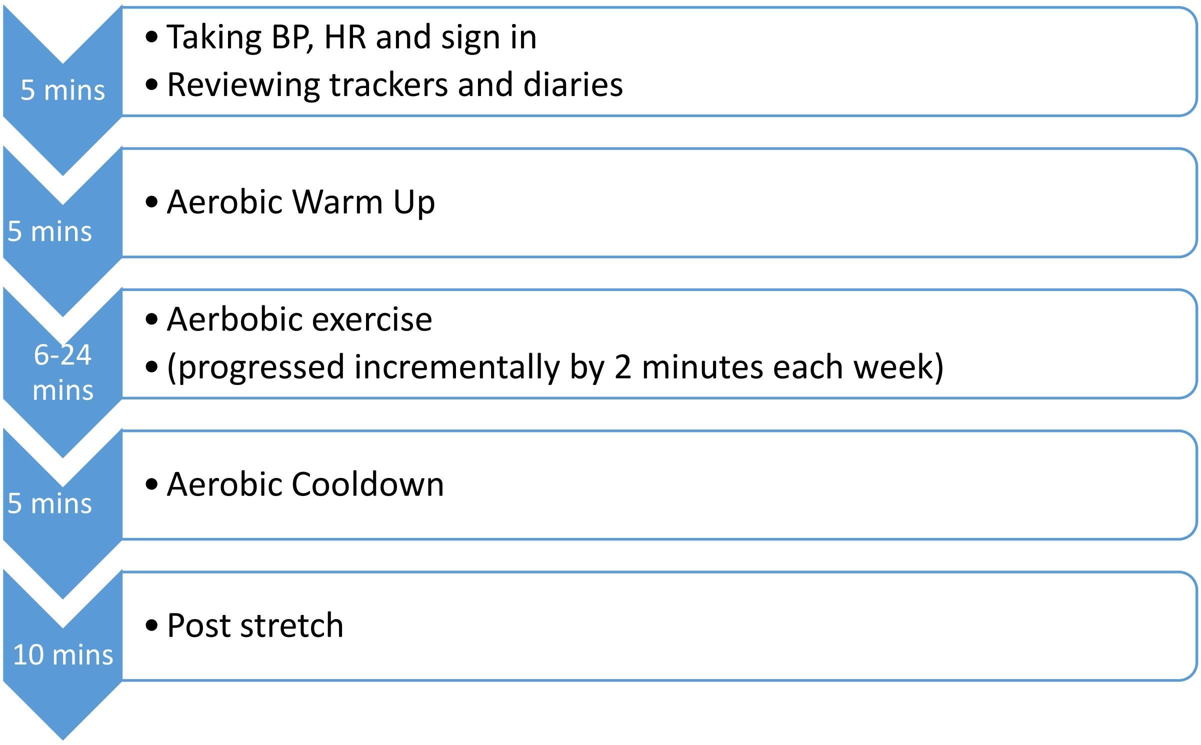


Figure 3.3: Sample exercise session

3.2.4.1.3 Initial exercise session

The first class was used mainly as an educational and information session. Participants were taught basic exercise principles and techniques such as warming up and cooling down, how to exercise at a moderate intensity, and how to monitor heart rate (HR) before, during, and after exercise. Participants were taught how to distinguish exercise intensities and use diaries to record PA, step counts, fatigue, and water intake. Diaries were provided at the first session and reviewed in subsequent classes. Education and self-monitoring were an important focus of the classes. The subjective intensity of effort was assessed using the Borg Rating of Perceived Exertion (RPE) scale. This is a visual analogue scale that ranges from 6 “very light” to 20 “very hard” (Borg, 1970). Participants were encouraged to increase their exercise duration gradually, and to decrease their intensity and duration on occasion when the diary evidence suggested excessive exercise-induced fatigue. A step counter and copy of the Borg RPE scale were also provided to each participant in the initial class.

3.2.4.1.4 Class structure

Participants signed in and measured their blood pressure and HR at the beginning of every exercise class. In accordance with the American College of Sports Medicine (ACSM) recommendations, the aerobic element of the exercise intervention was increased by 2 min per week until it reached 24 min in duration by week 10 (Kenney, 1995). Classes were tailored to fatigued individuals by emphasising brisk walking (RPE score 11–13; 65–85% HR max), stretching, exercise education, and self-efficacy enhancement. HR was continuously measured using a HR monitor. The primary investigator, who is also a qualified fitness specialist, supervised classes.

3.2.4.1.5 Behaviour change philosophy and strategies

It has been suggested that the use of behaviour theory can improve the effectiveness of behaviour change interventions (Glanz & Bishop, 2010). Each intervention in the study was grounded in theory. Social cognitive theory (Bandura, 1986) techniques, in terms of self-efficacy were used in both intervention groups of our study (Table 3.1).

Table 3.1: Social cognitive theory techniques incorporated to enhance self-efficacy in the exercise and health education groups

	Exercise group	**Health education group**
Self-efficacy	Feedback, monitoring progress, seeing the progress of others, setting goals, reinforcements	Feedback, monitoring progress, seeing the progress of others, setting goals, reinforcements
Motivation	Pedometers, step trackers, sign in sheet, setting goals, pros and cons of physical activity, physical activity contract, identifying social supports, barriers, and strategies to overcome barriers, cognitive behavioural therapy	Sign in sheet, goal setting, pros and cons of healthy eating, challenging negative thoughts, balancing activity and rest, sleep management, identifying social supports, barriers, and strategies to overcome barriers, cognitive behavioural therapy
Adherence	Weekly calls and texts, pedometers, trackers	Weekly calls and texts, trackers
Health competence	Promoting mastery through skill learning; heart rate, blood pressure, RPE scale	Promoting mastery through skill learning; meal planning, goal setting, cognitive behavioural therapy techniques, sleep management skills
Self-management	Tracker diaries, exercising at home tips, taking own blood pressure, cognitive behavioural therapy	Tracker diaries, meal planning, cognitive behavioural therapy, sleep management
Fear of PA	Skill learning, tracking progress, cognitive behavioural therapy	Not applicable
Social support	Peer support, buddy system, time, venue	Peer support, buddy system, time, venue

Social cognitive theory can be used to predict (Bandura, 1986; Graves & Carter, 2005) and positively increase PA (DeBusk et al., 1994). Self-efficacy is a key determinant of health behaviour change and is considered the key construct in social cognitive theory (Bandura, 1986). Self-efficacy was developed in the study using methods such as mastery, social persuasion, reinforcements, and tracking of progress, all of which are in line with social cognitive theory.

Each participant received weekly calls and texts to monitor any health-related problems and resolve any barriers to PA, and to provide reinforcements such as positive feedback and praise. A variety of techniques for promoting change in exercise behaviour were explored with participants during the sessions, such as overcoming barriers, setting goals, identifying key social supports, highlighting the pros and cons of exercise, using a PA contract, and providing positive reinforcements. Participants also received tip sheets and worksheets over the 10-week programme.

3.2.4.2 Health education intervention outline

HE sessions were supervised and took place at WIT, St. Joseph's Primary School, Dungarvan, and the Solas cancer support centre in Waterford. Attendance was recorded for all sessions. Sessions were of 1 hour in duration and were held once a week over a period of 10 weeks. Sessions looked at strategies other than exercise to help alleviate fatigue. The HE intervention consisted of four units: Unit 1, cancer-related fatigue; Unit 2, diet, nutrition, and cancer survivorship; Unit 3, cognitive behaviour therapy; and Unit 4, sleep hygiene and management. The HE intervention also used elements of social cognitive theory (Table 3.1). A buddy system was also offered to the HE group as a means of social support. A complete outline of the intervention can be found in Appendix 9.

3.2.4.3 Completion of the 10-week intervention

On completion of the 10-week intervention, the HE participants left the HE element of the study but were offered the option of taking the exercise programme.

3.2.5 Outcome measures and data collection

The main investigator could not be blinded to the intervention as she had to schedule and carry out the interventions. Testing was carried out before and after the intervention in both groups, with only the EX group tested at 26 weeks. Additional assessments of fatigue (FACT-F) were carried out at 4 and 8 weeks in both groups.

Table 3.2: Measurable factors, time of testing and data collection methods

Factor	**Time point**	**Data collection method**
Fatigue	Pre, week 4, week 8, post and 26 weeks (FACT-F) Pre /post/26 weeks (EORTC)	FACT-F scale, a 13-item cancer-specific multidimensional fatigue scale (Yellen et al., 1997)**(Section B Appendix 1)** EORTC Quality of Life Questionnaire-C30; fatigue subscale (Aaronson et al., 1993)**(Section C Q25 & 26, Appendix 1)**
Global quality of life	Pre/Post/ 26 weeks	EORTC Quality of Life Questionnaire-C30; global QOL subscale (Aaronson et al., 1993)**(Section C Q42 & 43, Appendix 1)**
Cognitive function	Pre/Post/ 26 weeks	EORTC Quality of Life Questionnaire-C30; cognitive function subscale (Aaronson et al., 1993)**(Section C Q33 & 38, Appendix 1)**
Sleep disturbance	Pre/Post/26 weeks	Insomnia Severity Index (ISI) (Morin, 1993)**(Section D, Appendix 1)**
Fear of PA/exercise	Pre/Post/26 weeks	Fear of Physical Activity Exercise Scale-Breast Cancer (FPAX-B) – 23 item scale survey (Sander et al., 2011)**(Section E, Appendix 1)**
Perceived health competence	Pre/Post/26 weeks	Perceived Health Competence (PHCS) (Smith et al., 1995)**(Section F, Appendix 1)**
Vascular function	Pre/Post/26 weeks	Arterial stiffness via cfPWV
Inflammation biomarkers	Pre/Post/ 26 weeks	Blood samples; CRP
Leisure-time physical activity & inactivity	Pre/Post/ 26 weeks	International Physical Activity Questionnaire (IPAQ)
Aerobic fitness	Pre/Post/26 weeks	6-min walk test (6MWT)
Flexibility	Pre/Post/26 weeks	Sit-and-reach test
Leg strength/endurance	Pre/Post/26 weeks	30-s sit-to-stand
EORTC = European Organisation for Research and Treatment of Cancer		

3.2.5.1 Primary outcome: fatigue (FACT-F)

The FACT-F questionnaire (Yellen et al., 1997), specifically developed for cancer populations, was used to measure the primary outcome of fatigue. This is a 13-item self-report subscale of the FACIT-F 41-item tool for evaluating fatigue including the physical and functional consequences (Yellen, Cella, Webster, Blendowski, & Kaplan, 1997). For the purpose of this study, the scoring method used was that of Downie, Mar Fan, Houédé-Tchen, Yi, & Tannock (2006). Scores range from a possible 0 (representing maximum fatigue) to 52 (representing minimal fatigue). Total fatigue scores were classified as follows: >45 = normal; 33–45 = mild; 20–32 = moderate; and <20 = severe fatigue (Downie et al., 2006). Participants were only included in the study if they had a score of <45 at baseline. Fatigue was measured at baseline, at 4 weeks, 8 weeks and after the intervention in both groups, and at 26 weeks in the EX group. FACT-F was originally developed to assess fatigue experienced during the previous week, so that was the timescale used in this study.

Table 3.3: Fatigue scoring using FACT-F (Downie et al., 2006)

FACT-F score	Fatigue indication
>45	**Normal**
33–45	**Mild**
20–32	**Moderate**
<20	**Severe**

An improvement in fatigue is reflected by an increase in FACT-F score.

3.2.5.2 Secondary outcomes: QOL

QOL was assessed using the EORTC QLQ-C30 version 3.0, a 30-item tool comprising five functional (physical, role, emotional, social, and cognitive) and three symptom (fatigue, pain, and nausea and vomiting) scales (Aaronson et al., 1993). There are also six single items that assess further symptoms often mentioned by cancer patients. The questionnaire has been validated and tested cross-culturally over a variety of cancer populations (Sprangers et al., 1996). The present study considered dimensions of fatigue (symptom scale), global QOL, and cognitive, physical, role, and social functions (functional scales). Each element of the EORTC QLQ-C30 can be scored between 0 and 100. Scores were calculated using the scoring manual provided by the EORTC.31. Higher scores for global QOL, cognitive functioning, physical function, role function, and social function represent good QOL, whereas higher scores for symptom scales such as fatigue represent a high level of symptoms present (Aaranson et al., 1993). A change of 5–10 points represents a small change, 10–20 points a moderate change, and >20 points a large change in health-related QOL (Osoba, Rodrigues, Myles, Zee, & Pater, 1998).

3.2.5.3 Secondary outcomes: fear of PA and exercise in breast cancer survivors

Fear of PA was assessed using the Fear of Physical Activity and Exercise-Breast Cancer (FAPX-B) questionnaire (Sander et al., 2011) among breast cancer survivors only. This is a 23-item scale measuring pain and other factors specific to breast cancer that can influence an individual's decision on whether to exercise or not. The scale was scored by totalling the individual item scores; a higher score signifies a greater fear of PA. The minimum possible score is 0 and the maximum is 92.

3.2.5.4 Secondary outcomes: insomnia severity

The Insomnia Severity Index (ISI) was used to assess sleep difficulties among the participants. The ISI is a seven-item scale that assesses the nature, severity, and impact of insomnia (Bastien, Vallières, & Morin, 2001; Morin, 1993) using a five-point Likert scale. Items are scored from 0 to 4 and totalled, giving a range between 0 and 28. Scores of 0–7 = absence of insomnia, 8–14 = subthreshold insomnia, 15–21 = moderate insomnia, and 22–28 severe insomnia. An ISI score of between 15 and 28 is classified as clinically significant insomnia. Smith & Trinder (2001) suggested that a cutoff score of 14 distinguished individuals with insomnia from normal controls. A reduction of 6 points is representative of a clinical meaningful difference in individuals with primary insomnia (Yang, Morin, Schaefer, & Wallenstein, 2009).

3.2.5.5 Secondary outcomes: perceived health competence

Perceived health competence was measured using the eight-item Perceived Health Competence Scale (PHCS) questionnaire, a tool often used to predict health outcomes and behaviours. A higher PHCS score (possible range from 8 to 40) suggests greater health competence and higher self-efficacy belief in performing behaviours to achieve desired health outcomes (Smith, Wallston & Smith, 1995). Studies in cancer have posited that patients with higher self-efficacy and competence are more likely to succeed in self-management activities and observe more positive health outcomes (Beckham, Burker, Burker, Feldman, & Costakis, 1997; Cunningham, Lockwood, & Cunningham, 1991; Lin, 1998). The PHCS is a domain-specific measure of self-efficacy that measures perceptions of self-efficacy that are specific to health-related circumstances; however, it is not restricted to any single behaviour.

3.2.5.6 Demographics

Demographic data and characteristics were obtained via a questionnaire completed by the study participants. Data on health status, including information on cancer stage, type of treatment, time since diagnosis, treatment dates, contraindications for exercise, and physical and psychological health history, were obtained via medical clearance forms completed by the participants' general practitioners.

3.2.5.7 Height, weight, BMI, and blood pressure

Height, weight, BMI, and blood pressure were measured at baseline, after the intervention in both groups, and at 26 weeks in the EX group.

A stadiometer was used to measure height (m). Participants removed shoes and stood up straight, with head in a neutral position looking straight ahead with heels and shoulders against the backboard. With shoes removed, weight (kg) was assessed using a digital scale. BMI was then calculated using the two measures according to: weight (kg)/[height (m)]^2.

Blood pressure was measured when the subject was seated with legs uncrossed after a resting period of 5 min. An Omron upper-arm digital blood pressure monitor was used for measurements. The cuff was placed approximately 2.5 cm above the elbow crease and the start button was pressed.

3.2.5.8 Physical fitness and PA measures

3.2.5.8.1 PA and inactivity

PA and inactivity were measured using IPAQ, which is the most widely used PA questionnaire (Chinapaw, Mokkink, van Poppel, van Mechelen, & Terwee, 2010) and is available in two versions, the 31-item long form (IPAQ-LF) and the nine-item short form (IPAQ-SF). The short form was used in this study; it considers four different intensity levels in terms of metabolic equivalent of task (MET): vigorous (≥3000 MET-min/week), moderate (≥600 MET-min/week); walking (<600 MET-min/week); and sitting. Authors recommend the short version to reduce the burden on participants (Craig et al., 2003). There are two alternative reference periods for recalled PA: the last 7 days or a usual week. The last 7 days was used in this study.

In addition to recording PA activity and inactivity via the IPAQ, all participants were asked to wear a pedometer, which was used as a motivational and tracking tool as part of review sessions. Participants were instructed to wear the device from when they woke up until they went to bed at night. They were asked to record the number of steps they took in their step diary once they went to bed. The pedometer was then reset for the next day.

Owing to lack of completeness of the data and the fact it was not our primary outcome, the pedometers were not used to determine the intervention effect on PA, but rather as a motivational and tracking tool. However, some data were used from those who returned their tracking sheets. We were able to obtain data regarding total steps on exercise class days and other days. Class day steps were totalled and averaged, as were steps per day on non-class days.

3.2.5.8.2 6MWT

The 6MWT was performed as a measure of aerobic fitness. The distance in meters an individual can cover in 6 min is measured. The test is performed on a flat surface with a marked out predetermined distance. The American Thoracic Society (ATS) guidelines (Crapo et al., 2002) were followed, although the layout of the walkway was adjusted, but not the total walkway length (30 m). In this study the layout was 10 m + 5 m + 10 m + 5 m (marked every 2.5 m) owing to the lack of a suitable indoor space of 30 m in length. Many modifications of the 6MWT protocol walkway length have been utilised. A recent systematic review and meta-analysis of the protocol variations and 6MWT performance among stroke survivors noted that only 27 of the 127 studies reported using an indoor 30-m walkway in accordance with the ATS guidelines (Dunn et al., 2014). The same layout was used on all occasions and testing was carried out on an individual basis.

Participants were instructed to walk as far as they could during the 6 min at a self-determined walking speed, stopping to rest if needed. Participants were allowed to stop the test at any time if they felt pain, dizziness, or shortness of breath. The total walking distance covered during the 6 min was measured and recorded. 6MWT results range from 400 to 700m among healthy individuals, and improvements of ≥70 m are considered to be of clinical importance to patients (Enright, 2003). The 6MWT procedure is provided in Appendix 2.

3.2.5.8.3 Standard sit-and-reach test

The standard sit-and-reach test was used as a measure of flexibility. The test requires a sit-and-reach box consisting of a distance scale with centimetre gradations on top of a box approximately 40 cm high with an overhang of 26 cm. The procedure for the test is given in Appendix 2.

3.2.5.8.4 The 30-s sit-to-stand chair test

The 30-s sit-to-stand test is used as a predictor of leg strength and endurance. A chair with a straight back without arm rests and a stopwatch are needed to carry out the test. The test procedure is described in Appendix 2.

3.2.5.8.5 Pulse Wave Velocity (PWV)

Pulse wave velocity (PWV) is deemed the gold standard measurement of arterial stiffness (Laurent et al., 2009). Carotid–femoral PWV (cfPWV), a surrogate for aortic stiffness, was determined using a commercially available instrument (Complior, Alam Medical, France) that detects pressure waves at the carotid and femoral arteries. The pulse transit time between the carotid and femoral arteries is then calculated. Taking into account the vertical distance between these points (measured with a tape measure), PWV is calculated in m/s. Higher values denote faster transit times due to stiffer arteries, and this is a cardiovascular risk factor. The PWV protocol is provided in Appendix 3.

3.2.5.9 Inflammatory marker assays

3.2.5.9.1 Collection and storage of blood samples

Bloods were drawn by personnel trained in venepuncture. Participants were not fasting. Each blood vial had a unique identifier code assigned to each individual participant. Whole bloods were gathered in Vacutainer Plus 4.5-ml tubes (K3 EDTA 15%). Samples were centrifuged at 20°C for 15 min at 3053 rpm (1500 × *g*). Plasma from the samples (0.5 mL) was pipetted into Eppendorf tubes and stored at −80°C until further analysis.

3.2.5.9.2 Blood analysis

Complete blood counts were determined using EDTA samples. The Beckman and Coulter AcT Diff 2 Haematology Analyser (AcT Diff2, Beckman Coulter, USA) was used for whole blood analysis of haematological factors and to rule out any infection and anaemia among participants. The haematology analyser provided results for total leukocyte count (10^3/µL), lymphocytes (10^3/µL), monocytes (10^3/µL), granulocytes (10^3/µL), erythrocytes (10^6/µL), platelets (10^3/µL), haemoglobin (g/dL), and haematocrit (L/L). CRP was determined using an immunoturbidimetric assay on an automated Roche/Hitachi Cobas C system. Results are presented in mg/L**.**

3.2.6 Data analysis and statistics

3.2.6.1 Sample size

The minimal clinically important difference (CID) on the FACT-F scale is 3 points (Cella, Eton, Lai, Peterman, & Merkel, 2002). Standard deviation of ~10 points has been reported previously (Cella et al., 2002). On the basis of these assumptions, the study would require 45 participants per group to have 80% power for detecting a 6-point difference (2 × CID) between the groups post-intervention, with significance set at $p < 0.05$ and equal numbers in the EX and HE groups. It was considered unlikely from the outset that this group size would be reached. However, it was considered likely that efficacy would be achieved for a lower number of participants as the group was more homogeneous than those in previous studies, and all the participants had documented fatigue. In this sense, the study should be regarded as a pilot study.

3.2.6.2 Data analysis

All data were analysed using SPSS (version 22.0). Questionnaire data were scored and entered systematically into the SPSS database along with physical fitness scores, PWV, haematological values, and CRP results.

A normal distribution for each continuous variable was verified using the Shapiro-Wilk test (Pallant, 2007). For continuous variables with a normally distribution, the results are presented as the mean and standard error (SE). Categorical data are presented in terms of frequency and percentage.

The efficacy of the 10-week exercise intervention was determined with reference to the interaction term in a mixed model (group × time point) analysis of variance. The significance of time point differences was also determined separately for the EX and HE groups. Differences in the HEG were determined at two time points (pre- and post-intervention) using paired t-tests. The significance of changes in the EXG was determined at three time points (pre- and post-intervention and 26 weeks) using one-way repeated-measures analysis of variance, followed by a post hoc least significant difference test when the main effect for a time point was significant. Possible differences between groups at baseline were tested using independent t-tests. Differences in numbers of steps between exercise class and non-class days were compared using a paired t-test. Pearson correlations were used, where appropriate, to examine relationships between continuous variables. Significance was set at $p < 0.05$.

3.3 Results

3.3.1 Participant demographics

There were no significant differences between the groups with respect to age, height, weight, and BMI. A χ^2 test did not reveal any differences between the groups in marital status, access to a medical card, education level, or menopausal status. At baseline, the mean age of participants was 53.9 ± 2.3 years in the EXG and 56.3 ± 2.0 years in the HEG. The majority of participants in both groups were female. Most of the participants were either married or cohabiting, had access to a full medical card (EXG 58% vs HEG 89%), and had completed second level education (EXG 68% vs HEG 56%). Menopausal status varied among the participants.

Table 3.4: Participant characteristics in the exercise (EX) and health education (HE) groups. Results are presented as the mean (standard error)

Variable	**EX (n = 19))**	**HE (n = 18)**
Age (years)	53.9 (2.3)	56.3 (2.0)
Height (m)	1.6 (0.2)	1.6 (0.2)
Weight (kg)	78.7 (3.7)	74.5 (3.1)
Body mass index (kg/m^2)	29.4 (1.3)	27.7 (1.2)
Gender n (%)		
Female	17 (89.5)	16 (88.9)
Male	2 (10.5)	2 (11.1)
Marital status, n (%)		
Married/living together	13 (68.4)	10 (55.6)
Single	2 (10.5)	1 (5.6)
Widowed	0 (0)	2 (11.1)
Separated	2 (10.5)	2 (11.1)
Divorced	2 (10.5)	3 (16.7)
Access to a medical card n (%)		
Full medical card	11 (57.9)	16 (88.9)
GP card only	1 (5.3)	0 (0)
No	7 (36.8)	2 (11.1)
Educational status, n (%)		
Primary	2 (10.5)	6 (33.3)
Secondary	13 (68.4)	10 (55.6)
Third level	4 (21.1)	2 (11.1)
Menopausal status, n (%)		
Peri-menopausal	4 (21.1)	2 (11)
Menopausal	3 (15.8)	5 (27.8)
Post-menopausal	10 (52.6)	8 (21.6)

3.3.2 Clinical characteristics

There was a significant difference in time since treatment between the groups at baseline (p = 0.040). Time since treatment is not significantly associated with CrF (Prue, Rankin, Allen, Gracey, & Cramp, 2006; Servaes, Verhagen, & Bleijenberg, 2002). No significant differences in any other variables at baseline were observed between the groups (p > 0.05). Breast cancer (n = 30) was the cancer most frequently reported among participants, and treatments varied. The mean time since treatment was 2.9 years in the EXG versus 1.6 years in the HEG. Almost two-thirds (63.2%) of the EXG and half (50%) of the HEG were taking some form of anti-inflammatory medication. Ongoing hormonal therapy as part of their cancer treatment was being taken by 80% of the breast cancer cohort in the EXG and 66.7% in the HEG, with tamoxifen being the most common in both groups. Among the breast cancer cohort, of those reporting severe fatigue at baseline (n = 17), 76.4% were taking medication related to their cancer.

Table 3.5: Clinical characteristics in the exercise (EX) and health education (HE) groups

Variable	EXG (n = 19)	HEG (n = 18)
Type of cancer, n (%)		
Breast	15 (78.9)	15 (83.3)
Prostate	2 (10.5)	0 (0)
Lung	0 (0)	1 (5.6)
Endometrial	1(5.3)	0 (0)
Oesophageal	1 (5.3)	0 (0)
Multiple myeloma	0 (0)	1 (5.6)
Cervical	0 (0)	1 (5.6)
Type of treatment >6 weeks before enrolment, n (%)		
Surgery	17 (85.9)	17 (94.4)
Radiation	15 (78.9)	16 (88.9)
Chemotherapy	17 (85.9)	12 (66.7)
Mean time after treatment, years (standard error)	2.9 ±0.5	1.6 ±0.4
Medications, n (%)		
Anti-inflammatory	12 (63.2)	9 (50.0)
Medication related to cancer treatment	12 (63.2)	10 (55.6)
Tamoxifen (breast cancer only)	11 (73.3)	5 (33.3)
Arimidex (breast cancer only)	1 (6.7)	4 (26.7)
Exemestane (breast cancer only)	0 (0)	1 (6.7)

3.3.3 Characteristics of outcome measures

Other than the sit-and-reach test (p = 0.021), there were no significant differences between the EX and HE groups at baseline (p > 0.05) for the outcome measures assessed in the study (Table 3.6). Two fatigue measures were used to take into account the social impact of fatigue, which is not included in the EORTC QLQ-C30 measurement tool. Almost 55% of the group had a FACT-F score <20 at baseline, indicative of severe fatigue; 30% had moderate fatigue, while the remainder had mild fatigue. Just over 40% of the group had moderate insomnia, 24.3% had severe insomnia, 18.9% had mild insomnia, and the remaining 16.2% reported no insomnia. The majority of the participants were not undertaking any form of moderate to vigorous PA. EX participants were sitting for approximately 6 h/day and HE individuals for an average of 6.5 h/day.

Table 3.6: Baseline physiological function, psychological function, physical activity, and sedentary time in the exercise (EX) and health education (HE) groups.

Variable	EX (n = 19)	HE (n = 18))
Fatigue (FACT-F)	19.3 (2.0)	21.9 (2.4)
Fatigue (EORTC)	53.1 (5.6)	52.5 (4.6)
Cognitive functioning (EORTC)	41.2 (7.4)	51.9 (8.2)
Global quality of life (EORTC)	50.0 (3.7)	48.1 (5.5)
Physical function (EORTC)	63.0 (5.7)	67.8 (5.9)
Role function (EORTC)	53.7 (6.7)	54.9 (6.8)
Social function (EORTC)	34.2 (7.7)	52.0 (8.1)
Insomnia severity	15.2 (1.7)	15.5 (1.7)
Perceived health competency score	24.8 (1.3)	23.7 (1.3)
Fear of physical activity (breast cancer only)	28.9 (7.0)	28.3 (5.7)
6MWT (m)	438.3 (15.4)	462.0 (19.3)
Sit and reach (cm)	27.1 (2.0)	20.9 (2.2)*
Sit to stand (repetitions in 30 s)	13.4 (0.7)	11.6 (0.9)
Moderate–vigorous activity (min/week)	3.7 (3.2)	3.3 (3.3)
Sedentary time (min/day)	357.5 (35.5)	390.0 (38.0)

*Results are reported as mean (standard error). * p<0.05 compared with Exercise Group*

3.3.4 Haematological parameters, CRP, and arterial stiffness

At baseline, the EXG and HEG had similar haematological parameters and CRP, with no significant differences ($p > 0.05$). There was a significant difference in PWV between the groups at baseline ($p = 0.024$). All haematological parameters were within the normal range according to the reference values reported by Wakeman et al. (2007).

Table 3.7: Baseline haematological parameters, CRP levels, and arterial stiffness in the exercise (EX) and health education (HE) groups.

Variable	EG (n = 19)	HE (n = 18)
Total leukocytes (10^3/µL)	6.2 (0.5)	6.8 (0.4)
Lymphocytes (10^3/µL)	2.0 (0.9)	1.9 (0.2)
Monocytes (10^3/µL)	0.4 (0.7)	0.4 (0.6)
Granulocytes (10^3/µL)	3.8 (0.4)	4.7 (0.4)
Erythrocytes (10^6/µL)	4.0 (0.9)	4.0 (0.9)
Platelets (10^3/µL)	211.0 (19.1)	223.8 (19.1)
Haemoglobin (g/dL)	12.1 (0.3)	11.9 (0.3)
Haematocrit (L/L)	0.40 (0.0)	0.4 (0.0)
cfPWV (m/s)	5.8 (0.9)	7.9 (0.5)*
CRP (mg/L)	3.1 (0.7)	2.9 (0.9)

*Results are reported as mean (standard error). * $p<0.05$ compared with Exercise Group*

3.3.5 Intervention summary

There were 15 classes during the exercise intervention over the 10-week intervention period and 10 sessions for the HEG. All were delivered by the main investigator (P.S.). The attendance rate was 80.7% for the EXG and 88.3% for the HEG (Table 3.8). Some 50% of the EXG engaged in 95% of the exercise classes, while 61% of the HEG attended 95% of the HE sessions. One participant (5.3%) completed all 15 exercise sessions, and eight participants (44.4%) completed all 10 HE sessions. The retention rate at 10 weeks was 100% in both experimental groups, with two EX participants lost to follow-up at 26 weeks.

Table 3.8 Attendance rates in the exercise (EX) and health education (HE) groups.

Variable	**EX (n = 19)**	**HE (n = 18)**
Attendance (%)	80.7	88.3

3.3.6 Fatigue

3.3.6.1 FACT-F scores

The minimal CID on the FACT-F scale is 3.0 points (Cella et al., 2002). Although there was a significant reduction in fatigue in the HEG (p < 0.05), the intervention effect in the EXG was significantly greater (p < 0.05; Table 3.9). The net change in fatigue (13.3 points) over the 10-week intervention period was four times the recognised CID for the FACT-F scale. The intervention effect size (Cohen’s d) was 1.38.

Table 3.9: Comparative effects (mean ± SE) of an exercise intervention (EX) and a health education intervention (n=18) on FACT-F fatigue

	EX (n = 19SE)		**HE (n = 18)**		**Interaction p value**
Outcome	**Pre**	**Post**	**Pre**	**Post**	
Fatigue (FACT-F)	19.3 ± 2.0	40.3 ± 2.2 *	21.9 ± 2.4	29.6 ± 2.7 *	<0.001

The intervention effect on fatigue in the EXG was largely achieved by week 4 and maintained to 26 weeks (Figure 3.4 and Table 3.10). The proportion of EX participants with a fatigue score of <20 (severe) was 63.2% at baseline, which decreased to 5.3% at 10 weeks, and was maintained at 26 weeks (5.9%). The proportion of HE participants with severe fatigue was 44.4% at baseline and decreased to 16.7% at 10 weeks (post-intervention).

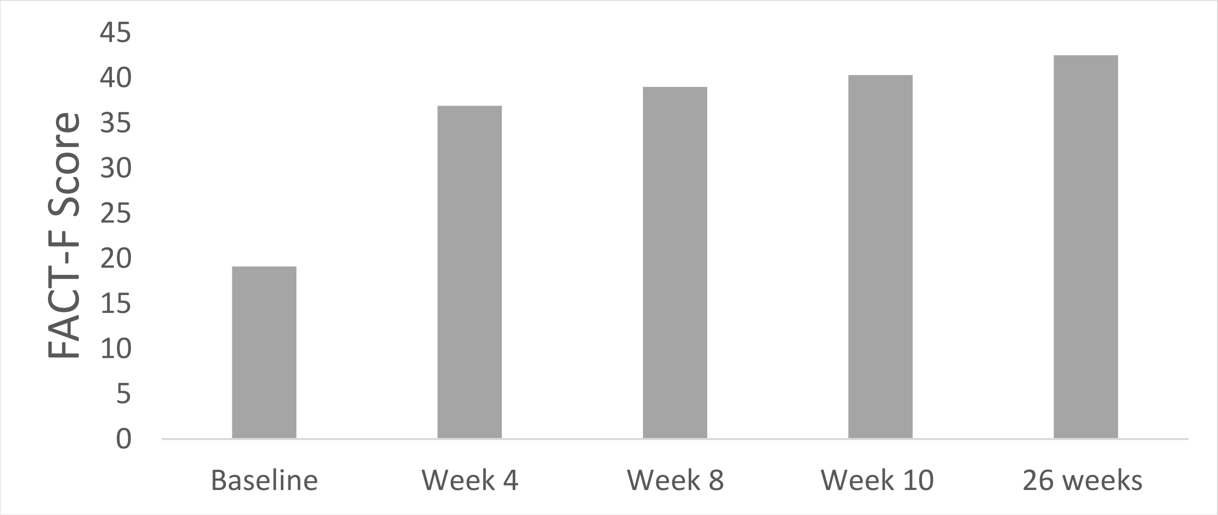


Figure 3.4: Time course for the change in fatigue (FACT-F) during a 10-week exercise intervention and 26-week follow-up among cancer survivors with fatigue (n=17).

Table 3.10: FACT-F scores (mean ± SE) before and after a 10-week exercise intervention and at 26 week among cancer survivors with fatigue.

	Exercise group (n = 17)		
Outcome	**Pre**	**Post**	**26 weeks**
FACT-F score	19.3 ± 2.1	40.3 ± 2.6 *	42.8 ± 2.9 *

** p <0.05 for pre-exercise score compared to post-exercise or 26 weeks.*

3.3.6.2 EORTC QLQ-C30 fatigue, global QOL, and cognitive, physical, role, and social functions

The EORTC QLQ-C30 is a measure of QOL and is a 30-item tool comprising five functional (physical, role, emotional, social, and cognitive) and three symptom (fatigue, pain, and nausea and vomiting) scales. There are also six single items that assess further symptoms cancer patients often mention. The intervention had a positive effect on fatigue, global QOL, and cognitive function measured using the EORTC QLQ-C30, as evidenced by a significant group × time point interaction ($p < 0.05$). In the EXG there was a significant decrease in fatigue ($p < 0.05$) and significant increases in cognitive function, global QOL, and physical, role, and social functions ($p < 0.05$). These changes were not observed in the HEG (Table 3.11). All changes were sustained to 26 weeks in the EXG (Table 3.12).

EORTC QLQ-C30 fatigue scores decreased by 25.9 points (large) from pre to post and by 31.4 points (large) from pre to 26 weeks in the EXG. Cognitive function scores increased by 30.7 points (large) from pre to post and by 34.4 points (large) from pre to 26 weeks in the EXG. Global quality of life increased by 19.3 points (moderate) from pre to post and by 26.5 points (large) from pre to 26 weeks in the EXG with no changes observed in the HEG. A large change in physical function was observed in EXG who changed by 24.4 points from pre to post and 24.7 from pre to 26 weeks. Role function scores increased by 33.3 points (large) from pre to post and by 38.3 points (large) from pre to 26 weeks in the EXG. Social function scores increased by 43.9 points (large) from pre to post and was maintained at 26 weeks in the EXG. No changes were observed in the HEG for any of the EORTC QLQ-C30 domains (Table 3.12).

Table 3.11: Comparative effects of an exercise (EX) and a health education (HE) intervention on EORTC QLQ-C30 fatigue, global QOL, and cognitive, physical, role, and social function scores (mean ± SE).

	EX (n = 19)		**HE (n = 18)**		**Interaction p value**
Outcome	**Pre**	**Post**	**Pre**	**Post**	
Fatigue	53.1 ± 5.6	27.2 ± 4.7 *	52.5 ± 4.6	48.1 ± 6.7	0.016
Cognitive function	41.2 ± 7.7	71.9 ± 6.5 *	50.9 ± 7.9	51.9 ± 6.7	0.009
Physical function	63.0 ± 5.7	87.4 ± 4.8 *	67.8 ± 5.9	66.2 ± 4.9	<0.001
Role function	53.7 ± 6.7	87.0 ± 5.7 *	54.9 ± 6.8	61.8 ± 5.8	0.003
Social function	34.2 ± 7.7	78.1 ± 6.9 *	52.0 ± 8.1	50.0 ± 7.3	0.001
Global QOL	50.0 ± 4.6	69.3 ± 4.7 *	48.1 ± 4.7	50.5 ± 4.9	0.012

** $p < 0.05$ compared to the pre-intervention score in the same group*

Table 3.12: EORTC QLQ-C30 fatigue, global QOL, and cognitive, physical, role, and social function scores (mean ± SE) pre- and post-intervention and at 26 weeks after a 10-week exercise intervention in cancer survivors with fatigue.

	Exercise group (n = 17)		
Outcome	**Pre**	**Post**	**26 weeks**
Fatigue	53.6 ± 6.0	26.1 ± 4.9 *	22.2 ± 5.0 *
Cognitive function	43.1 ± 8.1	72..5 ± 5.7 *	77.5 ± 4.7*
Physical function	61.2 ± 6.0	87.1 ± 3.6 *	85.9 ± 4.2 *
Role function	52.9 ± 6.4	86.3 ± 4.1 *	91.2 ± 4.3 *
Social function	33.3 ± 7.8	77.5 ± 6.4 *	82.4 ± 6.1 *
Global QOL	49.0 ± 4.0	74.0 ± 4.5 *	75.5 ± 4.1 *

** $p < 0.05$ for pre-exercise score compared to post-exercise or 26 weeks.*

3.3.7 Insomnia severity index

The intervention had a positive effect on insomnia, as evidenced by a significant group × time interaction ($p < 0.05$). Insomnia was significantly reduced in the EXG ($p < 0.05$), but not in the HEG (Table 3.13). A clinically meaningful improvement in insomnia was observed in the EXG from pre to post and pre to 26 weeks (Table 3.14). The proportion of EX participants with clinically significant insomnia (score 15–28) was 52.6% at baseline, 31.6% at 10 weeks and 15.8% at 26 weeks, compared to 72.2% at baseline and 38.9% at 10 weeks in the HEG.

3.3.8 Fear of PA in the breast cancer cohort

The intervention had a positive effect on fear of PA, as evidenced by a significant group × time interaction ($p < 0.05$) (Table 3.13). Fear of PA significantly decreased in the EXG ($p < 0.05$), but not in the HEG. The decrease in fear of PA was sustained at 26 weeks in the EXG (Table 3.14).

3.3.9 PHCS

Perceived health competence increased significantly in both the EXG and HEG ($p<0.05$; (Table 3.13). Changes were sustained at 26-week follow-up in the EXG. There was no group × time interaction (Table 3.14).

Table 3.13: Comparative effects of exercise (EX) and health education (HE) interventions (n=18) on insomnia severity, fear of physical activity and, perceived health competence (mean score ± SE)

	EX(n = 19)		**HE (n = 18)**		**Interaction**
Outcome	**Pre**	**Post**	**Pre**	**Post**	**p value**
ISI score	15.2 ± 1.9	8.2 ± 1.7 *	15.5 ± 1.9	13.3 ± 1.7	0.036
FPAX-B score	28.9 ± 6.9	13.1 ± 3.3 *	28.3 ± 5.7	27.1 ± 4.0	0.022
PHCS score	24.8 ± 1.3	29.4 ± 1.2*	23.7 ± 1.3	27.5 ± 1.2*	0.69

** $p < 0.05$ compared to the pre-intervention score in the same group.*

Table 3.14: Insomnia, fear of PA, and health competence scores (mean ± SE) pre- and post-intervention and 26 weeks after a 10-week exercise intervention in cancer survivors with fatigue.

	Exercise group (n = 17)		
Outcome	**Pre**	**Post**	**26 weeks**
ISI score	15.4 ± 2.0	7.7 ± 1.7 *	6.4 ± 1.6 *
FPAX-B score (breast cancer only)	30.5 ± 7.8	13.1 ± 3.9 *	9.2 ± 2.9 *
PHCS	24.6 ± 1.4	29.1 ± 1.4 *	32.6 ± 1.1 *

** $p < 0.05$ for pre-exercise score compared to post-exercise or 26 weeks.*

3.3.10 Fitness scores

The intervention had a positive effect on the 6-min walk, sit-and-reach, and sit-to-stand test results, as evidenced by a significant group × time interaction ($p < 0.001$; Table 3.15). Improvements in distance travelled were clinically important (Enright, 2003; O'Keeffe, Lye, Donnellan, & Carmichael, 1998; Perera, Mody, Woodman, & Studenski, 2006; Redelmeier, Bayoumi, Goldstein, & Guyatt, 1997) in the EXG over 26 weeks, with an improvement of 163.5 m observed between baseline and week 10 and of 161.8 m between baseline and week 26 (Table 3.16).

3.3.11 Moderate to vigorous PA levels

The intervention had a positive effect on weekly moderate to vigorous PA (MVPA) levels, as evidenced by a significant group × time interaction ($p < 0.001$; Table 3.15). EX participants significantly increased their MVPA from 3.7 min/week at baseline to 297.3 min/week at week 10 ($p < 0.001$; Table 3.15). This decreased to 215.3 min/week at 26 weeks (Table 3.16), but still represented a significant change from baseline ($p < 0.001$). No significant improvements were observed in the HEG. Before the intervention, no participant in either group was undertaking any MVPA. However, after the intervention, 88.9% of the EXG met the general recommendation of 150 min/week of MVPA whereas none of the HEG were meeting the recommendation. This rate had decreased slightly at 26 weeks, with 62.5% of the EXG meeting the general MVPA recommendation.

3.3.12 Sedentary time

The intervention had a positive effect on daily minutes of sedentary time, as evidenced by a significant group × time interaction ($p < 0.05$; Table 3.15). EX participants significantly reduced their sitting time by 145.6 min/weekday from baseline to post-intervention ($p < 0.05$; Table X) and by 195 min/weekday from baseline to 26 weeks ($p < 0.05$; Table 3.16). No significant changes were noted in the HEG.

Table 3.15: Comparative effects of exercise (EX) and health education (HE) interventions on functional fitness, MVPA, and sedentary time among cancer survivors with fatigue (mean ±SE).

	EX (n = 19)		**HE (n = 18)**		**Interaction**
OUTCOME	**Pre**	**Post**	**Pre**	**Post**	**p value**
6MWT (m)	438.3 ± 16.0	601.8 ± 18.3 *	462.0 ± 19.3	496.3 ± 22.1	<0.001
Sit and reach (cm)	27.1 ± 2.0	32.1 ± 1.8 *	20.9 ± 2.1	21.1 ± 2.4	<0.001
Sit to stand (reps in 30 s)	13.4 ± 0.7	23.8 ± 1.3 *	11.6 ± 0.9	12.6 ± 1.21	<0.001
MVPA (min/week)	3.7 ± 3.2	297.3 ± 52.8 *	3.3 ± 3.3	0.0 ± 0.0	<0.001
Sedentary time (min/weekday)	357.5 ± 35.5	211.9 ± 21.7 *	390.0 ± 38.0	383.6 ± 23.2	0.007

** p < 0.05 compared to the pre-intervention score in the same group.*

Table 3.16: Functional fitness, MVPA, sedentary time, and arterial stiffness scores (mean ± SE) pre- and post-intervention and 26 weeks following a 10-week exercise intervention among cancer survivors with fatigue.

	Exercise group (n = 17)		
Outcome	**Pre**	**Post**	**26 weeks**
6MWT (m)	457.8 ± 18.7	602.7 ± 20.1 *	619.6 ± 16.9 *
Sit and reach (cm)	26.7 ± 2.2	31.8 ± 1.9 *	33.8 ± 2.5 *
Sit to stand (reps in 30 s)	13.8 ± 0.6	23.2 ± 1.2 *	27.7 ± 2.4 *
MVPA (min/week)	4.4 ± 3.8	315.3 ± 60.3 *	215.3 ± 37.4 *
Sedentary time (min/weekday)	332.5 ± 44.8	202.5 ± 60.3 *	137.5 ± 16.7 *

** p < 0.05 for pre-exercise score compared to post-exercise or 26 weeks.*

3.3.13 Steps on non-exercise intervention day versus exercise intervention day

Participants in the EXG took an average of 7,918 steps on supervised exercise days versus 7,490 steps on other days. A paired t-test revealed that this difference was significant (p = 0.001; Figure 3.5).

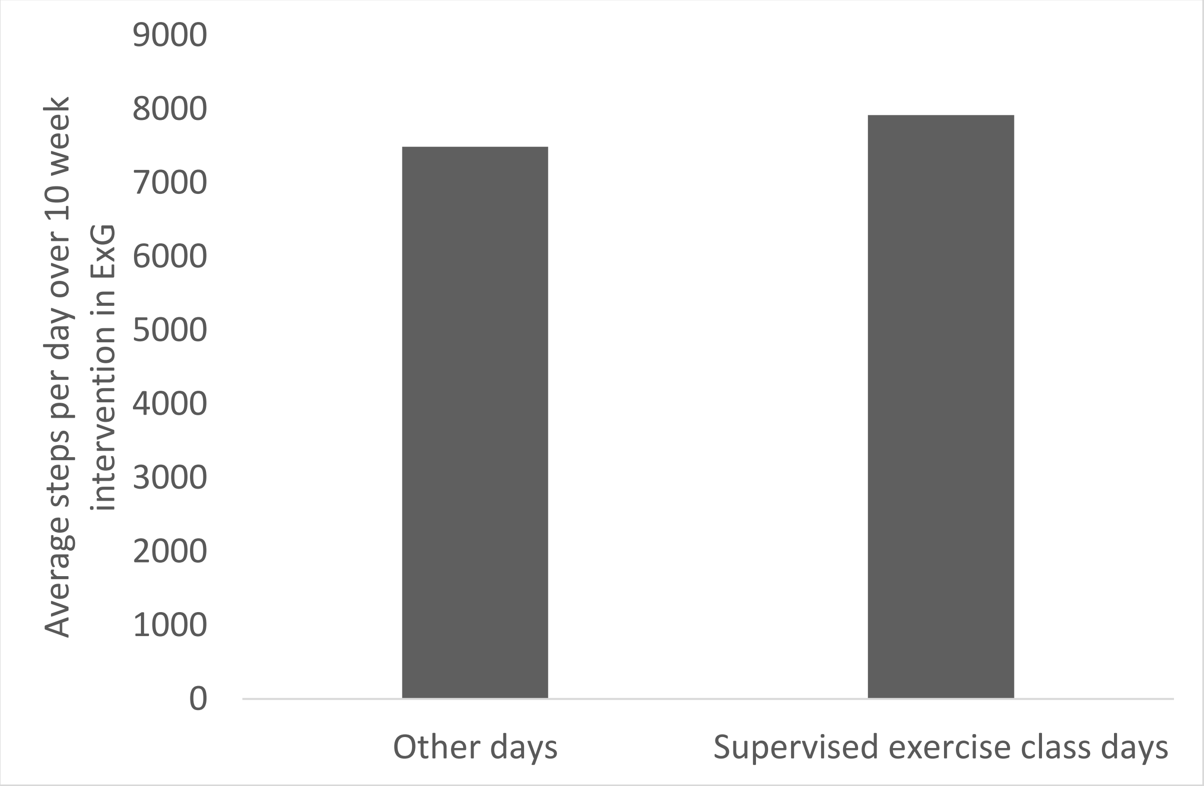


Figure 3.5: Average steps per day over the duration of the 10-week intervention in the Exercise Group: Comparison of Supervised Exercise Class Days and Other Days

3.3.14 Blood pressure, BMI, and PWV

The intervention had no effect on systolic blood pressure, diastolic blood pressure, or cfPWV in either the EXG or HEG (Table 3.17). There were no significant changes at 26 weeks in the EXG (Table 3.18). There was a small but significant (p = 0.034) negative intervention effect on BMI.

Table 3.17: Comparative effects of exercise (EX) and health education (HE) interventions on systolic blood pressure, diastolic blood pressure, BMI, and arterial stiffness (mean ± SE) among cancer survivors with fatigue.

	EX (n = 19)		**HE (n = 18)**		**Interaction p value**
Outcome	**Pre**	**Post**	**Pre**	**Post**	
Systolic blood pressure (mmHg)	128.7 ± 4.8	124.8 ± 4.0	131.8 ± 5.1	134.5 ± 4.2	0.17
Diastolic blood pressure (mmHg)	76.1 ± 2.2	78.6 ± 2.6	79.8 ± 2.3	79.1 ± 2.8	0.25
BMI (kg/m^2)	29.4 ± 1.3	29.8 ± 1.3	27.5 ± 1.4	27.1 ± 4.5	0.034
cfPWV (m/s)	5.8 ± 0.9	6.2 ± 0.6	7.9 ± 0.5	7.7 ± 0.6	0.68

Table 3.18: Systolic blood pressure, diastolic blood pressure, BMI, and arterial stiffness (mean ± SE) pre- and post-intervention and 26 weeks after a 10-week exercise intervention in cancer survivors with fatigue.

	Exercise group (n = 17)		
Outcome	**Pre**	**Post**	**26 weeks**
Systolic blood pressure (mmHg)	128..8 ± 4.3	124.2 ± 2.5	124.8 ± 2.9
Diastolic blood pressure (mmHg)	74.1 ± 1.9	77.8 ± 2.7	79.2 ± 2.6
BMI (kg/m^2)	28.8 ± 1.2	29.4 ± 1.3	29.1 ± 1.2
cfPWV (m/s)	5.7 ± 1.0	6.0 ± 0.6	4.8 ± 0.8

3.3.15 Changes in haematological parameters, arterial stiffness, and CRP

Other than monocytes, for which there was a significant group ×y time interaction, there was no intervention effect on CRP, total leukocytes, lymphocytes, granulocytes, erythrocytes, platelets, or haemoglobin (Table 3.19). There were no significant changes from baseline to 26 weeks in the EXG (Table 3.20).

Table 3.19: Comparative effects of exercise (EX) and health education (HE) interventions on haematological parameters, arterial stiffness, and CRP (mean ± SE) among cancer survivors with fatigue.

	EX (n = 19)		**HE (n = 18)**		**Interaction p value**
Outcome	**Pre**	**Post**	**Pre**	**Post**	
CRP (mg/L)	1.9 ± 0.6	2.6 ± 0.8	3.1 ± 0.7	2.9 ± 0.9	0.21
Leukocytes (10^3/µL)	6.2 ± 0.5	6.7 ± 0.8	6.8 ± 0.4	7.1 ± 0.8	0.78
Lymphocytes (10^3/µL)	2.0 ± 0.9	2.1 ± 0.2	1.9 ± 0.2	2.0 ± 0.2	0.88
Monocytes (10^3/µL)	0.4 ± 0.08	0.3 ± 0.05	0.4 ± 0.09	0.3 ± 0.07	0.62
Granulocytes (10^3/µL)	3.8 ± 0.4	4.3 ± 0.9	4.7 ± 0.4	3.9 ± 0.8	0.22
Erythrocytes (10^6/µL)	4.0 ± 0.9	3.9 ± 1.4	4.0 ± 0.9	6.0 ± 1.4	0.30
Platelets (10^3/µL)	211.0 ± 19.1	217.6 ± 20.8	223.8 ± 19.1	233.9 ± 20.8	0.89
Haemoglobin (g/dL)	12.1 ± 0.3	12.4 ± 0.3	11.9 ± 0.3	12.2 ± 0.3	0.92
Haematocrit (L/L)	0.37 ± 0.007	0.37 ± 0.009	0.36 ± 0.007	0.36 ± 0.009	0.45

Table 3.20: Haematological parameters, arterial stiffness, and CRP (mean ± SE) pre- and post-intervention and 26 weeks after a 10-week exercise intervention among cancer survivors with fatigue (n=17)

	Exercise group (n = 17)		
Outcome	**Pre**	**Post**	**26 weeks**
CRP (mg/L)	1.5 ± 0.5	1.4 ± 0.4	1.8 ± 0.6
Leukocytes (10^3/µL)	5.8 ± 0.4	5.8 ± 0.5	5.6 ± 0.5
Lymphocytes (10^3/µL)	1.9 ± 0.2	1.9 ± 0.2	1.9 ± 0.1
Monocytes (10^3/µL)	0.4 ± 0.1	0.3 ± 0.4	0.3 ± 0.4
Granulocytes (10^3/µL)	3.5 ± 0.5	3.6 ± 0.5	3.4 ± 0.5
Erythrocytes (10^6/µL)	3.9 ± 0.1	3.7 ± 0.3	4.0 ± 0.1
Platelets (10^3/µL)	185.2 ± 19.5	189.0 ± 17.1	194.4 ± 20.2
Haemoglobin (g/dL)	11.8 ± 0.4	12.3 ± 0.4	11.8 ± 0.4
Haematocrit (L/L)	0.36 ± 0.010	0.37 ± 0.012	0.37 ± 0.011

3.3.16 Correlation data

Factors related to cancer and treatment, such as disease stage, time since treatment, past chemotherapy, radiotherapy treatment, and current use of cancer-related medication were not correlated with pre-intervention fatigue scores. Correlation between baseline cfPWV and baseline serum CRP approached significance ($r = 0.38$; $p = 0.059$).

The change in FACT-F score between week 0 and week 10 was positively correlated with the change in cognitive functioning ($r = 0.64$, $p = 0.003$); as fatigue decreased, cognitive function increased. The change in FACT-F score was negatively correlated with changes in fear of PA ($r = -0.56$, $p = 0.013$) and insomnia severity ($r = 0.66$, $p = 0.002$); as fatigue decreased, scores for fear of PA and insomnia severity decreased. The change in FACT-F score was not significantly correlated with changes in the 6-min walk, sit-and-reach, or sit-to-stand tests, MVPA, sedentary time, CRP, or cfPWV.

The change in sedentary time was positively correlated with the change in QOL ($r = 0.52$; $p = 0.040$); as sedentary time decreased, QOL increased. The change in physical function was positively correlated with changes in role function ($r = 0.60$; $p < 0.001$) and social function ($r = 0.45$, $p = 0.005$); as physical function increased, role and social functions increased. There was a strong negative correlation between the change in insomnia severity and cognitive function ($r = - 0.80$; $p < 0.001$); as insomnia severity decreased, cognitive function increased.

3.4 Discussion

3.4.1 Introduction

The purpose of this quasi-experimental study was to determine the effects of a 10-week exercise intervention compared to a HE intervention on fatigue, psychological health outcomes, and physical fitness in post-treatment cancer survivors with documented fatigue. The study results revealed that although there were significant improvements in FACT-F scores in both groups, there were considerably greater changes in the EX group. The intervention effect on fatigue in the EXG was largely achieved by week 4. The EX participants but not the HEG experienced significant increases in cognitive, physical, role, and social functions, global QOL, perceived health competence, 6MWT test, sit-and-reach test, 30-s sit-to-stand scores, and MVPA, and significant decreases in insomnia, sedentary time, and fear of PA. The changes observed in the EXG were all sustained to 26 wk. There was no intervention effect on CRP, or cfPWV, potential mediators of the exercise effect. The retention rate at 10 weeks was 100% in both groups and no adverse events were reported.

A critical difference between studies undertaken to date and the present study is the control condition utilised. Previous studies typically utilise a “usual care” group in which participants do not receive the exercise intervention, the group/peer support, positive health focus and investigator attention. The comparison group (HEG) in our study received the same peer/group support, positive health focus and investigator attention. The study results represent a significant contribution to current knowledge, as any between-group changes in fatigue can be attributed to the exercise component rather than to peer group support and investigator attention. All study findings must be considered in this regard. This highlights the importance of considering an appropriate comparison condition when designing future studies.

3.4.2 Fatigue

In this study we assessed the effectiveness of a 10-week exercise programme in alleviating fatigue in post-treatment cancer survivors with documented fatigue. There was a positive intervention effect on fatigue. According to FACT-F scores, fatigue was reduced in both the EX and HE groups, with a greater reduction in the EXG. The magnitude of change observed in the EXG was maintained at 26 weeks. The significant change in the HEG may be attributed to the fact that strategies other than exercise that targeted fatigue were incorporated into the HE arm.

The magnitude of the exercise effect was considerable, as indicated by the CID and effect size. The minimal CID for the FACT-F scale is 3 points (Cella, Eton, et al., 2002). Although both groups experienced CIDs and results confirm that the EX and HE interventions can be viewed as efficacious non-pharmacological interventions, greater improvements were observed in the EXG even though both groups received the same investigator attention and group support. Most of the change in the EXG was evident at 4 weeks and carried through to 26 weeks. Therefore, in survivors with documented fatigue, progressive exercise training has beneficial and sustained effects of considerable magnitude on fatigue beyond those attributable to peer support and investigator attention.

While other studies revealed positive results for fatigue of small to medium effect size (Cramp & Byron-Daniel, 2012; Fong et al., 2012; Velthuis, Agasi-Idenburg, Aufdemkampe, & Wittink, 2010), the magnitude of the effect in the present study is much greater. This result can be attributed to the recruitment of participants who all were highly fatigued at baseline, which allowed for a greater opportunity to improve fatigue. Our results are consisted with those carried out by Cantarero-Villanueva et al. (2013), who only included participants with a clinically significant total fatigue score. Similar to the present study, they reported a large effect size (SMD -1.40) for fatigue, which they attributed to the inclusion of a selected population experiencing moderate to high levels of CrF. They used the revised Piper Fatigue Scale to measure fatigue, so it was difficult to compare baseline fatigue levels and changes in fatigue to our study results.

The numerous measurement tools used to measure fatigue is one of the limitations when trying to compare results. FACT-F has a validated clinically significant score change (Cella et al., 2002) and includes the social impact of CrF. Although FACT-F has been recognised as one of the best measurement tools for assessing fatigue, few studies on PA (Broderick et al., 2013; Kerry S. Courneya et al., 2003; Pinto, Papandonatos, & Goldstein, 2013; Saarto et al., 2012) have used it. Other studies using FACT-F that observed smaller or no changes in fatigue involved cohorts with considerably higher FACT-F scores at baseline, which are indicative of lower fatigue levels (Broderick et al., 2013; Kerry S Courneya et al., 2003; Pinto, Papandonatos, & Goldstein, 2013; Saarto et al., 2012).

In a study carried out by Broderick et al. (2013), participants had a mean baseline FACT-F score of 35.3 (mild) in the EX group versus 40.2 (mild) in the control group. This is representative of a high functioning cohort. Similarly, in other studies (Pinto, Papandonatos, Goldstein, et al., 2013) the EX and control groups were experiencing only mild levels of fatigue. The inclusion of a high functioning group does not leave much scope for improvement in terms of fatigue. An earlier study (Courneya et al., 2003) that used the FACT-F measure observes a significant reduction in fatigue in the EX (53%) compared to the control group (19%). The authors reported a clinically important 9.3-point change between baseline and post-intervention in the EX group. However, unlike our study, there was a significant difference in fatigue at baseline between the two groups.

The mean baseline scores of 19.3 in the EXG and 21.9 in the HEG are indicative of moderate to severe with no differences between groups. More than half of the participants in our study had severe fatigue and one-third had moderate fatigue. This may explain not only the magnitude of change in the EXG but also why a significant reduction in fatigue was also observed in the HEG. It should be noted that the HEG received an intervention using strategies other than exercise that also target CrF.

There was a significant change in fatigue in the EXG whether measured via FACT-F or the EORTC QLQ-C30 fatigue subscale. Although there was a significant reduction in FACT-F score in the HEG, there was no significant change in the EORTC QLQ-C30 fatigue score. Fatigue is a multidimensional condition that affects individuals physically, emotionally, and cognitively. While its severity can be assessed using several questionnaires, such as those used in the present study, the tools evaluate different elements of fatigue. Although it is a reliable tool, the EORTC QLQ-C30 fatigue subscale mainly assesses physical fatigue and does not provide information on functional impairments, while the FACT-F also evaluates the physical and functional consequences of fatigue. Furthermore, the EORTC QLQ-C30 fatigue subscale consists of only three questions. Hence, it has a restricted number of responses and may thus be less sensitive for detection of changes in fatigue levels.

The dose–response relationship for exercise and fatigue is still unknown. However, our results indicate that the intervention effect on fatigue in the EXG was largely achieved by week 4. Assessment of the lowest PA dose necessary to achieve beneficial effects warrants investigation in future studies. The majority of studies on PA investigate chronic adaptations, even though evidence shows that isolated exercise sessions induce beneficial changes in chronic disease risk factors (Thompson et al., 2001). Many of the chronic effects are derived from single bouts of exercise that provoke cellular changes at the gene level, leading to increasing effects of training. Hence, single bouts of exercise have a positive impact on health. Anecdotal evidence suggests fatigue increases immediately after an exercise session, therefore exploring the interaction of acute and chronic exercise warrants further investigation. While positive effects on life expectancy have been reported for just 15 min/day of MVPA, even in those with elevated cardiovascular risk (Wen et al., 2011), no study to date has examined the minimum dose required to positively affect fatigue in cancer survivors with documented fatigue. Knowing how much exercise is needed for a positive dose response would allow correct management and treatment of CrF.

3.4.3 Physical fitness

Because of the known adverse effects of cancer and its treatment on muscle function, aerobic fitness, and physical abilities among cancer survivors (Thorsen, Gjerset, Fossa, & Loge, 2011), it was anticipated that EX participants would experience improvements in measures of physical function and fitness, as in previous studies (Kerry S. Courneya et al., 2012; McMillan & Newhouse, 2011). Along with improvements in fatigue, our results revealed that participation in a 10-week moderate aerobic exercise programme significantly improved aerobic fitness, flexibility, muscle strength, and total daily PA, and significantly reducing sitting time among cancer survivors with CrF. These changes were sustained at 26 weeks. No significant changes were observed for these measures in the HEG.

The 6MWT is a measure of submaximal functional capacity, which is the level at which most activities of daily living are carried out. It has been postulated that the 6MWT reflects the functional exercise level for activities of daily living (Patel & Bhise, 2017). Post-treatment cancer survivors who suffer from cardiorespiratory deconditioning may experience more physical difficulties in carrying out activities of daily living, which may in turn impact negatively on fatigue. A mean increase of 43–54 m in the 6MWT is deemed clinically meaningful in various patients cohorts (O’Keeffe et al., 1998; Perera et al., 2006; Redelmeier et al., 1997). In the current study, there was a clinically important increase in 6MWT distance travelled in the EXG compared to the HEG. In comparison to other studies, we observed a greater magnitude of change in 6MWT results. Patel & Bhise (2017) observed a 31.6-m improvement among post-treatment cancer survivors that was not deemed a clinically important improvement in 6MWT distance. However, it should be noted that the duration of their study was only 6 weeks, which might not have been long enough to observe a clinically important improvement, and no follow-up was included. Cheifetz et al. (2014) observed a significant improvement among cancer patients of 30.1 m from baseline to post-intervention. However, unlike our study this was not maintained at follow-up, as the change between baseline and 12 weeks was 25.3 m. Our study cohort comprised post-treatment patients, whereas participants in their study were receiving treatment, which may have caused a ceiling effect and could have contributed to the decline in aerobic function from 6 weeks to 12 weeks (Cheifetz et al., 2014).

The positive results observed in our study are promising, as the 6MWT is predictive for survival in patients with various chronic diseases (Boxer et al., 2010; Cahalin, Mathier, Semigran, Dec, & DiSalvo, 1996; Pinto-Plata, Cote, Cabral, Taylor, & Celli, 2004). In addition, improving aerobic capacity enhances the ability of individuals to undertake activities of daily living (Mock et al., 1994; Winningham, 1986). It has been hypothesised that cardiorespiratory deconditioning plays a role in the development and persistence of CrF after treatment (Neil, Klika, Garland, McKenzie, & Campbell, 2013). Although the aetiology of CrF is largely unknown and is probably multifactorial, increasing the cardiorespiratory fitness of cancer patients and survivors may aid in preventing the development and persistence of fatigue.

Along with cardiorespiratory deconditioning, cancer patients experience muscle dysfunction, decreases in muscle mass (sacropenia; Prado et al., 2008), and lower flexibility (Cheema, Gaul, Lane, & Fiatarone Singh, 2008). Along with prolonged bed rest following surgery for cancer, side effects such as CrF and pain can further reduce PA levels among cancer survivors. CrF is exhausting, with rest often prescribed by physicians (Curt et al., 2000). However, avoidance of PA can lead to physical deconditioning, resulting in reduced aerobic fitness and muscular strength (Huijnen, Verbunt, Wittink, & Smeets, 2013). A study reported a 16% decline in muscle strength in healthy elderly individuals following 10 days of bed rest (Kortebein, Ferrando, Lombeida, Wolfe, & Evans, 2007). As well as improvements in aerobic capacity, we observed significant improvements in leg strength and lower body flexibility in the EXG, and these changes were maintained at follow-up. Although the programme did not emphasise strength and local muscular endurance, changes in muscular endurance and strength occurred. Improvements in these parameters would probably make completing tasks of daily living easier, contributing to enhanced QOL, independence, and social connectedness. Even in the absence of correlations, it is reasonable to assume that increased fitness facilitated greater PA, which in turn contributed to greater muscular endurance and strength. Improvements in cardiorespiratory fitness, muscular function, and strength may also provide additional health benefits linked to lower relative risks of chronic illness and mortality (Artero et al., 2011; Sui et al., 2007).

Previous studies have posited that supervised exercise programmes improve physical functional capacity more effectively than unsupervised exercise and self-exercise (Mutrie et al., 2007). Along with all the strategies used to enhance exercise self-efficacy and increase motivation to exercise in the EXG, the positive physical fitness results observed in our study may also be attributed to the fact that the exercise classes were supervised. However, it is not possible to exclude the possibility that the same results might have been achieved with a non-supervised home-based programme.

3.4.4 Total exercise volume, sedentary time, and number of steps

Almost three-quarters of cancer patients (Blanchard, Courneya, & Laing, 2001) and the majority of cancer survivors (LeMasters, Madhavan, Sambamoorthi, & Kurian, 2014) do not meet the American Cancer Society PA guidelines. In our study the EX participants observed a positive effect on self-reported MVPA and sedentary time post-intervention that was maintained at 26 weeks. EX participants significantly increased their PA volume from 3.7 min/week MVPA at baseline to 297.3 at 10 weeks and 215.3 at 26 weeks, which exceeds the ACSM PA guidelines for cancer survivors. These results are encouraging, as research suggests that achieving or exceeding the target leisure-time PA levels 2 years after diagnosis is associated with a 30–40% lower risk of breast cancer mortality (Meyerhardt et al., 2006). Furthermore, higher PA levels are associated with lower risks of recurrence and mortality for cancers such as breast cancer (Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005). For EX participants there was a significant difference in daily steps taken between supervised intervention days and other days in the week, with more steps taken on intervention days. However, we were unable to capture sedentary levels before and after the supervised exercise intervention days. It is possible that although participants accumulated more steps on the intervention days, they might have been more sedentary and rested more throughout the day, whereas they might have spread their activity throughout the remainder of the day and interrupted their sitting more on other days.

There was a positive intervention effect on sedentary time. EX participants decreased their sedentary time from a mean of 357.5 min/weekday at baseline to 211.9 min/weekday at 10 weeks and 137.5 min/weekday at 26 weeks; this trend of significant effects was not observed in the HEG. Interestingly, decreases in sedentary time were significantly correlated with increases in QOL. Many cancer survivors experience declines in QOL and increases in fatigue as a result of their cancer and treatments, so rest is often prescribed as a means of addressing these issues and cancer survivors are sedentary for the vast majority of their time (Lynch, Cerin, Owen, & Aitken, 2007), which can lead to further deconditioning and functional decline. Our results suggest that cancer survivors can improve their QOL by reducing their sitting time. This is in agreement with results from a study among colorectal cancer survivors indicating a clinically significant association between television viewing time and QOL (Lynch et al., 2011). Individuals who watched television for >5 h/day had a 16% lower total QOL score in comparison to those who watched for ≤2 h/day. These findings suggest that reducing sedentary behaviour could enhance QOL among cancer survivors. On the contrary, it is possible that sedentary time is simply a marker of QOL; in other words a high level of sedentary time may be a marker for individuals with low QOL from persistent fatigue. The effect of reducing sedentary time warrants further investigation in future studies.

3.4.5 Insomnia severity

Sleep disturbance is another, often neglected, complaint among cancer patients (Savard & Morin, 2001) and has been reported to be one of the primary determinants of fatigue (Okuyama et al., 2000). A cross-sectional study found that overly fatigued patients were 2.5 times more likely to suffer from insomnia (Davidson, MacLean, Brundage, & Schulze, 2002). In fact, 51% of cancer survivors report difficulties sleeping (Savard et al., 2001).

The intervention had a positive effect on insomnia severity. For the ISI, reductions of >7 points and >8 points were identified as minimally important differences for moderate and marked improvements in insomnia, respectively (Morin, Belleville, Bélanger, & Ivers, 2011). Another study suggested that a reduction of 6 points represents a clinical meaningful difference in individuals with primary insomnia (Yang et al., 2009). A mean 7-point improvement from baseline to post-intervention was seen in the EXG, whereas there was no change in the HEG. The marked improvement observed in the EXG was maintained at 26 weeks.

A review suggested that although CrF and insomnia are distinct from one another, there is strong evidence to indicate a strong correlation between them (O'Donnell, 2004). Our results revealed a significant positive relationship between decreases in CrF and improvements in sleep in the EXG. Studies have shown that that correlations between fatigue and sleep persist in some individuals for up to 1 year after treatment completion (Bower et al., 2000; Broeckel et al., 1998). However, our results suggest such correlations last for years following treatment, as the mean time since treatment in the EXG was 3 years. We also found that higher fatigue levels were significantly associated with higher insomnia severity, in line with a previous study (Broeckel et al., 1998). Of the 31 participants reporting moderate to severe fatigue, 77% reported moderate to severe insomnia. Our results suggest that fatigued groups may be further characterised by insomnia and that exercise should be acknowledged as a primary treatment for both fatigue and insomnia among cancer survivors. Further investigation of this relationship via a wearable device or a sleep diary may complement the self-reported ISI scores used to measure insomnia.

A greater number of nighttime awakenings because of pain, anxiety, hot flushes, increased need to urinate, and the impact of illness and medications may reduce nighttime sleep and lead to an increase in daytime napping. Cancer survivors and patients who spend a lot of time napping also report higher levels of sleep problems (Ancoli-Israel, Moore, & Jones, 2001). Broeckel et al. (1998) found a significant link ($p < 0.001$) between daytime sleeping and fatigue in post-treatment cancer patients. Our study did not capture nighttime awakenings or daytime napping. The possibility of capturing such data via a sleep diary and/or a wearable device warrants further investigation.

Similar to fatigue, there is limited evidence on the minimal amount of exercise needed to positively affect sleep quality. Such evidence might allow health professionals to prescribe the correct exercise dose for treatment of poor sleep quality and achieve the best clinical outcome for cancer survivors in terms of fatigue.

Up to almost 90% of those with chronic pain disorders report sleep disorders (Morin, LeBlanc, Daley, Gregoire, & Mérette, 2006; Smith & Haythornthwaite, 2004) and half of those with insomnia suffer from chronic pain (Taylor et al., 2007), suggesting a relationship between the conditions. Pain is frequent and reported by almost 60% of cancer patients and survivors (Chang et al., 2000). Although pain was not an outcome measure included in our study, the interrelationships between pain and sleep quality and the effects of exercise on pain in fatigued cancer survivors warrant further investigation.

3.4.6 Cognitive function

A number of studies have identified a decline in cognitive functioning following cancer treatment (Wefel, Kesler, Noll, & Schagen, 2015), suggesting that cancer therapy may be linked to cognitive impairment (Mandilaras et al., 2013), often referred to as "chemo brain" (Hede, 2008). Cognitive dysfunction can have a major impact on the daily lives of cancer patients (A. J. Mitchell, Kemp, Benito-León, & Reuber, 2010; Taphoorn & Klein, 2004). Studies have found that almost three-quarters of patients report issues with memory and almost two-thirds report problems with concentration (Shilling, Jenkins, Morris, Deutsch, & Bloomfield, 2005; Shilling & Jenkins, 2007). Cognitive difficulties following treatment also impact on a patient's ability to return to work, with a negative knock-on effect on their self-esteem (Gokal et al., 2015). Similar to fatigue, cognitive function impairments among survivors can last for years following treatment (Boykoff, Moieni, & Subramanian, 2009; Fitch, Armstrong, & Tsang, 2008).

When interpreting health-related QOL scores using the EORTC QLQ-C30, Osoba et al. (1998) suggested that 5–10 points represented a small change, 10–20 points a moderate change, and >20 points a large change. Unlike the HEG, there was a large (31 points) positive intervention effect on cognitive function in the EXG, and the improvement was sustained at follow-up.

Research concerning the biological mechanisms underlying the link between PA and cognitive function among cancer survivors is sparse. It has been postulated that increases in physical fitness improve cognition because cardiovascular fitness increases cerebral blood flow and oxygen delivery to the brain, which enhances neuron formation and maintains brain volume (Etnier, Nowell, Landers, & Sibley, 2006). On the contrary, hypotheses suggest that cancer and its treatment are linked to cardiovascular injury and lower cardiorespiratory fitness in cancer survivors (Jones et al., 2012). A recent study found that greater cardiorespiratory fitness and PA were positively associated with improved memory performance in breast cancer survivors (Mackenzie et al., 2016). However, our correlation analyses revealed no associations between increases in physical fitness, PA volume, sedentary time, and cognitive function. The self-reported measure of cognitive function may have been a limitation, and use of an objective measure of cognitive function is worth considering in future studies. This may shed some light on the mechanisms underlying the effect of exercise on cognitive function in cancer survivors.

There were significant positive relationships between the changes in fatigue and in cognitive function, and between the changes in fatigue and in insomnia severity. EX participants reported a significant improvement in sleep, cognitive function and fatigue, which are interesting common effects. Similarly, other researchers reported a correlation between sleep and cognitive function: improvements in sleep were associated with increases in cognitive function (Hartman, Marinac, Natarajan, & Patterson, 2015). Sleep might be considered a facilitator of changes in fatigue and changes in cognitive functioning. It is important that all three variables are measured in future exercise studies in this field.

3.4.7 Physical, role, and social functions and global QOL

3.4.7.1 Physical function

Physical inactivity along with physical changes (fitness and bodily changes) experienced by cancer survivors can lead to diminished physical functioning and a negative impact on overall QOL (Crevenna, Maehr, Fialka-Moser, & Keilani, 2009; Simonavice, Liu, Ilich, Kim, & Panton, 2011). Physical function is a person’s ability to carry out normal activities of daily living without being restricted by their physical capabilities. Patient-reported physical function declines at a faster rate among individuals with a cancer diagnosis in comparison to age-matched individuals free of cancer (Petrick, Foraker, et al., 2014; Petrick, Reeve, et al., 2014). The inability to carry out movements because of a restricted range of motion following surgery and treatment may also be linked to difficulty in carrying out activities of daily living such as climbing stairs, getting in and out of bed, lifting and carrying objects, and bending and kneeling (Brown, Harhay, & Harhay, 2016; Hurley & Roth, 2000). Along with objective measures of physical function such as the 6MWT and 30-s sit-to-stand test, outcomes were subjectively assessed via the EORTC QLQ-C30 questionnaire. We observed a positive intervention effect on physical function according to the EORTC QLQ-C30. EX participants experienced a clinically meaningful difference, with a large change from baseline to post-intervention that was maintained at follow-up. These results are promising, as a recent study postulated that cancer survivors with higher physical function are less likely to die prematurely in comparison to their counterparts with lower physical function levels (Brown, Harhay, & Harhay, 2014). Preserving and enhancing functional status is vital in improving long-term health outcomes and QOL among cancer survivors. With the increase in survivorship among cancer patients, a person's QOL can be as crucial as their survival time (Andersen, 1992; Ganz, Lee & Siau, 1991; Mock et al, 1994; Young-Maccughan & Sexton, 1991). The fact that individuals have overcome their cancer but are left with a lower ability to perform activities of daily living and a diminished QOL warrants the implementation of exercise interventions such as the one used in our study to correct such deficits.

3.4.7.2 Role function

Owing to physical dysfunction and the emotional effects of cancer, individuals may have trouble in returning to work, which can place a financial burden on individuals and their family and prevent them from pursuing hobbies and other leisure activities. Hence, improving role function is also important to a cancer survivor's overall QOL. The exercise intervention in our study had a positive effect on role function. Clinically important improvements in role function were observed in the EXG, but not in the HEG. The EXG maintained their positive improvements at follow-up. In addition, there was positive relationship between increases in physical function and in role function. This suggests that as the participants' physical function improved they were more likely to engage in activities of daily living and pursue hobbies and leisure activities. This could potentially allow individuals to feel more socially connected by making it easier for them to engage in family life and social activities

3.4.7.3 Social function

Social isolation involves a lack of contact with others, diminished social support, and feelings of loneliness and/or not belonging (Cornwell & Waite, 2009; Decker, 2007). A lack of social relationships has been consistently linked to poorer health status and survival among cancer patients (Pinquart & Duberstein, 2010). Cancer survivors whose physical function has been compromised due to cancer and its treatment may also suffer from social isolation. Cancer survivors may find that they are unable to take part in social activities and hobbies because of side effects such as CrF. In addition, they might not be able to take part in conversations with family and friends owing to severe fatigue. Participation in such activities allows survivors to feel more socially connected. However, an inability to engage in social interactions because of fatigue could have a negative impact on patients' psychological health and QOL. The study results revealed a positive improvement in social function in the EXG along with a positive relationship between physical function and social function. The EXG observed a clinical meaningful improvement in social function which was not evident in the HEG. As physical function improved, so did social function.

3.4.7.4 Global QOL

An additional main finding in our study was the positive intervention effect on global QOL (an individual's overall physical condition and QOL), in agreement with previous studies (Burnham & Wilcox, 2002; Courneya et al., 2003; Ergun, Eyigor, Karaca, Kisim, & Uslu, 2013). Clinically important improvements in the EXG after the intervention were maintained at follow-up. This supports the notion that exercise improves QOL during cancer survivorship (Courneya et al., 2003). Improving QOL is the key emphasis of cancer rehabilitation (Graydon, 1994) and participation in an exercise intervention such as the one in this study can help with such improvements and should be considered as an important component of rehabilitation for cancer survivors.

3.4.8 Fear of PA

Research postulates that fear controls avoidance of a behaviour (Bolles, 1975; Herrnstein, 1969). According to self-efficacy theory, there is a shared link between perceived self-efficacy and fear arousal, with self-judged efficacy having the greatest impact. Individuals who perceive themselves as ineffective in managing possible threats tackle a situation in an anxious manner, which triggers a negative arousal that in turn lowers their sense of self-efficacy regarding their ability to carry out the behaviour in a positive manner.

Self-efficacy is a key determinant of health behaviour change and is considered the key construct in social cognitive theory (Bandura, 1986). If a person feels more confident in their ability to carry out a task, they are more likely to engage successfully in the activity. Hence, interventions that decrease fear may improve self-efficacy and could potentially enhance behaviour compliance. In this study, fear of PA was measured in the breast cancer cohort only using the FAPX-B questionnaire. The intervention had a positive effect on fear of PA in the EXG after 10 weeks, which was maintained at follow-up. No changes were observed in the HEG. These results may be attributed to the fact that only the EXG were participating in PA and exercise, and gaining mastery skills, obtaining information, and enhancing their self-confidence. The reduction in fear of PA may also have resulted from an increased sense of accomplishment in reaching goals and taking part in the exercise programme as opposed to taking part in a HE programme. The decrease in fear in the EXG may be particularly relevant to the sustained increases in PA between 10 and 26 weeks, albeit at slightly lower levels. A key part of any rehabilitation intervention is to give participants the confidence and skills to direct their own PA.

3.4.9 Perceived health competence

Similar to self-efficacy, perceived health competence is an individual's perceived ability to manage their own health (Smith, Wallston, & Smith, 1995). As the number of cancer survivors continues to increase, it is important that these individuals improve their self-management behaviours to enhance their overall QOL and reduce the risk of other chronic illnesses that often occur in this patient group. Multiple chronic conditions exist among cancer survivors, including CrF, and may increase health care costs for both the survivor and the health care system. In addition, the management of cancer survivors in an already stressed health care system highlights the importance of implementing effective self-care strategies in the rehabilitation care for this patient population.

Lower perceived health competence has been linked to lower levels of physical activity among non-Hodgkin's Lymphoma survivors (Bellizzi et al., 2009). Additionally, perceived health competence has been correlated with many health behaviours such as exercise, improved dietary habits, reduction in smoking and drinking, and increased health seeking behaviours (Arora et al., 2002; Bellizzi et al., 2009; Marks & Lutgendorf, 1999; Tromp et al., 2005). In our study, we observed a positive effect for perceived health competence. Perceived health competence was increased in both the ExG and HEG. Self-management support has been defined "the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem-solving support"(Institute of Medicine, 2003, p. 57).

Information plays a vital role in improving patients' competence and efficacy expectations (Ream & Richardson, 1996). Education was a key part of both interventions. Enactive mastery, vicarious experience, verbal and social persuasion, and physiological cues are all sources of self-efficacy (Bandura, 1997), which both groups experienced through strategies such as tracking progress, identifying and overcoming barriers, goal setting, identification of key social supports to aid in problem solving, and incorporation of a buddy system. This may explain why there was a significant effect on perceived health competence in both groups. Improvements in perceived health competence in the EXG were maintained at 26 weeks. This further highlights the importance of the role of education in changing health competence among cancer survivors. Providing cancer survivors with the education, skills, and information they require may increase confidence in their ability to deal with their illness and side effects such as CrF, and in turn might enhance their health outcomes.

Perceived health competence has been closely linked to self-efficacy, and it has been observed that cardiac rehabilitation programmes improve self-efficacy along with a range of psychological health outcomes (Rodgers, Murray, Selzler, & Norman, 2013; Woodgate & Brawley, 2008). The change in perceived health competence observed in our study is very important in terms of cancer rehabilitation, as low perceived health competence could represent a target for rehabilitation interventions. Similar to cardiac rehabilitation programmes, post-treatment cancer survivors with low perceived health competence could be encouraged to enrol in an outpatient cancer rehabilitation programme following discharge. Recent research carried out in the USA suggests that cancer survivors who adhered to their PA recommendations achieved average savings in total health care expenditure of $4686/year for survival times of 1–5 years and $2874.5/year for survival times of ≥11 years (Yan, Wang, & Ng, 2018), highlighting the need to enhance survivors' perceived health competence. Increasing their perceived health competence and empowering them to take control of their own health may motivate cancer survivors to adhere to their PA recommendations, which in turn could help alleviate pressure on health care systems and reduce total health expenditure for cancer survivors.

3.4.10 PWV and CRP

Despite the large decrease in fatigue in the EXG, our study provides little evidence on the mechanisms involved, as there were no changes in PWV or CRP and no correlation with changes in fitness measures. Chemotherapy and radiotherapy are known to cause issues such as cardiotoxicity, including arterial vascular damage (Beckman, Thakore, Kalinowski, Harris, & Creager, 2001; Bentzen, 2006; Curigliano, Mayer, Burstein, Winer, & Goldhirsch, 2010; Eckman et al., 2013; Gajalakshmi et al., 2013; Mulrooney, Blaes, & Duprez, 2012; Vassilakopoulou et al., 2010) resulting in arterial stiffness (Chaosuwannakit et al., 2010). A unique aspect of this study was the assessment of vascular function as a health indicator and as a potential mediator of any intervention effect on fatigue.

In this 10-week moderate-intensity aerobic exercise intervention, we observed no effect on cfPWV. One plausible reason for the failure to see an effect may be the programme duration. Structural changes that regulate the tone of smooth muscle possibly take longer than 10 weeks. A recent study among cardiac patients revealed a larger decrease in cfPWV for participants who exercised for a longer duration (20 vs 12 weeks; Laskey, Siddiqi, Wells, & Lueker, 2013).

Almost two-thirds of the EXG were taking anti-inflammatory medication and 80% of the breast cancer cohort were taking medication related to their cancer treatment. It has been shown that tamoxifen after chemotherapy for breast cancer significantly reduces levels of cardiovascular disease risk markers such as CRP (Romero et al., 2012). It has also been demonstrated that anti-inflammatory medication reduces arterial stiffness (Maki-Petaja & Wilkinson, 2009). Hence, medications were a confounding factor and could have masked any exercise effect on CRP and PWV. Whilst the 10-week aerobic exercise intervention resulted in improvements in fatigue, physical fitness, QOL, cognitive functioning, and sleep, these improvements were not due to CRP or PWV. Despite the absence of an intervention effect, there is justification for measuring CRP and PWV in this population. Testing should be carried out before and after treatment as an indicator of the effects on these parameters.

3.5 Study strengths and limitations

3.5.1 Study strengths

This study has a number of strengths.

1. The study involved an appropriate comparison group, allowing the effects of exercise to be separated from the effects of investigator attention and peer support.
2. The inclusion of a fatigue cutoff score for inclusion ensured that there was greater scope for improvement.Furthermore, inclusion of only fatigued particpants in this study adds to the validity of our findings that exercise reduced fatigue levels.
3. Another strength of this study was the inclusion of a follow up timepoint. This enabled the investigation team to observe if fatigue returns to pre-intervention levels when supervised exercise ceases.
4. The high attendance rate was an additional strength of this study. The attendance rate was very high in both groups, 80.7% in the EXG and 88.3% in the HEG. There were no dropouts in either group after the 10-week interventions, with only two subjects lost to follow up. Comparisons with other studies is difficult, as very few have reported on adherence rates (Friedenreich & Courneya, 1996). Adherence is critical to the success of any exercise intervention and can pose a challenge in exercise programme research. Many strategies were included in this study to aid adherence, such as supervision within both interventions; inclusion of an exercise and health professional, which allowed for a great deal of control over the exercise load required in the intervention; implementation of a number of behavioural strategies in both groups; and a focus on the principles of progression in the EXG. Use of these strategies and the fact that the study was theoretically guided may have facilitated attendance and adherence to the interventions.
5. A further strength was the completion of comprehensive measurements of fatigue, physical activity, physiological and psychological health outcomes through the use of established measurement tools/instruments.

3.5.2 Study limitations

Although this study revealed a number of clinically important findings, a number of limitations must be highlighted.

1. The inability to blind the assessments, the small sample size, the non-random allocation to the intervention groups, and the considerable variation in time since treatment among the participants. In studies of this nature where the exercise intervention is organised and led by the investigator, blinding is not possible unless an external individual, competent in all testing measures, was engaged to undertake the pre-, post- and follow-up assessments. When dealing with a vulnerable group such as cancer survivors, it is important that the participants feel safe and at ease with the instructor. Therefore, having just the researcher carry out assessments facilitated a sense of familiarity and security, which might have had a positive effect on attendance and adherence to the programme.
2. Recruitment was difficult in this study, resulting in a small sample size recruited in 3 blocks. This recruitment pattern made randomisation impossible. The small sample size might also have resulted from the inclusion of a specific cohort (i.e., those with documented fatigue). Though, fatigue itself is a barrier to participation in PA among cancer patients, the recruitment of cancer populations to trials also seems to be an issue in general. Courneya et al. (2003) reported a recruitment rate of just 14% even though no specific CrF score was needed for inclusion. However, as also observed by Courneya et al. (2003), once enrolled, the EX participants complied with the programme and adherence rates were good, similar to the findings reported by others (Speck, Courneya, Mâsse, Duva, & Schmitz, 2010).
3. Another important limitation is that the 26 week follow-up timepoint did not include the HE participants. Therefore the results at this timepoint are not controlled. From an ethical and recruitment point of view, opinion was that it was necessary to offer the HE participants the exercise intervention after 10 weeks. As very few changes were experienced in the HE intervention between 0 and 10 weeks, it is unlikely that changes would have been evident at 26 weeks.
4. The use of self-report to measure PA and sedentary behaviour is an additional limitation. The use of a a research grade wearable device would have provided: 1. more accurate determination of PA and sedentary behaviour levels, 2.information on exercise intensity and, 3.information on PA and sedentary behaviour, and sleep

in relation to individual structured exercise sessions. Additionally, such data may be used to monitor PA and sedentary behaviour in the days following exercise to observe the acute effects of exercise on fatigue over the course of the intervention.

5. Sleep quality was also measured subjectively via a questionnaire. The addition of a research-grade wearable device would have provided details on nighttime awakening and activity due to issues such as pain, anxiety, hot flushes, increased need to urinate, impact of illness and medications; and daytime napping which has been found to be associated with fatigue in post treatment fatigued cancer patients (Broeckel et al., 1998). Future studies should collect data related to activity, sedentary behaviour, napping, and sleep over the full course of an intervention via an appropriate wearable device.

3.6 Conclusion

In survivors with documented fatigue, progressive exercise training has beneficial effects on fatigue, physical fitness, and other QOL outcomes beyond those attributable to peer support and investigator attention. This was evident from two different instruments used to assess CrF. Peer support and investigator attention may influence fatigue scores, and all studies need to consider an appropriate comparison condition when designing interventions. The effects of exercise are clinically meaningful and of considerably greater magnitude than those reported previously. The magnitude of the change observed here was possibly related to the level of fatigue in the cohort before the intervention, as more than half of the participants were severely fatigued at baseline. Most of the reduction in fatigue occurred during the first 4 weeks of the programme, so careful participant education and management during this time is essential to promote adherence. The exercise effects do not appear to be mediated by changes in inflammatory factors or vascular function, despite the toxic effects of some treatments on the cardiovascular system. Interventions involving moderate-intensity exercise with small weekly progressions tailored to individuals with fatigue can be successful in promoting adherence, decreasing fear of PA, and achieving increases in PA and fitness that last beyond the initial intervention period. Health and cancer services need to make provision for survivor-tailored structured exercise rehabilitation that will greatly enhance QOL, the ability to carry out activities of daily living, and assist in a return to work. Developing working relationships and collaborations with policy makers and stakeholders is vital to ensure that cancer survivors receive such exercise rehabilitation.

CHAPTER 4.

Exploring the experiences of cancer survivors with documented CrF in an exercise trial.

"So all we could do was to Sit ! Sit ! Sit ! Sit ! And we did not like it. Not one little bit".

The Cat in the Hat, Dr. Seuss

Chapter 4: Exploring the experiences of cancer survivors with documented CrF in an exercise trial.

4.0 Abstract

This qualitative exploratory study, explored survivors' perceptions and experiences of CrF, management of this fatigue, and experiences of the 10-week exercise programme. Two focus groups and four individual interviews were held with 14 programme participants. The results provide a deeper understanding of the quantitative results observed in Study 1, the efficacy study. Results suggest that CrF not only affects cancer survivors physically, it affects them mentally, socially and financially. Barriers, facilitators, preferences, and motives to exercise in fatigued survivors are also elucidated. It was concluded that a tailored exercise programme designed specifically to the needs of cancer survivors can have a multitude of physical, psychological, social and educational benefits. The combination of elements in the exercise programme was identified as fundamental and access to such a programme should be a routine part of cancer care.

4.1 Introduction

This chapter presents the results for and discusses the qualitative element of the PhD study, which followed on from the quantitative study detailed in Chapter 3. This qualitative study explored three issues: fatigued cancer survivors' perceptions and experiences of CrF; their experiences of how this fatigue was managed and treated; and how they experienced participation in the 10-week exercise programme described in Chapter 3. The research was carried out via semi-structured focus groups and one-to-one interviews with participants who were involved in the exercise programme.

While almost 3.5 million individuals are diagnosed with cancer annually in Europe (Ferlay et al., 2013), an increasing number are surviving the disease (Smedby, 2014). In many instances, cancer can now be managed as a chronic disease. However, such management requires the correct structured rehabilitation services for survivors. One of the most distressing side effects of cancer and its treatment reported by survivors is CrF, which often persists for years after treatment. CrF has a huge impact on patients' overall health, affecting them physically, psychologically, cognitively, socially, and emotionally, and hence reducing their overall QOL.

Exercise is an intervention that is attracting increasing attention. Meta-analyses of the effects of exercise on CrF have identified many positive outcomes (McMillan & Newhouse, 2011; Meneses-Echávez, Ramírez-Vélez, & González-Jiménez, 2015; Tian, Lu, Lin, & Hu, 2016; Van Vulpen, Peeters, Velthuis, Van Der Wall, & May, 2016). According to the results presented in Chapter 3, exercise has a large effect on CrF. A 10-week group-based exercise intervention compared to a matched health education comparison group was tested in a quantitative repeated-measures quasi-experimental study (n = 37) among cancer survivors who had documented fatigue and not currently undertaking ≥90 min of moderate to vigorous PA per week. The results showed significant improvements in fatigue on the FACT-F scale for both interventions, but the magnitude of the effect was greater for the exercise group. In addition, the results showed significant improvements in all aspects of QOL, insomnia severity, fear of PA, perceived health competence, physical fitness, moderate to vigorous PA levels, and sedentary time in the exercise group. These improvements were not observed in the health education group, suggesting that the positive effects observed can be attributed to the exercise. This points to a need for health and cancer services to provide survivor-tailored structured exercise rehabilitation to enhance survivors' QOL and their ability to carry out activities of daily living and assist in their return to work.

While quantitative data are essential to highlight the effects of exercise on survivors' health outcomes, little focus has been given to the subjective experiences of participants in cancer-specific exercise programmes, particularly programmes designed for fatigued cancer survivors. Capturing such qualitative data can shed light not only on their experiences of this incapacitating condition at personal and interpersonal levels but would also provide insight into barriers, preferences, and motives to exercise. In addition, it allows participants to express their views on the value of rehabilitation after treatment, consider what is available or not available, and to suggest improvements. Collection of qualitative data can therefore facilitate the development and implementation of exercise rehabilitation programmes to meet the specific needs of fatigued cancer survivors.

4.2 Study aim

The aim of this research was to explore fatigued cancer survivors' perceptions and experiences of CrF, management of this fatigue, and their experiences of the 10-week exercise programme.

4.3 Objectives

The objectives of this study were to:

1. Examine fatigued cancer survivors’ perceptions and experiences of CrF;
2. Explore their experiences of how CrF was managed and treated;
3. Explore their experiences and views on participation in the 10-week exercise programme;
4. Explore their perceptions of the barriers and facilitators for exercise with CrF; and
5. Identify their views on how care for fatigued cancer survivors could be improved.

4.4 Methods

4.4.1 Study design

To address the study aim and objectives, a qualitative exploratory design was applied. Qualitative research is often used to explore the effectiveness of programmes in health care and identify how they can be improved (Patton, 2002) and is an important method of data generation, especially when little is known about the problem (Krathwohl, 1998; Polit & Beck, 2012). Therefore, it is well suited for research on an exercise intervention that was unique in targeting individuals with documented fatigue, for which the literature is sparse. A qualitative methodology also provides those affected by the issue with a chance to voice their concerns, which will in turn inform and guide the outcomes of the research. In essence, qualitative research is concerned with how individuals makes sense of a situation and their experiences, with a focus on gaining an understanding from the participants themselves (Merriam, 2009).

4.4.2 Setting for data collection

The data collection took place in the same venue as the exercise intervention, 1 week after the last class in the programme at a time that suited participants. This setting was an environment that participants felt comfortable. Moreover, group interviews recapitulated the safe space and the company of those who had been a central part of the participants' experience to facilitate sharing their experiences, beliefs, and ideas, as opposed to individual interviews (Schulze & Angermeyer, 2003). Individual face-to-face interviews took place at a time and place that was most suitable for the participants. Refreshments were offered to all participating in either the focus group or individual interviews.

4.4.3 Participants and recruitment

Participants who had completed treatment at least 6 weeks previously and who had completed the exercise arm of the study outlined in Chapter 3 were invited to take part via a letter. Three separate 10-week exercise interventions were delivered over the course of the study period. After delivery of programmes 1 and 2, participants were invited to attend a focus group. After delivery of programme 3, participants were invited to individual interviews. Those interested in participating contacted the researcher for further information on receipt of the invitation letter.

4.4.4 Ethics and data protection

The WIT Research Ethics Committee and the Research Ethics Committee, Health Services Executive, South East approved this study. The trial was registered with BioMed Central (ISRCTN 58635908). All participants provided written informed consent before data collection and were allocated a unique identifying code for the purpose of confidentiality. The data collected were stored in a locked cabinet in the Postgraduate Room in WIT. No data that could have identified the participants were held on computer files. Notwithstanding this, computers and computer files with study data were password-protected.

4.4.5 Data collection methods and procedure

Focus group interviews and one-to-one interviews were used to collect the qualitative data. Participants were interviewed in either a focus group (2 groups with 5 participants in each) and four individual face-to-face interviews. Both the focus group discussions and the individual face-to-face interviews followed the same semi-structured topic guide and lasted between 45 and 60 min (Appendix 11).

The same format was applied in both focus groups according to the principles and guidelines for focus groups (Morgan, Krueger, & King, 1998). The number of participants usually recommended for a focus group is between five and ten participants (Rabiee, 2004) as too many participants in a group may hamper an individual’s chances of engaging and contributing to the conversation.

Following an explanation of the study and assurance of confidentiality, all respondents were asked to verbally confirm consent and permission for the discussion to be recorded. The researcher also took notes throughout the discussions.

Both focus groups and individual interviews have strengths. Focus groups are particularly suitable for exploring subjective understandings on a specific issue (Denzin & Lincoln, 1994). Focus groups are often used in health research (Twohig & Putnam, 2002) and are a means to study what individuals are thinking and why they are thinking so (Barbour, 1995). They also allow interaction between the research participants, which allows participants to describe common experiences that they shared and to challenge and question other elements on which they might disagree. While focus groups have advantages, some participants may have a much greater speaking time than others, which may impact on the contribution of some group members. Two focus groups were held. A decision was then taken by the research team to undertake individual interviews with participants from programme 3. Individual face-to-face interviews are often referred to as the gold standard for qualitative data collection. This method allows researchers to obtain more in-depth information from participants because of the longer speaking time in interviews held on an individual basis (Morgan, 1997). Furthermore, the researcher has greater control over the interview process, in contrast to the unpredictable nature of group dynamics (Denscombe, 2010). The reason for including both forms of data collection was to ensure that no data were missed using focus groups rather than individual interviews.

According to Gillham (2005, p. 5) "disclosing personal details to an impersonal medium can seem like letting part of yourself go, but in an interpersonal situation where trust is established that disclosure becomes possible". Therefore, as the principal investigator had created a bond with the respondents throughout the study, it was deemed appropriate that she should carry out all the interviews.

The researcher always restated and summarised what was said during the focus groups and face-to-face interviews to confirm that her interpretation corresponded to that of the participants. She ensured that everyone was given an opportunity to speak in the focus groups and all the group members were encouraged to participate in the discussion. Focus groups and the face-to-face interviews were recorded on two devices in the event that one should fail. Use of recording devices also allowed the researcher to note the tone of the verbal communication used.

4.4.6 Topic guide

The predetermined framework for the focus groups and interviews was based on broad open-ended questions relating to the experiences of being part of a 10-week exercise intervention, and followed previous exercise studies in cancer survivors (Appendix 11). Example questions included:

1. What motivated you to exercise?
2. What sort of barriers have interfered with exercise prior to the commencement of the intervention?
3. What were your reasons for taking part in this programme?
4. What was the main benefit of the exercise programme?

Probing questions were also used to allow for the emergence of further themes. Example questions included:

1. Had you received any information on CrF?
2. Were you given any advice on how to manage your fatigue?
3. Was fatigue something you would have experienced daily?

4.4.7 Data analysis

A thematic analysis approach was applied to the qualitative data following the guidelines set out by Braun & Clarke (2006) (Table 4.1). The focus group discussions and individual semi structured interviews were audiotaped, transcribed verbatim, and checked for accuracy. Notes taken were reread and further notes were written up soon after the focus group discussions and interviews took place so that no vital information was lost. The information gathered from the focus groups and individual interviews was read and reread to ensure that the researcher was very familiar with the entire body of qualitative data gathered. The researcher made notes throughout and jotted down early impressions. Coding was first data-driven through an inductive approach to ensure that a comprehensive analysis of the data was achieved (Braun & Clarke, 2006). In the next phase, the data were organised in a meaningful and systematic way. Theoretical thematic analysis was used to ensure that the research objectives were addressed in a meaningful way and that the data were analysed with this in mind. Hence, each segment that captured a point that was interesting or relevant to the research question was coded. Open coding was used and the researcher developed and modified the codes while working through the process. This was carried out manually, with the researcher working through the transcripts using pens and highlighters. The codes were then organised into broader themes relevant to and specific to the research objectives. As themes were developed, a working definition was assigned to each code. Hence, each time that the researcher read over the transcripts, the definition was repeatedly challenged. The analysis took place shortly after the interviews so that important information was recalled. The majority of the thematic categories were labelled using descriptive terms within the transcripts, while others were guided by questions in the topic guide. A detailed description of the themes was included, and quotes extracted from the raw data were selected to illustrate how the data was understood. The data associated with each theme were read and reread to ensure that the data interpretation was supported.

Table 4.1: Thematic analysis process adapted from Braun & Clarke (2006)

	PHASE	ANALYIS PROCESS
1	Researcher became familiar with the data	a) Transcribe the data b) Read and reread the data, noting prominent points
2	Initial codes were generated	a) Code prominent and interesting points systematically across the entire data set b) Organise the data as they apply to each code
3	Search for themes	a) Organise codes into potential themes b) Gather all data associated with each possible theme
4	Review themes	a) Check that themes are relevant to the coded extracts b) Check that themes are relevant to the entire data set c) Reread and review the data to search for and identify any further emerging themes d) Generate a thematic map of the analysis
5	Define and name themes	a) Continue to read and analyse to refine the specificity of each theme and the overall picture that the analysis paints b) Generate clear and concise definitions and names for each theme
6	Produce report	a) Select clear and convincing extract/quote examples b) Finalise analysis of selected quotes/extracts c) Relate all analysis back to the research questions and objectives and previous literature reviewed

4.5 Results

4.5.1 Participant characteristics

A total of 14 participants contributed to the focus groups and individual interviews. The mean age of participants was 57.3 years (SD 9.1, range 38–72). Participants had been diagnosed with breast cancer (n = 10), prostate cancer (n = 1), prostate and bladder cancer (n = 1), endometrial cancer (n = 1), or oesophageal cancer (n = 1). Education level ranged from primary school to third level. Thirteen participants were married, and one was separated. The mean length of time since treatment was 2.4 years (SD 1.9). The mean FACT-F fatigue score at baseline among this cohort was 19.4 (SD 8.0), which is indicative of severe fatigue.

4.5.2 Findings

A number of key themes emerged for the qualitative data that shed light on fatigued cancer survivors: experiences of CrF; experiences of how CrF is managed and treated; and experiences of participating in 10-week exercise intervention.

4.5.3. Fatigued cancer survivors’ personal experience of CrF

When discussing their experiences of CrF, participants discussed the physical, emotional and psychological experiences of CrF along with the functional impact it imposes (Table 4.2).

Table 4.2: Summary of the subthemes identified when participants discussed their personal experiences of CrF after cancer treatment

Theme	Subthemes
Personal experience of CrF	• Physical • Emotional • Psychological • Persistent • Not alleviated by sleep or rest • Functional impact

Participants noted the persistence of CrF and that it is not alleviated by rest or sleep.

"A tiredness sleep won't cure or lying down won't cure" CRF022

Others identified how fatigue affected them functionally in carrying out even the simplest of activities of daily living, such as difficulty in emptying a dishwasher. One participant said she was not physically able to carry out such activities owing to the severity of her fatigue, but still having to.

"You kind of couldn't function you are so tired" CRF019

"The tiredness is unreal, I mean emptying the dishwasher I could be like 'Oh my God I am wrecked now I could go to bed'" CRF013

"Sometimes you wouldn't be able to do it but, you would have to make yourself do it". CRF018

While participants highlighted the physical dimension of CrF, they also referred to the emotional and psychological dimensions as having a major impact on their lives, and that they may in fact be associated.

"Emotionally big time" CRF019

"I think it is a mental thing cos you are looking after yourself when you are going through the treatment, that you are kind of minding yourself and then when the treatment is over you are kind of in that rut that you just kind of couldn't get up and get out" CRF014

One participant questioned the existence of CrF, wondering if it were in fact something she was imagining.

"Ah is this in my head, am I just after getting lazy, is that what is wrong with me" and "you kind of get to a point where tis like 'Ah come on like, is it in my head, when is it going to stop?'" CRF013

One participant commented on how CrF affected her sleep, which contributed to her depression.

"I wasn't sleeping at all, I would get very depressed with it" CRF014

Participants noted that they often disengaged from activity as a method of conserving energy and a means of coping and dealing with their CrF.

"I was afraid then to do something because it was a case of if I do it I will be tired then and I am own with the kids tomorrow so I have to be able to look after them, and you do

actually become 'Ah sure look I will do nothing now because I need to save my energy for tomorrow'" CRF013

Although some mentioned disengaging from activity, others commented on the fact that everyone's situation was different and although the fatigue was immense, they forced themselves to carry out the activity.

"It depends on your situation too, I had two kids and I had to get up whether I was tired or not I wanted, I was wrecked as well, you know everyone is different aren't they, they have different things to cope with as well and you just have to get on with it and that is it" CRF 012

4.5.4 Cancer survivors' experience of health care following treatment

When discussing their experiences of health care following treatment, five key subthemes emerged: a lack of follow-up; a need for exercise rehabilitation; isolation and loneliness; a need for counselling; and a feeling of being left with no after-care.

Table 4.3: Summary of subthemes identified when participants discussed their experiences of health care following treatment.

Theme	Subtheme
Cancer survivor's experience of health care following treatment	• Lack of follow-up • A need for exercise rehabilitation • Isolation and loneliness • A need for counselling • Left with no after-care

Participants continuously highlighted that while the care was there during treatment, it seemed to stop once their treatment was complete, with a lack of follow-up.

"You are literally thrown out as such, do you know what I mean, you are finished and that is it" CRF022

Others noted that having no follow up care following their treatment was one of the biggest things missing from their care.

"That was probably the greatest void in our treatment that there is no real follow up, sure there wasn't" CRF020

Participants felt that:

"You have all the help when you are going through the treatment, you are there every week when you are going through radiotherapy, you are every day for 7 or 8 weeks and it's all a roller coaster and all of a sudden it stops, bang there is nothing, you come off that bus of a Friday evening and there is nothing" CRF019

Others mentioned that the care they received during treatment was excellent however, once the cancer was cured they were left with the after effects and they could no longer take part in activities they were once able to.

"When I was diagnosed with my cancer they were very good, they cured the cancer but they left you with a broken body this notion of you can no longer do the things you want to do because of that and so my treatment" CRF030

One participant agreed that there was a lack of follow-up after cancer treatment and highlighted the need for and benefits of a programme such as an exercise intervention to fill this void.

"This is very true cos 6 months you are given a date you come back, but what do you do within the 6 months, so this is where your programme is more than beneficial" CRF020

Participants also highlighted the isolation, loneliness, and emotional toll of having been through cancer that they felt following their treatment.

"I would always say it is like being out in the ocean on a boat, you don't know, you are on your own out adrift" CRF019

This may be because of the hectic schedule patients experience during treatment, in contrast to the less busy schedule after treatment, with one participant commenting:

"I think emotionally after the treatment more so than before because you are going from A to B to C" CRF018

Another participant highlighted the necessity for counselling following treatment and echoed the emotional toll experienced following treatment.

"After the treatment I found terrible, the emotion end of it that we never got any counselling, which should have been I think should have been there"CRF019

One individual compared cancer survivors to war veterans who had fought a war and won but were left with war wounds.

"We have been there, we have done it, we have been to war. I have to go back to it being like a battle, you go to war and you fight but you have the war wounds"CRF025

Some highlighted the fact that they were left alone with broken bodies and minds following their treatment with nobody to look after them.

"you are left with a broken body, a broken mind and you do need help to rebuild all of that, you definitely do, it is not good enough to say that you are cancer free" CRF030

As noted from the following example, participants reported that there was a lack of emotional backup following treatment.

"Well I thought once your treatment was finished that they were only just checking up on your tablets, your medication, that they weren't they weren't advising on helping you cope after your treatment" CRF014

4.5.5 Experiences of dealing with health care professionals in relation to CrF

When discussing their experiences of dealing with health care professionals in relation to their CrF, several subthemes emerged (Table 4.4).

Table 4.4: Summary of subthemes identified when participants discussed their experiences of health care professionals in relation to CrF.

Theme	Subthemes
Experiences of health care professionals in relation to CrF	• Exercise not prescribed • Untreated for years • Lack of understanding of others • Important for health care professionals to realise that CrF is a genuine issue • Wrong attitude towards cancer survivors • Lack of knowledge • Lack of available information

When asked if any of them had ever received any information on CrF before commencing the study, all participants answered “no”, with one participant stating:

“*No, no information, just get on with it” CRF014*

No participant reported ever being prescribed exercise as a strategy for managing or treating their CrF, and many participants were never advised of the exercise guidelines to follow after their cancer treatment.

“I never heard anything like that before, like told what to do and how to train and how to start walking and how to do the stretches afterwards and you know” CRF009

One participant did mention that one of the nurses suggested taking a gentle walk during treatment if they felt up to it. However, this was not a prescribed exercise programme.

“*One of my nurses during my chemotherapy did say a little gentle walk if you felt like it, go for a walk” CRF022*

The failure of health care professionals to prescribe exercise was suggested as a reason that might lead to fear of participation, with one participant commenting:

“I was never told that I could and you have a fear then that you can’t” CRF030

One participant noted that patients were left for years with CrF and felt that there is no reason as to why this should occur.

"People are left, I know of one person who has been left for years suffering with that terrible fatigue and where there is no reason to be" CRF030

4.5.5.1 Lack of understanding from others

A recurrent emerging theme was the lack of understanding of CrF by family, friends, and health care professionals. Participants noted that their CrF was seen as something that patients should just get on with and was not viewed as a true condition.

"They kind of always said 'You get on with it now you are finished', you know that kind of a thing" CRF014

"Like everyone around you thinks 'Oh you're done now, you are grand' and you are kind of going (eyes thrown up)" CRF013

Other participants disengaged from going outside as they felt frustrated with themselves regarding how they felt versus how they looked. Comments on their physical appearance passed by people they met angered them, as they felt that how they looked on the outside was not replicated by how they felt on the inside.

"I know people are kind of willing you to be better, they mean the best by it, but there was one week where I didn't go outside, I didn't go into to town because I knew if one person said to me you look great I would have hopped" CRF013

Other participants mentioned that family felt they should feel grateful that their cancer was in fact gone and not complain about their CrF, with one participant stating:

"And you should be like grateful like now, what are complaining about, aren't you very lucky tis all gone now like" CRF 009

Another participant commented on the importance of someone finally realising CrF is a genuine issue for some post-treatment cancer survivors. She added that someone eventually found a way of getting to the root of the problem.

"It didn't register what it [the exercise intervention] was going to do for us, you see the first and foremost thing was that somebody, somebody being you Trish, that you realised that there was a problem, the fatigue was a major issue for cancer survivors which as far

as I was concerned, even though my consultant tried to find a way to help me medically, my GP both medically and psychologically tried to help me, I was seeing a psychologist and a psychotherapist, nobody was actually getting to the nub of the problem" CRF025

One participant suggested that health care professionals, family, and friends have the wrong attitude towards cancer survivors participating in PA. Their focus seems to be on what they cannot do rather than on what they can do, which a perception that they would be doing more harm than good.

"People trying to mind you and say you shouldn't do that really, because, and that is not the attitude to have, the attitude should be well you know you can do it"CRF025

The participant further highlighted the lack of knowledge regarding exercise for the treatment and management of CrF among health care professionals.

"I mean he was my GP for 30 years and he would have always said how important exercise was, but prior to this programme he wasn't aware of the actual benefits for fatigue" CRF025

Participants also spoke about the lack of understanding that cancer is not just a physical condition but also a psychological issue. They noted that just because a cancer patient may look well physically, this might not reflect how they are psychologically. One participant suggested that misunderstanding of CrF might be attributable to the fact that CrF is not externally visible to others.

"Ya, like, when you are finished the treatment, like you know people are saying 'Oh you look great, you look great and your hair is back' and this and that, but like it is not how you look at all, it is how you feel" CRF012

"… cause tis what you feel and not how you look at all" CRF012

4.5.5.2 Lack of available information

Reasons for misunderstandings regarding CrF were also discussed. One participant suggested that this might stem from a lack of available information on CrF. By not having the information, participants felt they were not prepared for CrF and were expected to return to normal life. However, they also highlighted that life was not normal because of the CrF they were experiencing.

“I would say like the lack of information, it would have been beneficial for us as we know now, but you see this was never explained once the cancer was cured, this was it you know, and you are expected to resume to normal life, but life wasn’t really that normal you know because you had this thing you know” CRF020

Another participant commented that had they known what to expect or how the CrF could be treated and managed, this would have helped.

“You are not spoken to at all, even if they if they said ‘You will be tired and you will feel like this and this is just you that is just tired’ and maybe tell you something you could do about then, like you just get into a rut of being tired and not able to do stuff” CRF009

Participants stated that the medical profession did not know what to do with them once their treatment was finished and they were cancer-free.

“This is life-changing, our medical profession healed us physically but they hadn’t a clue what to do with us afterwards” CRF025

4.5.6 Participants’ experiences of PA/exercise following treatment

When participants discussed their experience of PA following cancer treatment, one key theme that emerged was their fear of PA/exercise. When discussing this fear, further subthemes emerged (Table 4.5).

Table 4.5: Summary of subthemes identified when participants discussed their experiences of PA/exercise following cancer treatment.

Theme	Subthemes
Fear of exercise/PA	• Fear of exacerbating CrF • Information/advice received from health care professionals • Fear of injury • Fear of increasing pain

4.5.6.1 Fear of exercise

Many of the participants commented on their fear of participating in PA and exercise following cancer treatment. One participant thought that by doing nothing they were conserving energy and feared that exercising would exacerbate the fatigue. She opted to do nothing to conserve energy to allow her to engage in her parenting role.

"I was afraid then to do something because it was a case of if I do it will I be tired then and I am on my own with the kids tomorrow so I have to be able to look after them and you do actually become 'Ah sure look I will do nothing now because I need to save my energy for tomorrow'" CRF013

Another noted that fear stemmed from the information received from the health care team. She feared that by engaging in such activities she would increase the risk of injury or damage.

"We were told like 'Don't put a heavy handbag on that shoulder', mind the shoulder where I had the reconstruction, 'Mind the reconstruction, be careful you know with the safety belt in the car', all them things, like you know what I mean, and you were always kind of fearful and fretful that something could happen" CRF024

Another participant feared increasing not only the risk of injury but also the level of pain by engaging in PA/exercise.

"I was afraid of doing personal damage shall we say from surgery, you know that is what I was afraid of really, because I mean you are still sore" CRF027

4.5.7 Other feelings experienced following treatment

When asked to discuss any other issue they experienced following cancer treatment, further subthemes emerged, including survivor's guilt, fear of been seen ungrateful, financial burden, and the need for GPs to be more involved in patient care during treatment (Table 4.6).

Table 4.6: Summary of subthemes identified when participants discussed other issues experienced after cancer treatment.

Theme	Subthemes
Other issues experienced following treatment	• Survivor's guilt • Fear of being seen as ungrateful • Financial burden • Need for GPs to be involved in patient care during treatment

Participants spoke of feeling survivor's guilt as a reason why they had not spoken to others about what they had been through, and feared they would be seen as being ungrateful.

"I hadn't gone outside of a medical setting, hadn't really spoken to my family, definitely not to my friends, because there was that fear of being ungrateful … not able to say it because it has to come back to be grateful for what you have got" CRF025

"I am not the first cancer survivor who took to bed, and as I said the biggest barrier is you feel so guilty because you survived" CRF025

Participants commented on the financial strain of a cancer diagnosis, with the delay in receiving a medical card further adding to the burden.

"I was looking for a medical card, I was almost like, I applied when I was started and I had 4 chemo's over beforehand like, I had spent money on medication and I had lost my job and like financially I needed it" CRF012

Extra expenses incurred by patients such as fuel and parking costs when attending appointments were all noted as adding to the financial burden experienced not only by the cancer patients themselves but also by family members and friends.

"I drove up and down every day for my radiotherapy. I know there was the drive service too, but it didn't suit me with the times, like I used to just drop the kids to school and go down, like even that like €20 a day on petrol is gone like" CRF012

One participant highlighted the need for the GP to be more involved in patient care during treatment, and felt they were somewhat excluded from their cancer care.

"Your GP is actually cut off when you are going through the throws of cancer because you are attending, I suppose, you are gone to a higher level, you are attending consultants and professors and your GP is not as included in your care"CRF025

4.5.8 Suggestions for improving care

Participants discussed what is needed and perhaps missing in cancer care. Several subthemes emerged, including: a need for cancer rehabilitation to be embedded in cancer care; a lack of information and support in sourcing essentials following a cancer diagnosis; exercise as a missing link in cancer rehabilitation; and a lack of interventions to help with the psychological effects of a cancer diagnosis (Table 4.7).

Table 4.7: Summary of subthemes identified when participants discussed what is needed in cancer care.

Theme	Subtheme
What is needed/missing in cancer care	• Need for cancer rehabilitation to be embedded in cancer care • Lack of information/support in sourcing essentials • Exercise as the missing link • Lack of interventions targeting the psychological effects following a cancer diagnosis

Many participants highlighted the need for cancer rehabilitation to be incorporated as part of the whole treatment pathway for cancer patients.

"I think it should be incorporated into the cancer treatment, that the progression afterwards is important and if you want it you have that option" CRF020

Participants mentioned that they received a pack about their treatment as a patient and highlighted the need for this pack to include the rehabilitation element of their care. They felt that rehabilitation should be incorporated into cancer care.

"The welcome pack that you get in the hospital, like when you meet the oncologist, and it tells you here is all the numbers you need, here is about the treatment, and you are told you are going to have surgery, you are going to have chemo, you are going to have radiotherapy. It would be great if there were 5 points to that, like the standard for the treatment is you have surgery, you have your chemo, you have your radiotherapy, here is your appointment with the Solas centre, here is your appointment for your exercise programme, your assessment that you will do afterwards, that it is, this a full package" CRF 013

One participant noted that exercise rehabilitation is what is missing from cancer care.

*"*We *knew that this was going to be the best thing for us because we knew it had been missing from our cancer treatment. While we were given all of the physio and the reflexology and the tablets and the surgery and all that, but sure this is what we were missing like, and the exercise is not only helping us on our physical body, it is actually helping us with our mental health" CRF024*

Another participant commented on the lack information or support in sourcing essentials following a cancer diagnosis.

*"*We *have enough to be doing but financially then as well, and like I found too, I got no support either in where to go to get the bra, you know, stuff like that"CRF012*

Many participants highlighted the emotional impact of cancer on their mental wellbeing, with the post-treatment period lacking interventions such as counselling. One participant commented:

"I felt awful down after chemo, terrible. At that time I nearly needed counselling, some kind of counselling" CRF019

4.5.9 Value of participating in the exercise intervention

Several subthemes emerged when discussing the most valued components of the 10-week exercise programme described in Chapter 3 (Table 4.8).

Table 4.8: Summary of the most valued components of a 10-week exercise intervention for cancer survivors with documented fatigue.

Theme	Subthemes
Value of participating in intervention	• Sense of normality • Sense of belonging • Being in the company of people in the same situation • Programme specificity • Builds exercise self-efficacy • Learn skills to self-manage fatigue • Encouragement received • Camaraderie

Many participants valued being with people who were experiencing the same issues, such as CrF. This provided them with a sense of normality and belonging, as they were with people in the same situation.

"For me, I suppose, meeting a group of people that were after going through the same or similar situation to me, cos we were all different types of cancer, so I suppose that was the first thing that I felt, for me was really, really good because we were all in the same

boat and then the effect that we're all going through the same sort of symptoms, like the fatigue and things" CRF024

***"**I think it was the fact that it didn't matter how unfit you were, that you felt it was ok, no one was giving out to us, we were doing it at our own pace and we were with likeminded people, if you understand me. We had all been down the same route and we were floundering, well I was floundering, but I feel the others were too, and it was suddenly ok to feel the way we felt" CRF025*

Other participants valued that the intervention was specifically designed to meet the needs of individuals recovering from cancer who were suffering from CrF. The design and implementation of a programme specifically addressing their needs and tailored to them gave participants the feeling that they were able to work within their capabilities.

"The most valued component was that it was exercises specifically for people who were recovering from major illness, ie cancer and fatigue, and so you didn't feel like you couldn't do it"CRF030

Participants also valued the encouragement they received in providing them with a sense of ability and confidence to carry out the exercises. In addition, they appreciated the positivity and the camaraderie that the intervention provided.

"From the very off you were encouraged to and you were able to go ahead and do whatever you had to do for, and the sense of I can do this and I was able to do it, and that was the best so the component for me, then was all the positivity and the camaraderie that the programmed infused" CRF030

A recurrent subtheme was the notion that the intervention reduced their fear of exercise and enhanced their exercise self-efficacy. One participant mentioned:

"I suppose the most valuable part of it for me personally was, I was afraid ,like with exercise and coming from hospital, like you have to be very careful, like someone after having major surgery, you must take things slowly, like that was a huge help to me, like that I could do, over time build up confidence and muscle, and so, like I mean, that is life, isn't it?" CRF027

Others valued the self-management skills that they learned for controlling their fatigue, and felt had they not been part of the exercise programme, they would still be without such skills.

"We got rid of our fatigue, at least we learned to control it, you know, and if we hadn't a programme like this we could be still found in the dark" CRF020

4.5.10 Benefits/improvements following intervention

The participants identified and discussed many benefits/improvements perceived from taking part in the 10-week exercise intervention (Table 4.9). Four main themes emerged that shed light on the perceived benefits/improvements of the exercise programme.

Table 4.9: Summary of benefits/improvements.

Theme	Subthemes
Physical benefits/improvements	• Reduction in fatigue • Decrease in pain • Increased strength, flexibility, and mobility • Improvements in breathing and reflux issues • Increased PA levels • Improved sleep • Ease in activities of daily living • Off some medications
Psychological benefits/improvements	• More positive-minded • Increase in motivation and appreciation • Reduced sense of isolation and loneliness • Improved role identity • Increased confidence • Reduction in fear of exercise
Social benefits/improvements	• Increased social connectedness • Sense of camaraderie • Made new friends • Chance to be heard

	• Increase in social engagement • Sense of belonging • Peer support
Educational benefits/improvements	• Obtain information • Share information • Learn new skills • Skill mastery

4.5.10.1 Physical benefits/improvements

Physical benefits mentioned by the participants included a reduction in fatigue. Some suggested that they felt that their fatigue improved immediately.

"My fatigue, straight away I noticed my improvement, in that the fatigue it started to improve straight away" CRF030

For others the improvement took a little longer.

"It took a while, mind you, I must say, probably after maybe about a month you know" CRF027

Some participants commented on their improvements in strength, noting that they were able to carry out some activities of daily living with more ease, such as opening jars and holding a hair dryer to dry their hair. They also noticed an improvement in pain when carrying out such activities. Furthermore, they felt that these improvements led to a reduction in their fear of exercise.

"I feel stronger actually across my chest. Even to hold a hairdryer to dry my hair used to be so sore, but like I can actually style my hair better now cos my arm is not aching the way it used to ache and it is because I am using it in the exercises, and then I am not afraid to use it when I am not exercising as such."CRF024

Several participants commented on their improvements in mobility and pain. One attributed her reduction in pain to her improvement in mobility.

"I think stretching and the mobility really helped with nerve pain" CRF022

"The immediate improvements in myself was that I had the nerve damage in my back after the meds and I was very immobile and my mobility was much improved" CRF030

Others observed improvements in other issues they were experiencing, such as breathing. One participant commented:

"I had a problem with breathing, but since I started doing the exercise I learned to breathe from the diaphragm, taking good deep breaths in. Before 'twas just shallow breaths and you are wondering why you are feeling tired because you are not getting enough air or oxygen into your lungs, you know" CRF020

Another participant noticed improvements in reflux and coughing within 2 weeks of commencing the programme.

"Within 2 weeks of starting exercise my reflux improved immensely, and coughing at night has also improved"CRF025

The group also identified improvements in their PA levels. One participant was convinced her PA levels would not be at the same level, nor would she have returned to full-time work or have improved her QOL, had she not seen the recruitment advertisement in a national newspaper.

"I say this with full conviction, if I hadn't seen your advertisement in the paper and was lucky enough to be included in that initial programme, I wouldn't be as active as I am today and I do not think I would be back in work full time and the quality of my life would not be as good. I fully firmly believe that" CRF030

An important benefit reported by one of the participants was feeling well enough to come off antidepressant, sleep, and pain medications after receiving GP clearance.

"When I went down to you 12 months ago I was taking two different types of an antidepressant and also a sleeping tablet and I was taking Panadol. I had got to the point I was only taking Panadol. I was off all painkillers. I was on 4–8 Panadol a day and I would say within 6–8 weeks the Panadol was reduced. I would take 2 in the morning when I would get up, because of, you know, stiffness and things like that, which was not to do with my cancer, and last April I felt well enough, with the agreement of my GP, naturally, to come off the sleeping tablet and the antidepressant, and I haven't had a reason to go back on those and I don't expect I will" CRF025

4.5.10.2 Psychological benefits/improvements

As well as the physical benefits/improvements arising from the 10-week exercise intervention, the participants also discussed the many psychological benefits/improvements they experienced.

Participants reported feeling more positive and having a better outlook on life after taking part.

"I am feeling positive after the study and exercise" CRF008

Others highlighted their sense of motivation and appreciation after completing the 10 weeks of exercise.

"I do feel more motivated, only for you I might have gone off my head — thank you so much" CRF011

Participating in the study helped in reducing the sense of isolation and loneliness experienced by some individuals, with others stating that it gave them back their lives.

"It gives you back your life, that elephant in the room is gone, that terrible, terrible blackness that comes down over people with diagnoses of cancer and they are going through the treatment, all of that you have, it is wellbeing body and soul" CRF30

Other participants acknowledged that the medical profession healed them physically but it was their participation in the exercise programme that put them back on their feet, to return to normal life.

"You put me back on my feet, not the medical profession. You made me feel comfortable, you made me whole again. This is life-changing, our medical profession healed us physically but they hadn't a clue what to do with us "CRF025

Another important psychological benefit of the programme mentioned by many was the perceived increase in confidence in a physical ability to exercise and be physically active. Participants recognised that CrF is in fact something they could get over by participating in the tailored exercise programme. One participant stated:

"Know that you are going to get past it, you can remove it, you can do it" CRF022

Another acknowledged that knowing how to manage her fatigue made her feel better.

"You know if you feel tired it is not straight into the chair or go up and lie down, once you get into a bit of fresh air and do what you can, you really do feel better" CRF020

Another participant reported being able to push herself more than she was.

"… learned that we can push ourselves a little bit more" CRF022

While many participants mentioned the negative impact that a cancer diagnosis has on mental health, they also commented on the positive effect the 10-week exercise intervention had on mental wellbeing. One participant stated:

"I found that after the exercise programme, I found that my mind, 'twas clear, kind of thing. I can't express it, the fuzziness was gone" CRF019

4.5.10.3 Social benefits

Overall, participants thought that the exercise intervention provided them with a sense of camaraderie.

"The encouragement that we get from one and other and the camaraderie, you know, it is really important" CRF027

Taking part in the exercise programme allowed participants to meet new people and make new friends who were experiencing the same feelings.

"… made new friends who are going through the same things" CRF014

The increased sense of social connectedness and engagement was highlighted on numerous occasions.

"We were in it together and have all been through it" CRF024

One participant said that it provided an opportunity to get out of the house for a chat.

"… just to get you out of the house, even for the chat" CRF014

Spending time with people going through the same thing allowed individuals to open up and gave them a chance to voice their concerns.

"I found it very good, cos as I said, I wasn't talking to anybody that I was bad, and the people I did [talking about before joining the group] they kind of always said 'You get on with it now you are finished', you know, that kind of a thing" CRF012

Other social benefits included positive effects experienced by individuals within their social support network, such as family and friends, and a feeling that they had regained their role and identity. This also resulted in social engagement and a return to greater participation in social activities, which in turn enhanced the feeling of social connectedness.

"So you see you haven't only saved me, you have given a family back their mother and their wife and their sister and friends back. I am heading off to a birthday party tonight with former colleagues, I would not have done that a year ago, I would have used an excuse "'Oh I am not really up to it'" CRF025

4.5.10.4 Educational benefits

Finally, participants reported that being part of the 10-week exercise programme gave them a chance to be educated, learn new skills, obtain and share information, and gain a sense of mastery. Participants noted that the education and knowledge they received gave them a positive outlook, as they felt they now had the self-management skills needed to identify what was wrong and how to fix it.

"The knowledge, that was part of it. It gives you a more positive outlook, you know yourself what is wrong and you now have the power to break that with the knowledge you have" CRF020

This resulted in some feeling more proficient and confident in self-managing. Additionally, they felt only for the programme they would still be non the wiser as to how to manage their fatigue.

"We got rid of our fatigue, at least we learned to control it, you know, and if we hadn't a programme like this we could be still found in the dark" CRF020

Others learned that they were not pushing themselves enough to reap the health benefits of exercise, and how to exercise correctly and at a proper intensity.

"… learned that we can push ourselves a little bit more and learned what moderate feels like" CRF022

Others highlighted that they had learned the correct techniques needed to exercise at the correct intensity.

"I learned how to walk properly, like, and it was done, cos I hadn't a clue, like, I used to be just, like, and as you said, just going out for a long walk, you are nearly better doing a shorter walk but at a brisk pace, you get more from it. So I learned that" CRF013

In addition, the educational element of the intervention reached others outside the research setting, such as participants' GPs and consultants..

*"*I *mean my consultant and my GP have both said how, I don't know what word, surprised, I suppose, I mean my last visit with both of them they actually recorded my words to them as to what this exercise group has done for me, because they were both trying for 3 years to get me beyond that hump, they didn't know" CRF025*

One participant mentioned that both her consultant and GP have even been educated because of the study.

"Our consultants are learning. I mean, my consultant has said to me he has learned from my exercise programme, that actually he can push his patients further than he thought he could" CRF025

Other participants commented on the fact that the programme gave them the chance to obtain and share information regarding their health issues, which in turn led to reassurance that they were not the only ones experiencing these problems. One participant commented:

"Well you can kind of compare notes and realise, like, I thought I was the only one that was tired every night and I thought I was the only one that was getting these hot flushes, that the itching from the tablets, but everyone else goes through some sort of stuff" CRF014

While another participant noted that it allowed them to:

"… pick up tips from people as well, like, you know, everyone has their own little tips that they could share, like" CRF009

4.5.11 Barriers to PA

When discussing participants' barriers to PA, three main themes and associated subthemes emerged (Table 4.10).

Table 4.10: Summary of barriers to participation in PA.

Theme	Subthemes
Physical barriers	• Fatigue • Body image
Psychological barriers	• Fear • Body conscious • Lack of motivation • Lack of information
Environmental barriers	• Location • Distance

4.5.11.1 Physical barriers

Participants discussed some of the barriers to engaging in PA and exercise that they faced, with the majority agreeing that CrF was the main barrier.

"The tiredness" CRF018

"The tiredness, energy levels, mostly I found" CRF022

Others suggested that lack of information

"I would say, like, the lack of information. It would have been beneficial for us, as we know now, but you see this was never explained once the cancer was cured, this was it, you know, and you are expected to resume to normal life, but life wasn't really that normal, you know, because you had this thing, you know" CRF020

and lack of motivation were also barriers to participation in exercise.

"Once the treatment was finished you just kind of relaxed, you just couldn't be bothered getting up and getting out again, ya" CRF014

Another participant noted:

"It was the thought of it, really, was worse than anything, you know. Once you got out you were kind of fine, but just kind of to get yourself out the door" CRF009

4.5.11.2 Psychological barriers

Several participants highlighted the fear of PA/exercise they experienced since completing their cancer treatment. Participants mentioned they feared doing exercise:

"You know, the way one of your questions was 'Have you a fear of doing exercise', I had before I did the study. I was afraid then to do something because it was a case of if I do it, I will be tired then and I am on my own with the kids tomorrow, so I have to be able to look after them, and you do actually become 'Ah sure, look, I will do nothing now because I need to save my energy for tomorrow'" CRF013

Others noted their fear stemmed from the information they received:

*"W*e *were told, like 'Don't put a heavy handbag on that shoulder', mind the shoulder where I had the reconstruction, 'Mind the reconstruction, be careful, you know, with the safety belt in the car', all them things, like, you know what I mean, and you were always kind of fearful and fretful that something could happen" CRF024*

While others fear was personal to them and they feared they would do more harm than good.

*"*I *was afraid of doing personal damage, shall we say, from surgery, you know, that is what I was afraid of really, because, I mean, you are still sore, shall we say" CRF027*

One participant reported that body image issues following surgery were a barrier:

"Particularly for people who have had breast cancer and that, you know, when you have had that kind of surgery you can be very body conscious, you, that could put you off going to a gym" CRF030

Another reported psychological barriers to participation in PA/exercise:

"I think it is a mental thing, cos you are looking after yourself when you are going through the treatment, that you are kind of minding yourself, and then when the treatment is over you are kind of in that rut that you just kind of couldn't get up and get out" CRF014

4.5.11.3 Environmental barriers

Location and distance from interventions were also reported as barriers because of the CrF experienced by cancer survivors.

"The Solas centre in Waterford have things and The Arc in Cork have things, but that is ok if you are living near them. We are 30 miles from there, we are not going to go there for that, you haven't the energy to do that" CRF022

4.5.12 Reasons for participating in the study

Participants had both practical and social reasons for participating in the study (Table 4.11).

Table 4.11: Summary of practical and social reasons for joining a 10-week exercise intervention for cancer survivors with CrF.

Theme	Subthemes
Practical reasons	• Location • A chance for follow-up • Cancer-specific • Recruitment advertisement
Social reasons	• Meet new people • In the company of likeminded people • A third space

4.5.12.1 Social reasons

Social reasons included a chance to meet new people,

"I love to meet new people, see were they feeling it" CRF018

and to connect with individuals who had been through the same experiences,

"To be honest the main reason I joined was that I would meet other people that were in the same boat" CRF020.

4.5.12.2 Practical reasons

Practical reasons included the location and a chance to use the intervention as a follow-up opportunity, which was identified as missing from cancer care

"The reason I did was that I had no other follow-up afterwards and I so happened to see it and I texted you then, and I was all for it, especially as it was based here as well [Dungarvan], you know, I wasn't interested in going down to Waterford" CRF012

Others suggested the specificity of the intervention, and the recruitment advertisement, as reasons for taking part.

"… and as a result of that, your ad in the health section of the Irish Independent jumped out at me one morning and I said 'This is what I have got to do', and I don't know where I got the courage to pick up that phone. and it was so easy after that because you made it easy" CRF020

4.5.13 Facilitators and preferences

Table 4.12 summarises the facilitators and preferences for exercise mentioned by the participants

Table 4.12: Summary of subthemes identified when discussing fatigued cancer survivor's preferences and facilitators for exercise.

Theme	Subthemes
Facilitators/preferences	• Cancer-specific • Individually tailored • Structured programme • Progressed incrementally • Smaller group format • Inclusion of an exercise professional • Informal teaching and instruction • Real-world practical approach • Programme simplicity • Exercising with other cancer survivors rather than the general population or others with other health issues

	• Walking and stretching • Praise, encouragement, positive feedback and reinforcement, acknowledging achievements

The majority of participants reported that having a programme specific to the needs of cancer survivors is hugely important

"I felt that this programme was specifically tailored to all our needs." CRF025

"I would prefer the cancer-specific for the group because that is the only way it is going to get stronger and stronger, and then, like that, with the different cancers it is better because we help one and other. Again, I am coming back to if you are telling a lay person on personal issues, you really don't understand, so it is definitely better as a cancer-specific group" CRF024

"… because even when we are exercising and one of them has reconstruction or one of them has prosthetics or a bag or whatever, because we all feel the same, we nearly kind of protect and get strength from one another, whereas if I had someone that wasn't a cancer patient there I would nearly be like comparing myself to them, or you would be thinking why they are perfect and I am not, so giving yourself kind of doubts. You would be giving yourself low self-esteem and that is what happens, unfortunately, it is part life, you know what I mean" CRF024

Some participants drove up to 40 miles to be part of the exercise intervention, as they felt that ordinary community gyms, with which they were very familiar, did not have cancer-specific exercise programmes that met the needs of cancer survivors. Therefore, they were willing to travel to address their unmet needs. One participant commented:

"Trish, I can actually put on my shoes and walk 1 mile down the hill, across the bridge and over the avenue to a gym to the loveliest of people who I personally know and do all I am doing in the arena, but it is not specific to my needs. I get into my car and drive my 40 miles on a Tuesday morning" CRF025

Participants also reported preferring to exercise with other cancer patients than with the general population, as it gave them an opportunity to discuss their problems, which provided them with a sense of reassurance that they were experiencing the same issues as others. One participant stated:

“Well you can kind of compare notes and realise like, I thought I was the only one that was tired every night and I thought I was the only one that was getting these hot flushes and the itching from the tablets, but everyone else goes through some sort of stuff” CRF014

One participant reported feeling more comfortable and preferring to be with people who understood what they were going through because they had been there too.

“I used to enjoy this, cos, like I used to say, before, when I was going to counselling in the Solas, like they are my cancer friends, the counsellor could never understand that I would prefer to be with them talking to them because they are all the same as me, we’re with others, they didn’t know what I was going through” CRF009

Participants reported that having their own exercise prescription was important and preferred. They felt that this allowed them to work within their own capabilities without feeling as if they were in competition with one another. One participant commented:

“Apart from the walking, you know, when you did the aerobics, like everyone could kind of do their own level, you know, whereas, you know, when you come out after surgery they give the same advice to, say, a woman in their 80s who wouldn’t have exercised much to someone who is in their 20s, it is ‘Don’t use your arm’, it is kind of a one-fits-all, they are giving the same advice. It is covering themselves” CRF013

Another participant said:

“… walk at your own pace, like, and everyone had different paces at walking and you didn’t feel like you had to keep up, you could do what you liked” CRF 009

Participants preferred the fact that the programme was participant-centred, with nobody admonishing them if they were unable to carry out a task.

“I think the fact that it didn’t matter how unfit we were, that you felt it was OK, no one was giving out to us, we were doing at our own pace and we were with like-minded people, if you understand me. We had all been down the same route and we were floundering, well I was floundering, but I feel the others were too, and it was suddenly OK to feel the way we felt” CRF025

“… you could do the parts that you were able to do” CRF 014

Having a structured programme tailored to the needs of the individual that increased the intensity incrementally and progressed within the ability of the participant was a facilitator mentioned by the participants.

"… more structured and, you know, you start slowly and I would have to reign myself in, and in fairness it was enough, like that first walk I slept 13 hours solid that night, and 10 minutes [referring to the exercise completed in the first session], like you know, it doesn't happen all of the time, but that first walk it was enough, like, and I would never have copped that myself, so …" CRF013

"I think as well the fact that it is specific, whereas if you kind of got a leaflet in the hospital saying, you know, it is recommended you started with 10 minutes of walking a day, I dunno, if I had gotten something like that, say, before all this, would I have taken, I would have kind of said 'Oh ya but, they are going to give that to the 80-year-old as well.' I probably would have disregarded and said 'Oh I am different', because, you know, I used to do exercise, whereas meeting someone who, you know, kind of telling you 'This is enough for you' is good, you know, it is" CRF 013

Smaller groups were also identified as a facilitator affecting the participants' motivation to exercise, as they felt that they would be missed more if they were in a smaller group, whereas the motivation to attend would have been lower in a bigger group.

"I think that having not a huge group as well, I think works [All agreeing], if it was a big group you would be saying 'Ah sure they won't miss me this week'" CRF013

"You would miss someone very fast. When it's a bigger group you would be saying 'Will I get the text "Where are you"'"

The smaller group also allowed participants to feel more at ease with each other; it created a more relaxed environment and participants were more likely to open up and voice their concerns. Smaller groups also enhanced the creation of cohesion within the group.

"… a small group, which I thought was very important, because none of us were lost. We were such a small group that we gelled quickly and without there being any agenda. Because it was so relaxed and easy, we were able to open up and voice, which I hadn't done outside of a medical setting"CRF020

It was highlighted that the inclusion of an exercise professional who could empathise with participants and ensure confidentiality was very important.

"You are younger than us but you were able to identify with our age group, you could be our daughter, but you were able to identify with our personal problems" CRF019

"… easy to talk to and if anyone had a complaint [medical] or anything, it was treated in confidence" CRF020

Many participants highlighted a preference for informal teaching and instruction, and the adaptability of the programme to allow individuals of various abilities to take part in the programme without feeling any different from anybody else. Having a common sense approach to the practicality of the programme in a real-world setting was also identified as a facilitator, along with seeing each participant as a whole person rather than focusing on specific elements. One participant commented:

"I think what has really made it what it is, is because you are so adaptable you weren't regimental, you were able to go with the flow, Trish. You might have had a certain idea, I mean, as you said you thought you were getting a certain age group, a certain cancer type, but because it threw up to you the wobblers, you went with that flow, and it was like when I take you back to when we were training in Templemore and there were people who were very academic and they would come out with 98% and 99% in their exams, and there were people who were very exercise-orientated and they would come out very well on that end of things, but I remember very well our instructor looked at you overall for the assessment. You know, the common sense factor. So what you have done is you had certain ideas and your research was leading you in a certain way, but when it came down to the practical appliance of it, you had to adjust and you had to amend your programme probably" CRF025

"… even though we had a group, you didn't make any of us stand out" CRF022

Other participants mentioned the simplicity of the programme as a facilitator.

"It was simple, but we benefited from that" CRF022

"… pointing out it is as simple as going for a walk, I think, is what sells it, because anyone can do that, like" CRF013

In general, participants preferred walking and stretching as a means of exercise.

"The stretching, I found it made a huge difference" CRF022

"I used to love the walking" CRF009

"The walking and the chatting and that" CRF012

"Well it got me into walking and I am going to do the marathon, no, like, and the stretches were brilliant as well. They were so relaxing, like something you would never do at home, well I wouldn't, anyway" CRF009

Praise, encouragement, positive reinforcement, and acknowledgment of achievements were not only reported as facilitators to exercise but also in turn made the participants feel better and motivated them to continue. One participant commented:

"I mean the praise and that, if someone was doing good, you were like 'Go on, you are going brilliant', like, and it encourages you then and it makes us feel good too then as well" CRF019

4.5.14 Motivation to exercise

Many strategies were incorporated to develop, enhance, and maintain motivation among the study participants. The group members discussed a variety of motives for exercising that could be divided into internal and external themes (Table 4.13).

Table 4.13: Summary of internal and external motives to exercise mentioned by participants

Theme	Subthemes
Internal factors	• Competitiveness • Acquiring health benefits • Personal ability • Personal fulfilment • Sense of progress • Curiosity about what they might miss if they did not attend • Sense of achievement
External factors	• Group achievement • Long-term goal • The instructor

	- Social support - Praise, positive feedback, acknowledgment of achievements, and encouragement

4.5.14.1 Internal factors

Internal motives included competitiveness, acquiring health benefits, personal ability, personal fulfilment, achievement, progression, and curiosity about what they would be missing if they did not attend. Participants highlighted seeing, feeling, and acquiring the health benefits of exercise as a motivator.

"Feeling better almost after 2 weeks" CRF022

"… getting rid of the fatigue" CRF018

"… seeing your little improvements every week" CRF013

"You don't see it, is just when you are shown the results, this is where you were and this is where you are at and this is now, and that is evidence, that is evidence that you can see, and you do feel it, but there it is, like this is what you could do then and this is what you can do now and that is hard proof that you are improving, and that can only encourage you to go on" CRF03

Another participant feared missing out on something, and felt that competitiveness and hunger to achieve were motivators to exercise.

"If you were doing it yourself you wouldn't bother, whereas you would be going 'I better go now, I don't want to be missing a week. I might miss out on something and they will all be ahead of me, I'd be Paddy last.' [All laughing] That competitive streak that you have to go, you know, and keep up with them, and it would get you out, like, you know" CRF009

One person noted that a long-term goal to walk the Dublin City Marathon and progression were motivators.

"Well it got me into walking and I am going to do the marathon now, like, I am progressing now and training for the marathon" CRF009

4.5.14.2 External factors

External motives discussed included a group achievement, goal setting, the instructor, social support and praise, positive feedback, acknowledgment of achievements, and encouragement. The instructor was mentioned as key to participants' motivation.

"I think it has to be someone like Trish that is jolly and, you know, because, you know, when you are feeling down you meet someone like you… You would say 'I will go into her, she is bubbly too' and you need a bubbly person" CRF018

"*You, you were the motivator" CRF019*

"Your voice" CRF022

Another participant identified the use of a professional as being key to motivation.

"Having the professional there was very important for me because I just didn't have the get up and go, the knowledge, or the enthusiasm to do it by myself" CRF024

"All the encouragement came from you. I say that honestly, that is what kept me going back" CRF027

Social support via weekly contact by text to check in on the participants and ensure they were keeping on track with progress was also identified as a motivator. One participant commented:

"Probably the texts that were coming through, like, as well, and you keeping track on us" CRF013

Numerous participants mentioned that the use of tracking devices and tracking progress were a key to motivation, along with personal fulfilment in reaching targets.

"Recording, that you could see your own progress" CRF020

"You wouldn't want to be coming in without having your 10000 steps done" CRF018

"But that step thing, I still use it, it is an incentive to move, like" CRF020

"That was excellent, the pedometer, that really got me going. I counted my steps, which I never done before" CRF009

"I think you have to measure your progress as well. I think it is important that when you start as you did, we measured the various fitness stuff that we did, and that is reviewed

regularly. You won't do that at home, you will do it in a group setting if you meet a professional who has that ability" CRF030

Group achievements in seeing other participants who were perceived as being in worse physical condition succeed was also identified as a motivator to exercise by one participant.

"The group of course, and when I was looking at some of the others who were unfortunately in a worst condition than I was, and to see their improvements was a huge help to me" CRF027

Praise, positive feedback, acknowledgment of achievements, and encouragement were also mentioned as motivators to exercise. One participant stated:

"The praise and that, if someone was doing good you were like 'Go on, you are going brilliant' like, and it encourages you then" CRF019

4.5.15 Experiences of being part of a post-treatment exercise intervention

Many experiences of being part of a pot-treatment exercise intervention for individuals with CrF were explored. When asked about their experiences, the participants mentioned a reduction in fear, getting the good from cancer, sharing the burden of a cancer diagnosis, the sense that there is life after cancer, a sense of giving something back, and feeling reassured that others felt the same way as their main dimensions.

Table 4.14: Summary of experiences of being part of a post-treatment 10-week exercise programme for fatigued cancer survivors.

Theme	Subthemes
Experiences of being part of a post-treatment exercise intervention	• Reduction in fear of exercise/PA • Getting the good from cancer • Sharing the burden • Sense of life after cancer • Giving something back • Opportunity for reassurance

4.5.15.1 Reduction in fear of exercise/PA

Fear was a huge issue for participants before commencing the exercise intervention, particularly fear that they might do more harm than good. Participants noted that the programme was a chance to get some peace of mind and reduce their fear.

“For peace of mind that we can do activities, etc. after cancer” CRF028

Another noted that they

“learned that we can push ourselves a little bit more” CRF022.

4.5.15.2 Getting the good from cancer

One participant commented that being part of the 10-week exercise programme was the best thing that had happened to her since receiving the news that she was clear of cancer.

“This exercise programme has been the best thing that has happened to me since getting the first all-clear cancer result” CRF025

4.5.15.3 Sharing the burden

Many of the participants described how the experience allowed them to share their burdens and gave them the reassurance that others were also experiencing the same issues.

“I was able to discuss things about my cancer with other survivors” CRF025

“… from the start, when you’re starting, it makes it very interesting, cos it makes you think, like, at least you know there is a group of us that feel like this” CRF024

4.5.15.4 Life after cancer

One participant’s experience of the programme made her realise that there is life after cancer, providing her with a sense of hope.

“There is a life after cancer now, cos we have that bit of positivity” CRF019

4.5.15.5 Giving something back

Another noted that the programme gave them the opportunity to give something back, that participating in the study created an opportunity for other cancer survivors to identify the positive impact it could have on them too.

“… a bit of encouragement now for people to see they could be out doing what I am doing, you know what I mean” CRF030

Table 4.15: Summary of results

Objective 1: Examine fatigued cancer survivors’ perceptions and experiences of CrF	
Theme	**Subtheme**
Personal experience of CrF	• Physical • Emotional • Psychological • Persistent • Not alleviated by sleep or rest • Functional impact
Objective 2: Explore their experiences of how CrF was managed and treated	
Theme	**Subtheme**
Experiences of health care professionals in relation to CrF	• Exercise not prescribed • Untreated for years • Lack of understanding of others • Important that health care professionals realise that CrF is a genuine issue • Wrong attitude towards cancer survivors • Lack of knowledge • Lack of available information
Objective 3: Explore their experiences and views on participation in the 10-week exercise programme	
Theme	**Subtheme**
Value of participating in intervention	• Sense of normality • Sense of belonging • Being in the company of people in the same situation • Programme specificity • Builds exercise self-efficacy • Learn skills to self-manage fatigue • Encouragement received • Camaraderie

Physical benefits/improvements	• Reduction in fatigue • Decrease in pain • Increased strength, flexibility, and mobility • Improvements in breathing and reflux issues • Increased PA levels • Improved sleep • Ease in performing activities of daily living • Off some medications
Psychological benefits/improvements	• More positive frame of mind • Increase in motivation and appreciation • Reduced sense of isolation and loneliness • Improved role identity • Increased confidence • Reduction in fear of exercise
Social benefits/improvements	• Increased social connectedness • Sense of camaraderie • Made new friends • Chance to be heard • Increase in social engagement • Sense of belonging • Peer support
Educational benefits/improvements	• Obtain information • Share information • Learn new skills • Skill mastery
Experiences of being part of a post-treatment exercise intervention	• Reduction in fear of exercise/PA • Getting the good from cancer • Sharing the burden • Sense of life after cancer • Giving something back • Opportunity for reassurance
Objective 4: Explore perceptions of the barriers, facilitators, and motivators to exercise in relation to CrF	

Theme	**Subtheme**
Physical barriers	• Fatigue • Body image
Psychological barriers	• Fear • Body conscious • Lack of motivation • Lack of information
Environmental barriers	• Location • Distance
Facilitators/preferences	• Cancer-specific • Individually tailored • Structured programme • Progressed incrementally • Smaller group format • Inclusion of an exercise professional • Informal teaching and instruction • Real-world practical approach • Programme simplicity • Exercising with other cancer survivors rather than the general population or others with other health issues • Walking and stretching • Praise, encouragement, positive feedback and reinforcements, acknowledging achievements
Internal motivators	• Competitiveness • Acquiring health benefits • Personal ability • Personal fulfilment • Sense of progress • Curiosity about what might be missed if participants did not attend • Sense of achievement
External motivators	• Group achievement • Long-term goal • The instructor

	• Social support • Praise, positive feedback, acknowledgment of achievements, and encouragement
Objective 5: Identify their views on how care for fatigued cancer survivors could be improved	
Theme	**Subtheme**
What is needed/missing in cancer care	• Need for cancer rehabilitation to be embedded in cancer care • Lack of information/support in sourcing essentials • Exercise is the missing link • Lack of interventions targeting psychological effects following a cancer diagnosis

4.6 Discussion

4.6.1 Introduction

The main purpose of this study was to explore experiences of being part of a 10-week exercise programme for post-treatment cancer survivors with documented fatigue. Focus groups and individual interviews explored participants' experiences of CrF after treatment, the care they received following treatment, and their experiences of being part of a 10-week exercise intervention.

To the best of our knowledge, this is the first study to qualitatively explore the experiences of cancer survivors with documented fatigued of taking part in an exercise intervention. The study provides not only an insight into fatigued cancer survivors' perceptions and experiences of CrF but also an understanding of how CrF symptoms affect them physically, mentally, and socially, and how CrF is treated and managed after cancer treatment. It also highlights other issues commonly faced by cancer survivors following treatment that may in turn negatively affect QOL. Furthermore, the study gives an insight into the participants' experiences of a 10-week exercise programme. It also provides an understanding of individuals' preferences for exercise content and delivery methods. It yields an insight into the barriers and motivators identified by the participants not only to taking part in a 10-week group-based exercise intervention but also to maintaining their exercise and PA behaviours, as well as their views on the value of cancer rehabilitation. The findings add to previous studies among cancer survivors by identifying barriers, preferences, and motives to exercise. The results could also aid programme developers by providing essential information on possible reasons for the uptake of such interventions and the most valuable components of an exercise programme.

4.6.2 Participants' experience of CrF

Participants discussed their personal experiences of CrF, the most common and disabling side effect experienced by cancer survivors and one that leads to major reductions in QOL and functional status (Curt et al., 2000). An important feature of the descriptions provided by the participants, all of whom had documented fatigue, was the element of persistence and the lack of CrF alleviation by rest or sleep. This is in agreement with other studies that highlighted the persistence of CrF (Berger et al., 2015) and how it is unrelieved by rest or sleep (Cella, Lai, Chang, Peterman, & Slavin, 2002). This suggests that there may be a link between sleep disturbance and fatigue, as also supported by the quantitative results from this research study. Consistent with previous research (Mock et al., 2000), participants also mentioned that CrF interfered with their usual function and impacted on their overall QOL.

Some participants disengaged from activities to deal with their fatigue because of the belief that by doing nothing they would be conserving energy. They feared that engaging in activity would exacerbate their fatigue. Others contested this, reporting that they forced themselves to engage in activities even though they were not physically able to, and knowing that they would feel more tired later as a consequence. Participants suggested they felt an obligation to take part in the activity as part of their role identity. Others disengaged from certain activities to conserve their energy so they could undertake their functional roles in daily life.

Social disconnection can be typified as a lack of contact with other people. Individuals lacking social connectedness or reporting feelings of isolation and loneliness often experience higher rates of mortality and morbidity (Brummett et al., 2001). It has been shown that remaining socially connected decreases mortality rates (Giles, Glonek, Luszcz, & Andrews, 2005), increases cognitive functioning (Ertel, Glymour, & Berkman, 2008), and reduces the risk of depression (Hays, Steffens, Flint, Bosworth, & George, 2001), additional issues that are often reported by cancer survivors as having impacts on their QOL (H. R. Smith, 2015). Social engagement can be grouped into categories such as social activities, helping/coping activities, and educational/intellectual activities (Herzog, Ofstedal, & Wheeler, 2002). All of these categories were addressed in the exercise intervention, which may explain the feelings of social engagement and connectedness experienced by the participants that in turn reduced their sense of loneliness and isolation and had a positive impact on their overall QOL.

4.6.3 Participants’ experience of health care and social support after treatment

Following cancer treatment and the completion of hospital-based monitoring, cancer survivors return to their GP for health care. Patients have often reported feeling a sense of abandonment on this transfer of care, referring to it as the “black hole” (Kendall et al., 2006). Many participants in our study perceived a lack of follow-up and a sense of abandonment following treatment, and reported that their unmet needs contributed to their feelings of isolation and loneliness following cancer. Isolation and loneliness are linked to decreases in QOL and have been identified as barriers to illness recovery and remission

(Wahl, 2012). Participants compared themselves to veterans who had been to war and won, but were left with war wounds and nobody to look after them, again highlighting their sense of abandonment.

One explanation for the feelings of isolation and loneliness noted by the participants may be that they did not have as many hospital visits and appointments to attend. Having a busy schedule during treatment distracted participants and kept them busy. Their appointments also provided social interaction with other individuals who were experiencing cancer. Social engagement is linked to social connectedness and comprises an individual's participation in activities in her social environment. Throughout this study, participants highlighted the importance of and their preference for being with people who were "in the same boat". According to disengagement theory (Streib, Cumming, Henry, & Parsons, 1962), as people age they naturally "withdraw" and "disengage" from social roles and relationships. This can also apply to those who experience CrF, as many of the participants mentioned how their condition prevented them from taking part in social activities, with many also not returning to work, and thus there was also an impact on their previous role functions. This withdrawal from usual role functions may also partly explain the feelings of isolation and loneliness experienced after cancer treatment, as survivors find themselves not as socially engaged or connected as they were when they were receiving treatment.

Being part of an exercise intervention with individuals experiencing the same issues has the potential to help cancer survivors to cope during this vulnerable time. This may in turn help to reduce their sense of abandonment, especially if the exercise programme is embedded in the cancer care continuum, with health care professionals involved in patient referral. On numerous occasions, the participants in this study discussed how being part of the exercise intervention helped to alleviate their sense of loneliness and social isolation and promote social connectedness and engagement by being in the company of likeminded people all experiencing the same issues. In addition, the physical fitness improvements mentioned during the focus group discussions and interviews and observed quantitatively, as described in Chapter 3, may have enhanced the ability of participants to engage in social and leisure activities. This greater ease may have led to increased contact with other people, which in turn could have enhanced feelings of social engagement and connectedness.

It has been posited that social context is highly significant in how representations are shaped (Sinding & Gray, 2005). The lack of support from health care providers and their general social network regarding their CrF may explain the feelings of loneliness reported, as many participants said that they did not talk to anyone about their fatigue. Participants did not want to give the impression that they were complaining for fear of appearing ungrateful, which increased their sense of guilt. This finding is comparable to a recent Irish study (Corbett, Groarke, Walsh, & McGuire, 2016) in which the investigators explored the post-treatment experience of fatigue among cancer survivors. Focus groups were used to allow participants to discuss their experiences of fatigue in depth. Participants in that study also reported feeling under pressure to not be seen as though they were complaining.

4.6.4 Participants' experience of management and treatment strategies for CrF

The mean baseline FACT-F score among participants in this study measured was 19.4, which is representative of severe fatigue, and the mean time since treatment was almost 2.5 years. No participant had ever received any information on CrF. Thus, participants may have felt misunderstood and that their health care team did not view CrF as a true condition, but rather something they should just get on with. Similarly, previous research identified a lack of understanding of CrF among both family members and health care professionals (Rosman, 2009). Participants in our study felt that CrF was considered as something they had to get on with. This highlights how the role of others affected their experience of CrF. The lack of understanding regarding CrF may contribute to the feelings of isolation experienced by cancer survivors, adding to their symptom burden (Dickson, Knussen, & Flowers, 2007). The lack of understanding may be attributable to the "invisible" nature of CrF, which may lead people to question the sufferers' experiences of the condition (Scott, Lasch, Barsevick, & Piault-Louis, 2011).

If CrF is to be treated correctly, health care professionals need to be aware of how serious and debilitating this condition is. CrF needs to be viewed as a condition that patients should not be left to cope with for years following treatment, as highlighted by one of the participants. However, the lack of information and knowledge about CrF may explain why it is so misunderstood, misdiagnosed, and underdiagnosed. Thus, obtaining information from individuals who experience this disabling side effect increases the likelihood that those affected by CrF will receive the care and understanding they need.

Since none of the study participants received any information on CrF, it was not surprising that exercise was not recommended as a strategy for its management or treatment. Again, this suggests a lack of knowledge and information among health professionals about the benefits of and guidelines for exercise prescription for cancer patients. Prescribing exercise may be beyond the expertise of health care professionals. This highlights the need for exercise oncologists to be integrated into the care of cancer patients.

The lack of information on guidelines for exercise by cancer survivors was suggested as a factor that further exacerbated the participants' fear of exercise. Because they were not aware of the correct exercise guidelines, participants feared that they would be doing more harm than good, increasing their risk of injury and/or pain. This is not surprising, as a study carried out in Ireland revealed that only one-third of oncology nurses felt they had sufficient knowledge regarding exercise prescription in cancer care (O'Hanlon & Kennedy, 2014). In our study, participants suggested that the information they received from health care professionals regarding PA also created a sense of fear. Some health care professionals advised against engaging in certain activities, with a focus on what the patient could not do rather than on what they could, which contributed to an increase in fear among participants. Family members also added to participants' fear of exercise by over caring for them rather than allowing them to participate in PA and exercise. This highlights the need for education of health care professionals and family support networks and provision of the correct information regarding PA and exercise for cancer populations. The focus should be on motivating cancer survivors to initiate and maintain their PA levels to enhance positive health outcomes after a cancer diagnosis as opposed to reducing PA levels during and after treatment.

4.6.5 Improving cancer care

Participants in our study felt there was a void in their care following treatment, and they emphasised the need for an exercise rehabilitation programme to fill this void. Individuals with a chronic illness are often encouraged to self-manage their condition by acquiring the skills to do so from their primary care team (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Integration of a suitable exercise rehabilitation programme into primary health care has the potential to not only provide individuals the skills needed to exercise correctly and effectively but also to reduce the risk of developing further chronic illnesses. However, for integration of such a programme into primary care, cancer needs to be viewed as a chronic condition and included in a chronic care model.

Participants noted there is a need for GPs to be more involved in patient care during treatment. This could lead to a more collaborative and synchronised approach to patient care, as participants felt that their GP was left in the dark during the treatment phase of their cancer journey. Participants also continuously highlighted the need for a more holistic approach in the treatment of cancer. The focus should not be simply to get rid of the cancer but also to incorporate rehabilitation, as is done for cardiac care in Ireland and elsewhere. A one-stop shop that includes diagnosis, treatment, and rehabilitation in cancer care is essential to provide patients with the skills and knowledge to help them cope and enhance their QOL, and eventually return to their normal life. This would ensure that the needs of cancer patients are met in each stage of the cancer journey from diagnosis to survivorship.

Participants highlighted the lack of information, resources, and support in sourcing essentials following treatment, as well as a lack of emotional and psychological support. They felt that emotional and psychological care following treatment should be incorporated into the overall care for cancer patients. Individuals stated that participation in the 10-week exercise intervention helped them both emotionally and psychologically, so a suitable exercise programme is something that could be integrated into their overall care plan.

4.6.6 Reasons for participating in the study

Participants had both practical and social reasons for participating in the study. Practical reasons included a chance to obtain information and, an opportunity for follow up, which they felt was missing from their cancer care. Another practical reason for joining was the location of the programme. Participants highlighted the need for cancer support facilities to be located closer to their home, as distance to the location was viewed as a barrier, in agreement with previous research. They also reported that an exercise intervention specifically tailored for cancer survivors with CrF facilitated their decision to join the programme. Similarly, participants in a precious study felt that an exercise programme specifically for cancer survivors helped in their decision to join (Luoma et al., 2014). Cancer-specific programmes have been identified in the literature as a facilitator of exercise among fatigued cancer survivors (Blaney et al., 2010).

Social reasons for participating included a chance to meet new people and connect with likeminded people who were experiencing the same issues. Similar motives for participation were evident in previous studies (Wurz, St-Aubin, & Brunet, 2015): individuals took part because of the social support and networking opportunities and the chance to be around similar survivors. An interesting theme that emerged from our study was the need for a third space outside of the participants' health care and family support network, a need that they acknowledged was met by taking part in the exercise intervention.

4.6.7 Most valued components of the 10-week exercise intervention

The participants in the present study discussed in detail their fear of participating in both PA and exercise. They feared that exercise would not only exacerbate their fatigue but could also actually do more harm than good. They attributed this fear to the lack of guidance regarding PA following treatment and the information that they received from their health care team, which focused on what they could not do rather than on what they could. Participants also mentioned many unmet needs, particularly in relation to their CrF. They highlighted the lack of understanding, information, and effective management and treatment for this disabling side effect, suggesting low self-efficacy for managing the consequences of their CrF in daily life. Many mentioned that they opted to do nothing to conserve energy, whereas others forced themselves to undertake activity and face the consequences of doing so, admitting that it often worsened their fatigue.

It was not surprising, therefore, that one of the most valuable components of the exercise intervention was the increase in confidence to exercise and manage fatigue. The confidence/self-efficacy enhancement noted by participants can be attributed to the many strategies implemented to increase self-efficacy and confidence. These strategies included motivation, goal-setting, encouragement, assistance in the development and implementation of a plan of action, positive feedback, problem solving, incorporation of social support, reinforcements, assistance with coping, and identifying alternatives for when things did not go to plan. Education was a huge element of the study, and many participants highlighted the educational benefits they gained. Providing participants with key information and skills enabled them to self-manage their activity and CrF. Evidence suggests that self-management empowers cancer patients by increasing their confidence and ability to take control of and manage problems associated with their disease and treatment, which thus enhances their QOL (Barlow, Bancroft, & Turner, 2005; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). This was echoed in the conversations with the participants in the present study. Self-management and support for self-management have been identified as key components in recovery and wellbeing for cancer survivors (Foster & Fenlon, 2011), and were among the most valued components reported by participants in our study.

Others highlighted that a feeling of normality and common ground in the group was a very valuable component of the programme. A sense of belonging is vital to health, as included in the Maslow (1954) hierarchy of needs. Participants felt a sense of belonging in that they felt connected and accepted. Considering the prevalence of isolation and loneliness mentioned by the participants, the sense of belonging provided by an exercise rehabilitation programme has the potential to support the recovery of cancer survivors by decreasing their sense of isolation and loneliness and enhancing their overall QOL. The participants in the exercise intervention felt that because CrF was a common issue in the group, nobody felt any different or a need to keep up with others. They appreciated that there were no repercussions for not being able to do something and they viewed this as a valued component of the intervention. In addition, the participants felt that the skilled instructor’s focus on what they could do rather than on what they could not do was important and valuable. Similarly, a previous study postulated that acceptance of the physical limits imposed on the body by cancer and its treatment and normalisation of the cancer experience can enhance group cohesion (McGrath, Joske, & Bouwman, 2011). The positivity, camaraderie, and encouragement involved in the programme were also mentioned as valued components. An empathetic and positive approach by instructors was valued as a component in a previous study (Stevinson et al., 2009).

4.6.8 Benefits of the programme

The findings in this study demonstrate that participation in a post-treatment 10-week exercise intervention contributed to physical, psychological, and social wellbeing dimensions of health and provided educational benefits, all of which contributed positively to overall QOL. The discussions highlighted that health is established via participation in meaningful activities that are enjoyed (Henderson & Ainsworth, 2002) and the social relevance of exercising with individuals who have shared similar experiences in the context of health and wellbeing in cancer survivorship.

4.6.8.1 Physical benefits

Physical benefits mentioned by the participants are similar to those described in qualitative data analyses for other exercise interventions among cancer survivors (Anderson, Caswell, Wells, Steele, & MacAskill, 2010; Groeneveld, de Boer, & Frings-Dresen, 2013; Luoma et al., 2014; Parry, 2008; C. Stevinson & Fox, 2006). Physical improvements mentioned by the participants in our study included fatigue, sleep, pain, strength, flexibility, mobility, breathing, reflux, and PA levels. Other physical improvements included ease in carrying out activities of daily living and a decrease in the intake of antidepressant, pain, and sleep medications. Physical improvement meant that individuals were more physically able to carry out activities with greater ease. Better sleep at night, less fatigue and pain, and improvements in breathing enabled participants to engage in more social interactions with others and take part in leisure activities for longer, enhancing their sense of social engagement and connectedness.

4.6.8.2 Psychological benefits

Psychologically, participants felt more positive and confident, similar to previous qualitative research (Korstjens et al., 2008; Parry, 2008; Spence et al., 2011; Wurz et al., 2015). Participants in our study also commented on their sense of social connectedness as a result of taking part in the exercise programme, in accordance with other studies (Luoma et al., 2014; Sabiston, McDonough, & Crocker, 2007). The increase in social connectedness experienced by participants reduced their sense of isolation and loneliness, which in turn increased their motivation. Participants continuously highlighted that being part of the 10-week exercise intervention gave them confidence to exercise and reduced their fear. This in turn enhanced their confidence and competence to self-manage issues such as fatigue, all of which had a positive impact on their overall QOL. This can be attributed to the education and skills provided as part of the programme and the information shared by other individuals who had undergone the same experiences.

One participant highlighted how the programme had reinstated her role as a mother, wife, and friend. Other participants returned to full-time work. Reductions in role functioning due to physical ailments diminishes participation in social and PA activities (van Weert et al., 2005; Kurtz, Kurtz, Stimmel, Given & Given, 1997). Survivorship is a critical transition time when cancer survivors endeavour to return to their life roles and recommence their functional activities (Hwang, Lokietz, Lozano, & Parke, 2015; Lyons, Hull, et al., 2015). However, many survivors have reported difficulties engaging in activities of daily living and participating in roles (Palmadottir, 2009; Porter-Steele, Tjondronegoro, Seib, Young, & Anderson, 2017). Many factors can contribute to a survivor's ability to return to roles and engage in activities of daily living, including resilience, social support, and coping skills (Allen, Savadatti, & Levy, 2009; Mols, Vingerhoets, Coebergh, & Lv, 2005). The 10-week exercise intervention provided participants with the coping skills and social support needed to engage in activities of daily living with more ease and return them to their roles. Research suggests that successful engagement in meaningful activities and roles has a significant positive effect on self-esteem, motivation, stress, anxiety, and a sense of meaning and purpose (Doble & Santha, 2008). By contrast, throughout the discussions and interviews, participants highlighted that CrF was a barrier to PA and exercise. They noted that it limited their ability to engage in meaningful activities and undertake their roles, which has been associated with serious health outcomes, including stress-related illnesses, depression, and isolation, which can lead to the development of further chronic conditions and lower QOL (Fox, Morrow-Howell, Herbers, Battista, & Baum, 2017; Lyons, Svensborn, Kornblith, & Hegel, 2015).

4.6.8.3 Social benefits

Discussions about the social benefits of the exercise intervention highlighted the overwhelming positive social experiences, including an opportunity to feel more socially connected and increase social engagement, which in turn enhanced the sense of belonging. These factors may explain why some of the participants felt that the group gelled straight away. A few individuals mentioned that they missed the camaraderie involved in being treated for cancer, such as the bus journeys to their chemotherapy sessions. The group exercise sessions enabled participants to once again enjoy that camaraderie. This highlights the importance of a group environment to re-establish bonds of fellowship and underlines the significance of social connectedness for cancer survivors. The participants themselves brought cohesion to the group through their active input, shared experiences, and sense of belonging (Wenger, 1997). Participants made new friends and emphasised the camaraderie felt in the group, stating that it gave them a chance to be heard; this was very important, as many individuals reported that they were not seeking help from their social support network. The peer support received by participants had many important features; in particular, the sharing of information and experiences with others in the same situation gave individuals a sense of normality. A sense of normality gained via participation in an exercise programme for cancer survivors was also reported by Korstjens et al. (2008). Sharing experiences and comparing notes about side effects gave participants a sense that what they were experiencing was normal in this phase of their rehabilitation. Mixing with individuals who shared similar conditions and issues meant that participants felt more at ease and confident about discussing their problems and gave them a voice, as some had not spoken to anybody regarding the issues they faced after their treatment. There was a feeling that others would not understand, and many mentioned that they feared they would come across ungrateful because they should be grateful that the cancer itself was gone. Support from others who share similar experiences has been identified as helpful in facilitating post-traumatic growth (Tedeschi & Calhoun, 2004; Weiss, 2004). The supportive atmosphere in the group helped participants to feel more confident and positive, in agreement with previous research highlighting the social benefits of exercising with others who share the same background, such as being diagnosed with cancer (Midtgaard et al., 2006).

The Irish Longitudinal Study on Ageing (TILDA, 2011) found evidence to suggest that QOL increases with social interactions. The importance of support groups for cancer survivors has been highlighted for those who lack social support at home (Helgeson, Cohen, Schulz & Yasko, 2000). The small group sessions in this study created a safe and supportive group environment, as participants encountered others who had faced the same serious health problems and challenges in an encouraging setting. Other studies on exercise by cancer survivors have recognised the need for social and peer support when exercising (Grant et al., 2011; Rogers et al., 2010).

All the aforementioned strategies and features undoubtedly influenced the success experienced by individuals and of the intervention programme. Application of theory enhanced the effectiveness of the programme, as reported by many researchers (Davis, Campbell, Hildon, Hobbs, & Michie, 2014; Fishbein & Yzer, 2003; Glanz & Bishop, 2010). This allowed the investigator to link important behaviour factors to suitable change methods (Bartholomew & Mullen, 2011).

4.6.8.4 Educational benefits

Many participants commented on the educational benefits they gained. The exercise intervention gave them an opportunity to obtain and share information and to learn and master new skills. The programme not only educated and informed participants but also provided them with a sense of empowerment and competence to self-manage and adopt a healthier lifestyle. Involving patients in their care by providing them with the correct information for making decisions on their treatment is an effective approach (Coulter et al., 2011) and could enhance the care of cancer survivors after treatment. Knowledge about one's disease, oneself, and the support resources available (McAllister, Dunn, & Todd, 2011; Rodwell, 1996; Tengland, 2008) are all attributes of empowerment. Personal skills to positively influence one's situation such as self-efficacy, self-esteem, and personal competence (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008; Van Den Berg, Van Amstel, Ottevanger, Gielissen, & Prins, 2013), along with the coping skills to live with a chronic disease (Aujoulat et al., 2008; Small, Bower, Chew-Graham, Whalley, & Protheroe, 2013), have all been identified as attributes of patient empowerment. External skills such as negotiation and questioning to clarify a situation have also been highlighted as features of empowerment (Aujoulat, d'Hoore, & Deccache, 2007; Giesler & Weis, 2008). The education, information, and skills provided by the skilled instructor, along with the information obtained from and shared by the other individuals in the exercise intervention, may have led to participants to feel more empowered, competent, and confident in managing their health.

It has been observed that having more knowledge allows better-informed decision-making on lifestyle changes and the treatment of conditions (Anderson & Funnell, 2011; McAllister et al., 2008; McAllister et al., 2011). However, obtaining social support from family and friends is also vital (Giesler & Weis, 2008; Small et al., 2013; Van Den Berg et al., 2013), which was echoed throughout the conversations with the participants. The supportive environment that participants experienced in being part of the 10-week exercise intervention may have enhanced their empowerment. Evidence suggests that empowerment is associated with better health status (Holmström & Röing, 2010; Oudshoorn, 2005) and QOL (Aujoulat et al., 2007; Bulsara, Ward, & Joske, 2004; Oudshoorn, 2005). This highlights the importance of education and a supportive environment in the development and implementation of an exercise intervention for post-treatment cancer survivors. It further underlines the need for patient education and supportive environments once treatment for cancer has ceased, something that the participants felt was missing from their care. The provision of these elements would allow patients to feel more confident, competent, empowered, and involved in their ability to self-manage their condition. Referral to a programme such as the exercise intervention outlined in this study has the potential to help patients in this vulnerable stage of their care.

4.6.8.5 Reducing the financial burden

Studies have suggested that high economic costs are linked to functional impairment among cancer patients (Demark-Wahnefried, Aziz, Rowlan, & Pinto, 2005). However, participation in an exercise intervention such as the one in this study may help in alleviating this burden on health care systems. A promising finding was that a number of participants returned to work, and others went from working part-time to returning to work full time following the exercise intervention. However, it is also essential that employers do more for their employees who are recovering from cancer. This cannot be as clear cut as to work/not work. Cancer is a chronic illness, and more compassion and flexibility are needed from employers to ensure adequate recovery by employees following cancer. In a recent case, Dublin City Council was instructed to pay €25,000 to a breast cancer survivor who suffered from CrF for not allowing her to work from home (Deegan, 2017). However, such flexibility and understanding will require more education to provide a better understanding of how patients are affected physically, psychologically, and emotionally by cancer and its treatment. More education is needed in cancer health care to provide health professionals with the knowledge and skills to address issues such as CrF and the role that PA and exercise can play in the treatment and management of such problems.

4.6.9 Barriers to exercise

The participants experienced many benefits from the 10-week exercise programme, but it is essential to note that most cancer survivors at the population level are not active enough. It is important to identify the exercise barriers, facilitators, and preferences among cancer survivors. In addition, knowing what maintains activity participation is vital. Our study revealed three main themes regarding perceived barriers to participation in exercise. These were physical barriers (fatigue, body image), psychological barriers (fear, body conscious, lack of motivation and information), and environmental barriers (location, distance).

As all the participants suffered from documented fatigue, it was not surprising that they all mentioned fatigue as the most common physical barrier to exercise. Previous research also identified CrF as one of the most common barriers to exercise (Clark et al., 2007; Courneya et al., 2008; Rogers et al., 2008). This is worrying, as none of the participants received any information or advice on how to manage or treat their fatigue. Similarly, a previous study reported that only 14% of cancer survivors had received advice on how to manage their fatigue (Stone et al., 2000).

Research has highlighted that exercise and its various benefits are not routinely discussed with cancer survivors (Daley, Bowden, Rea, Billingham, & Carmicheal, 2008). A lack of exercise guidelines has been identified as a barrier to prescription of exercise (Donnelly et al., 2010). Although exercise guidelines exist and PA is promoted to help in the management and treatment of fatigue (NCCN, 2016), it is clear that health care professionals are not aware of these guidelines, and education in this area is essential. This lack of awareness provides a further understanding of why CrF, which is a chronic symptom, is often underdiagnosed and undertreated. A factor that contributed to participants not engaging in exercise was the lack of information they received regarding exercise after treatment. None of the participants in the study had ever received any advice on exercise following their treatment, other than one nurse advising an individual to go for a walk. However, the frequency or intensity was not mentioned. Participants felt that this lack of information on how to exercise properly after treatment led to an increase in their fear of exercise. Individuals feared that they would exacerbate their pain or fatigue.

Education of health care teams on the promotion of PA and exercise is essential and should be provided to all cancer clinicians to reduce the possibility of survivors not receiving essential information. Inclusion of a recognised exercise intervention in the patient care pathway may enhance the possibility of referral, as is the case for cardiac rehabilitation in Ireland. While it is important that patients are cancer-free, it is equally important that their QOL is good to allow them to age successfully and lead as normal a life as possible. It is incontrovertible that more can be done to help cancer patients to transition to survivorship. Providing individuals with information on how to cope with and manage problems is an upstream approach to addressing issues such as CrF.

However, this is cannot be achieved unless cancer care teams and clinicians are educated on the benefits of exercise and guidelines on how best to treat debilitating side effects such as CrF.

Environmental barriers discussed by the group were related to the location of and distance to cancer support services. Many felt that the accessibility and distance to the location of the exercise intervention facilitated their uptake. In addition, many felt that the cancer services were only located in Waterford city. Participants from outside the city mentioned that they felt the distance was too far and that travelling might actually worsen conditions such as fatigue. They highlighted the financial burden incurred for travel to such support services, with many choosing not to take up the services offered. This highlights the importance of overcoming transport-related barriers (location, distance, and cost) to ensure that exercise rehabilitation interventions reach those they are targeted to reach.

4.6.10 Exercise preferences and facilitators

Considering that all participants in our study were suffering from daily fatigue, it was encouraging that all were happy to engage in exercise and motivated to continue. In agreement with previous research, the most enjoyable mode of exercise was walking (Karvinen et al., 2006; Rogers et al., 2009; Vallance, Courneya, Jones, & Reiman, 2006). Others also commented on how they enjoyed the stretching.

Supervision plays a vital role in the benefits of exercise experienced by cancer survivors (Velthuis et al., 2010). This may be attributable to the greater attention, encouragement, or confidence provided by a professional instructor. In this study, participants highlighted their preference for a professional instructor to supervise their exercise, consistent with results reported by Whitehead & Lavelle (2009). Unlike previous research in which participants highlighted a preference for one-to-one supervised sessions (Spence et al., 2011), participants in our study tended to favour a supervised exercise programme among a group of cancer survivors, comparable to other studies (Hennessy, Stevinson, & Fox, 2005; Luoma et al., 2014). This might be attributable to the group format that participants we4re previously involved in. In the study carried out by Spence, Heesch, and Brown (2011) participants had experienced a one-to-one supervised format, whereas participants in our study and those carried out by Hennessy, Stevinson, and Fox (2005) and Luoam et al. (2014) were part of a supervised group format. Offering participants some element of choice may be important to consider in future studies and in the development of exercise interventions for cancer survivors, as previous studies have highlighted that cancer survivors have a variety of exercise counselling and programme preferences (Jones & Courneya, 2002a).

Similar to previous studies, participants reported that they preferred to exercise with other cancer patients (Adamsen, Rasmussen, & Pedersen, 2001) as individuals who have been "in the same boat" or situation (Adamsen et al., 2001; Emslie et al., 2007; Midtgaard et al., 2006; D. C. Parry, 2007). This highlights the need to specifically provide exercise interventions for cancer cohorts to meet the needs of cancer survivors and increase their likelihood of engaging in exercise. Participants also expressed a preference for a small group format, as reported by Stevinson & Fox (2006). Participants in their study valued a small group format as it gave them with an opportunity to receive social support and inspiration from one another; participants in our study felt they were more likely to attend because they felt they would not be missed as much if the group had been larger. This highlights the importance of smaller groups to achieve adherence and retention. Keeping things simple and the adaptability of the programme in a real-world setting was identified as both a preference and a facilitator to exercise by the participants.

Participants also highlighted the encouragement and praise they received from both the instructor and the group, the positive feedback and reinforcement. Acknowledgment of their achievements was not only a facilitator but also a motivator to exercise. Encouragement and the connection with the instructor have been identified as an important feature in previous exercise interventions for cancer survivors (Anderson, Caswell, Wells, Steele, & MacAskill, 2010; Stevinson & Fox, 2006).

4.6.11 Motivators to exercise

Participants discussed their lack of motivation as a barrier to exercise before commencing the 10-week exercise intervention. Motivation is crucial in supporting sustained exercise. The instructor implemented various strategies to increase motivation. Factors that motivated participants to initiate and sustain their PA and exercise can be categorised as intrinsic (competitiveness, health, competence, personal ability, personal fulfilment, progression, curiosity, achievement) and extrinsic (group, long-term goals, social support, the instructor, praise, positive feedback, acknowledging achievements, and encouragement) (Sebire, Standage, & Vansteenkiste, 2009; Vansteenkiste, Lens, & Deci, 2006). According to the social determination theory of motivation, individuals have distinctive tendencies for personal development and growth that they are either happy with or are impeded by their immediate environment (Deci & Ryan, 2000). The theory distinguishes between intrinsic and extrinsic forms of motivation. Intrinsic motivation (inside–out) relates to the satisfaction inherent to carrying out the activity for the feel good factor, enjoyment, mastery of the skill, personal accomplishment, and enjoyment (Deci, 1975). Conversely, extrinsic motivation (outside–in) relates to the logical and rational reasons why anyone should exercise. The reasons for and benefits of exercise come from external factors and sources that lead away for the exercise experience.

Participants identified a variety of internal and external motivators, some of which were also perceived benefits of exercise, such as increases in confidence, personal ability, health, and fulfilment. The social support they obtained and the opportunity to exercise with other cancer survivors provided them with feelings of physical, psychological, and social wellbeing. Exercise participation boosted their sense of normality and of progression with their physical function, fitness, and other side effects of their treatment, including their CrF. The perceived benefits of exercise on their CrF was the main reason why some participants joined the exercise intervention, as reported in previous studies (Adamsen et al., 2004, 2001). Hence, although CrF is a barrier to exercise, having information on how an intervention targets fatigue in the marketing material may facilitate getting the programme started, as highlighting the benefits may act as an exercise motivator.

The step counter, fatigue log, and pedometer were vital self-monitoring tools that participants mentioned as important motivation tools. The combination of tracking their progress and logging their steps and fatigue levels enabled the participants to self-monitor their PA and fatigue. Self-monitoring is an essential component to increase awareness in behaviour change (Bandura, 1986), with previous pedometer-based research suggesting that self-monitoring strategies such as keeping a diary can motivate individuals to increase their steps (Rooney, Smalley, Larson, & Havens, 2003). By recording their steps and fatigue levels on a daily basis, participants were able to self-monitor and quantify their PA and fatigue levels and see their progression, which they had never done before. This enhanced their awareness of their steps and fatigue levels, and participants mentioned how this motivated them to move more as they felt it made them more accountable.

4.6.12 Overall experiences of participating in a post-treatment 10-week exercise intervention

The feedback regarding overall experiences of participating in a post-treatment 10-week exercise intervention for individuals with CrF demonstrated that it contributed to their social, physical, psychological, and emotional health. These improvements in health in turn enhanced their cancer survivorship, with some participants suggesting that taking part in the exercise intervention allowed them to "get the good from cancer". This reinforces the notion that health is indeed established via participation in enjoyable and meaningful activities (Henderson & Ainsworth, 2002). Therefore, a recommendation emerging from this study is that exercise interventions for cancer survivors should incorporate fun and enjoyment as a component as an important means to encourage exercise and PA engagement.

The distraction of taking part in an enjoyable activity with others who had gone through similar experiences allowed the group to share their problems and created an informal environment where they felt safe and encouraged to share. Participation in the exercise intervention distracted them from the disease and provided them with a sense of life after cancer and positivity, as well as a chance to rebuild their self-confidence. The distraction/time out hypothesis suggests that exercising with others sharing similar health problems created an opportunity for the participants to "tune out" from life stresses and negative thoughts and emotions (Anshell, 2006). The environment is an important social cognitive theory construct in behaviour change programs. Hence, the creation of a safe and secure environment enabled participants to feel comfortable and more at ease when sharing information. Furthermore, relationships and interactions with other participants can have a major influence on behaviour. Therefore, it was imperative that the social environment in the study was specific to the needs of the participants, allowing for adequate formal and informal social support. Social engagement is an important component of successful aging (Depp, Vahia, & Jeste, 2010) that is vital, especially as cancer survivorship and life expectancy in general have increased greatly in the past decade. Taking part in the group exercise intervention enhanced the opportunity for successful aging by helping the participants to cope after their cancer treatment and in their transition from patient to survivor. In rehabilitation for cancer survivors, improving their QOL is essential. Hence, exercise interventions for post-treatment cancer survivors should pay closer attention to the importance of social influence and contacts in

PA/exercise engagement and health behaviour (Berkman, Glass, Brissette, & Seeman, 2000).

Participants were provided with a secure environment in which they exercised safely under the instruction of a trained exercise professional, which allowed them to build their confidence to exercise and was valued by them. This feeling was further enhanced by seeing what they and others could achieve and how they could push themselves and progress. The participants valued the incremental progression and specific tailoring to the needs and ability of each individual. They also highlighted that the encouragement and praise received from others played a huge role. In addition, they mentioned that their participation would give other cancer survivors a view of their progression and would perhaps motivate others to participate, which provided them with a sense of giving back.

4.6.13 Study limitations

Even though the sample included participants with various cancer types (breast, prostate, bladder, oesophageal, and endometrial), their views are not representative of survivors of all cancer types. In addition, the study may involve self-selection bias because of the voluntary enrolment method used, and the group members (n = 14) may have been more motivated than those who decided not to take part.

4.7 Conclusion

This study set out to examine the perceptions and experiences of CrF of fatigued cancer survivors; their experiences of how this fatigue was managed and treated; and how they experienced participation in the 10-week exercise programme described in Chapter 3. The qualitative results provide a deeper understanding of the quantitative results observed for Study 1. The findings here suggest that a tailored exercise intervention for post-treatment cancer survivors with documented CrF can have multiple physical, psychological, and emotional benefits and provide social support in their transition from patient to survivor. The results contribute to a better insight into how cancer survivors with documented fatigue experience fatigue and how CrF symptoms affect them physically, mentally, and socially. They also provide a clearer understanding of the barriers, facilitators, preferences, and motives to exercise, which can facilitate enhanced development and implementation of exercise interventions to meet the needs of cancer populations suffering from CrF. Furthermore, the findings highlight what is missing and needed in cancer care following a cancer diagnosis. The research underlines the importance of exercise and health to cancer survivors and the need to include and study the personal experiences of cancer survivors.

While participants appreciated the fact their cancer was gone, they felt there was a void in their treatment with respect to the transition from patient to survivor, highlighting how their motivation, confidence, health competence, engagement in social and leisure activities, and activities of daily living had been impaired by the effects of cancer and its treatment. This was emphasised by one quote in particular: “We have been there we have done it, we have been to war and won, I have to go back to it being like a battle you go to war and you fight but you have the war wounds”. This was echoed by the other participants, who all felt the same. The participants felt they were left without being provided with the coping skills and information needed to transition from patient to survivor. However, participation in the 10-week exercise intervention described in Chapter 3 addressed these unmet needs. The findings from this study also highlighted how social and health care environments can contribute to ongoing difficulties in returning to prediagnosis roles and activities. Again, this may be attributed to a lack of information, knowledge, and understanding in these environments. While participants mentioned how their social and health care environments had a negative impact on their return to roles and activities, they also highlighted how creating the correct environment, such as that in the exercise intervention, facilitated such a return. This underlines the importance of having such a programme integrated into the overall care for cancer patients to prepare them and provide them with the skills and knowledge needed to cope with the transition from patient to survivor. Participants in this study benefited greatly from the supportive environment and the peer support they shared and skills they learned in addressing their unmet needs regarding returning to functional activities and life roles, with some even returning to work.

Rehabilitation needs to be incorporated into the overall treatment for cancer patients to ensure that their unmet needs are addressed. An exercise intervention such as the one in this study could be offered as an accessible and effective option for larger populations of cancer survivors. This will only be achieved if a collaborative approach is taken among all those involved in the treatment and care of cancer patients.

CHAPTER 5.

Translational formative evaluation of an exercise intervention for cancer survivors delivered in a higher education fitness centre setting

"Knowing is not enough; we must apply. Willing is not enough; we must do"

Johannn Wolfgang von Goethe

Chapter 5: Translational formative evaluation of an exercise intervention for cancer survivors delivered in a higher education fitness centre setting.

5.0 Abstract

This qualitative feasibility study, examined the factors influencing the subsequent implementation of the exercise rehabilitation programme in a community setting. Semi-structured individual interviews (n=15) were undertaken with survivors who agreed and declined to participate in the programme, programme delivery agents, and cancer healthcare professionals. Implementation was examined using Fixsen's Active Implementation Frameworks with Glasgow's 'Reach, Effectiveness, Adoption, Implementation, Maintenance Framework'. Implementation appears to be most successful where an enabled environment is created, a collaborative multidisciplinary team are involved, champions exist in recruitment settings and an overall programme leader exists to co-ordinate. Barriers and challenges to programme scale up outside of a major urban centre included accessibility to the target population and financial support from relevant agencies. Future cost effectiveness research needs to be undertaken if exercise programmes are to be incorporated into routine cancer care.

5.1 Introduction

Previous chapters described measurement of the study's effectiveness and acceptability, and explored the experiences of cancer survivors with documented CrF in an exercise trial. This chapter presents data from a further qualitative study on the factors that influence the implementation of research into practice, what can be done for a more integrated and collaborative approach when implementing exercise programmes for cancer patients, the level of change needed to implement exercise into routine cancer care for Irish cancer patients whilst maintaining the fidelity of a programme, and the challenges and barriers to scaling up the MedEx MoveOn programme outside Dublin.

The studies described in Chapters 3 and 4 have shown that exercise benefits cancer survivors and significantly improves common side effects such as CrF. The literature reviews revealed correlations between being physically active and both the risk of cancer recurrence and longer survival (Thomas, Holm, & Al-Adhami, 2014; Davies, Thomas, & Batehup, 2010). PA guidelines for cancer survivors have been developed by various organisations, including the British Association of Sport and Exercise Sciences (Campbell, Stevinson, & Crank, 2012), The Australian Association for Exercise and Sport Science (Hayes, Spence, Galvão, & Newton, 2009), The American Cancer Society

(Rock et al., 2012), and The American College of Sports Medicine (Schmitz et al., 2010). Despite the many benefits of exercise and the availability of exercise guidelines for cancer survivors, the majority of cancer survivors do not follow any guidelines (Mason et al., 2013). While no data are available for Ireland, research carried out in the UK suggests that almost one-third of cancer survivors engage in no PA, with only one-fifth of subjects meeting the guideline of 30 min of activity at least 5 days/week (Department of Health, 2012).

At the end of 2014, there were 139,526 cancer survivors living in Ireland (National Cancer Registry, 2016). As was evident in Study 2, participants felt that the main focus of health care professionals is on treating and curing their cancer. However, the health care system is faced with a rise in cancer survivors, with a growing burden of side effects from cancer and its treatment, such as CrF. CrF has a major impact not only on survivors' QOL but also on their life roles, with many not able to return to work. The Clinical Oncology Society of Australia recently released a position statement on the necessity of embedding exercise in cancer care, and advocated that all members of multidisciplinary cancer care teams promote exercise and that patients adhere to the exercise guidelines set out for cancer patients and survivors (Cormie et al., 2018).

Few patients receive physician recommendations regarding PA (Demark-Wahnefried et al., 2000). Similar results were observed in Study 2, with no participant reporting ever receiving any exercise prescription or advice from any member of their multidisciplinary health care team during their cancer care. This seems to be the norm in cancer care. Research carried out in the UK revealed that only 13% of breast cancer patients were referred to an exercise rehabilitation scheme (Queen et al., 2016), even though it is recognised that a recommendation to exercise from an oncologist positively affects the PA levels of cancer survivors (Jones, Courneya, Fairey, & Mackey, 2004), as confirmed by the data obtained for Study 2. However, just like barriers to participation in exercise and PA experienced by cancer survivors, health care professionals also face barriers to the promotion of PA and exercise and referral to appropriate programmes. This issue may also affect translation of research into practice because of the lack of patient referrals. If appropriate exercise programmes are to be implemented and reach the right individuals, health care professionals need to refer the target cohort. Barriers include a lack of time for discussion and a lack of knowledge regarding PA and exercise for cancer patients (Keogh, Olsen, Climstein, Sargeant, & Jones, 2017). Exercise should be rooted in the care of cancer patients and survivors, and best practice cancer care refers individuals to accredited exercise specialists with experience in cancer care (Cormie et al., 2018). However, many factors can hinder the translation of research into real-world settings, including inadequate collaboration and communication between researchers and key stakeholders (Glasgow et al., 2012; Khoury, Gwinn, & Ioannidis, 2010), no inclusion of stakeholders in studies (Wolin et al., 2011), uncoordinated management of research collaborations (Glasgow & Emmons, 2007; Wallerstein & Duran, 2010), failure to consider a community perspective (Glasgow & Emmons, 2007), no shared interest or understanding of the purpose of the investment among key stakeholders (Grazier et al., 2013), the target setting (Basch et al., 1985), the research design (Glasgow & Emmons, 2007; Irwin, 2009; Santa Mina et al., 2012; Shadish, Cook, & Campbell, 2002), a lack of reimbursement for exercise/PA programmes (Alfano, Ganz, et al., 2012), health care factors (Blanchard et al., 2004; Demark-Wahnefried, Peterson, McBride, Lipkus, & Clipp, 2000; Durak, Harris, & Ceriale, 2001), and insufficient focus on context and external validity (Glasgow & Emmons, 2007; Schillinger, 2010).

Knowledge and understanding regarding exercise and cancer may need to spread beyond health care professionals. To address the lack of training and resources (Irwin, 2009) for the need to prescribe exercise for various cohorts including those with a history of cancer, key individuals with suitable knowledge and skills, such as clinical exercise physiologists and exercise oncologists, could be integrated into primary health care. This is turn could help in reducing the burden on already strained health care systems. Such a strategy could be facilitated via community-based exercise programmes such as MedEx MoveOn, developed specifically for cancer survivors, top reduce the burden on health care professionals and systems (McPhail & Schippers, 2012). Community-based exercise rehabilitation programmes for cancer cohorts can physiologically and psychosocially benefit participants (Irwin et al., 2017; Mutrie et al., 2007; Rajotte et al., 2012).

Translation of research findings into routine practice is perhaps the most salient current issue in cancer care. Understanding both programme- and institutional-level factors is key, and requires good process evaluation. One of the top 10 research questions related to PA and cancer survivorship as proposed by Courneya, Rogers, Campbell, Vallance, and Friedenreich (2015) is how to translate PA research into clinical and community oncology practice.

Process evaluation is important in assessing whether an intervention has been successful or not. Process evaluation provides an understanding of how interventions are interpreted and responded to by various individuals and if the strategies implemented are reaching and acceptable to the target cohort (Naidoo & Wills, 2000). Evaluation at the implementation stage can reveal if a programme is successfully reaching and retaining the target population. In addition, evaluation can be used to highlight intervention corrections for program implementation (formative evaluation) or elucidate implementation processes (process evaluation). Successful implementation of new programmes is linked to more positive results from the programme at an individual level (Durlak & DuPre, 2008). This can identify both the factors that worked and elements that can be improved or adapted to help in translation from an individual level to a population level so that the programme can reach and have a positive impact on a larger cohort. For community initiatives such as the MedEx MoveOn programme, formative and process evaluation can include assessment of the process by which collaborations are generated and sustained and ultimately succeed in practice.

5.2 Study aim

The aim of this feasibility study was to examine the factors that influence the initial implementation stage of the MedEx MoveOn programme using Fixsen's active implementation framework, the RE-AIM framework, and qualitative methodology.

5.3 Objectives

1. To identify the factors that influence implementation of the MedEx MoveOn programme in the routine care of cancer patients in Ireland;
2. To identify implementation barriers and facilitators of a research-based exercise trial to a community-based programme that may inform future scale-up of the MedEx chronic illness rehabilitation programme;
3. To explore the challenges and barriers to referral of the programme among health care professionals;
4. To explore what factors facilitate ease of referral to the programme for health care professionals;
5. To identify the challenges and barriers in scaling up the MedEx MoveOn programme outside Dublin city;

6. To identify strategies that can ensure the fidelity of the MedEx MoveOn programme;
7. To identify the level of change needed to implement the MedEx MoveOn programme in routine care for Irish cancer patients; and
8. To develop a model of best practice for incorporating exercise and PA into cancer care in Ireland, which could help in moving research beyond T0–T2 to have a population-level impact for implementation in a number of settings.

5.4 Research questions

1. What factors (barriers and facilitators) influence the implementation of a successful exercise rehabilitation programme for cancer survivors?
2. What is needed to ensure a more integrated and collaborative approach when implementing exercise programmes for cancer survivors in practice?
3. What level of change is needed to implement the MedEx MoveOn programme in routine cancer care for Irish cancer patients?
4. What is needed to ensure fidelity of the MedEx Move On programme?
5. What are the challenges and barriers to scaling up the MedEx MoveOn programme outside of an urban centre?

5.5 Theoretical Framework

This study will investigate the application of implementation science to the MedEx MoveOn programme in a cancer survivor setting. Implementation science suggests that stakeholders in a programme need to consider and create strategies around a formula for success (Figure 5.1). Each component of the formula is vital, and effective interventions alone are not enough to overcome challenges faced in implementing programmes such as MedEx MoveOn.

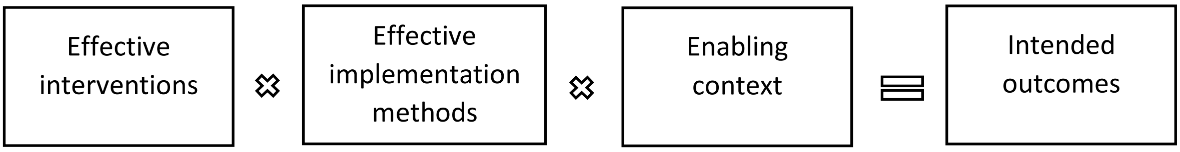


Figure 5.1: Implementation formula for success (NIRN, 2013)

The National Implementation Research Network (NIRN, 2014) formula for success (Figure 5.2) recognises that changes in behaviour can be best accomplished by combining effective interventions (good-quality evidence-based programmes such as MedEx

MoveOn) with effective implementation methods (good-quality supportive, accountable, and supported systems) and an enabling context (national policy, national monitoring and surveillance) to yield socially significant outcomes (exercise rehabilitation programmes embedded in cancer care to improve the physical function and QOL of Irish cancer patients and survivors).

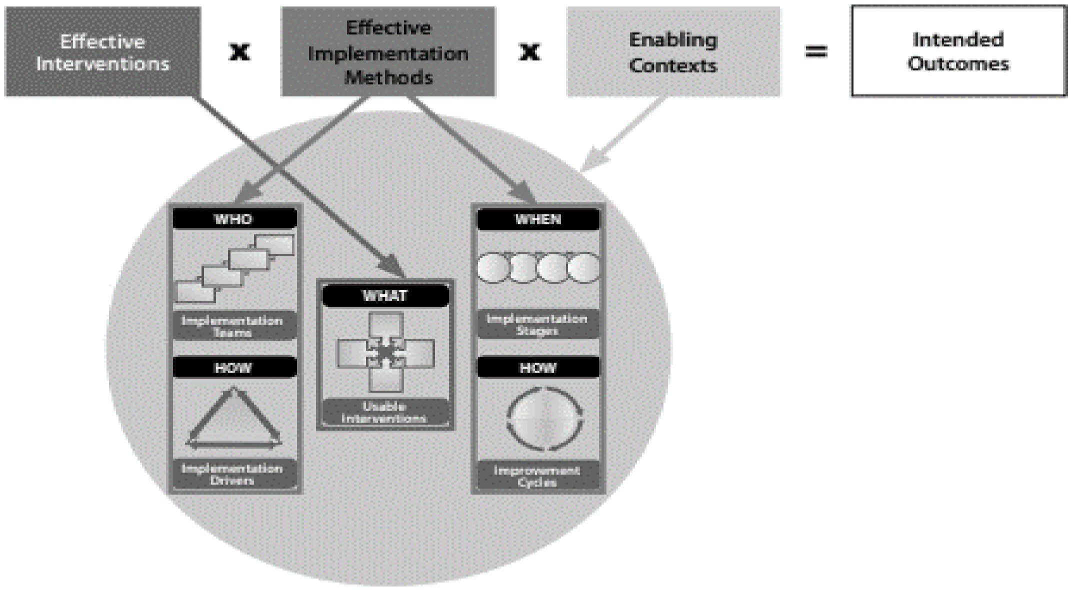


Figure 5.2: Linking the formula for success to the active implementation framework (NIRN, 2013)

The intervention described in Chapter 3 is an example of an effective intervention within a research setting. In this study we examine whether the environment (community setting at WIT Arena) can enable (enabling context) translation and implementation (effective implementation methods) of the research into practice in a real-world community setting to impact the target population at a population level (intended outcomes). Using implementation science we examine which strategies for implementation are successful (effective implementation methods) and how good they are, and recommend how they can be improved to develop a model of best practice for incorporating exercise and PA into cancer care in Ireland. This can help to move research beyond T0–T2 to have a population-level impact (social significant outcomes) and with potential for implementation in a number of settings (enabling context).

5.6 Methods

5.6.1 Study design

This feasibility study used a qualitative approach consisting of a number of semi-structured interviews with participants and non-participants in the MedEx MoveOn programme, agents delivering the MedEx MoveOn programme in WIT, the coordinator of a successfully implemented programme in DCU, and health care professionals involved in cancer care. The interviews were used to gain an understanding of the issues involved in answering the research questions listed above.

5.6.2 Frameworks used

A number of theoretical frameworks and models for evidence translation have been reviewed (Brouwers et al., 2015; Nilsen, 2015; Tabak, Khoong, Chambers, & Brownson, 2012). Using the active implementation framework (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005), the evaluation focused on the process and resources required to: (1) identify and engage key stakeholders; (2) identify implementation barriers and facilitators; and (3) address potential barriers to implementation. Reach, adoption, and implementation factors described in the RE-AIM framework were also explored (Glasgow, Vogt, & Boles, 1999).

5.6.3 Recruitment of the study population

Data were collected from participants in the MedEx MoveOn programme, individuals who showed interest in MedEx MoveOn but did not join, agents delivering the MedEx MoveOn programme in WIT and DCU, and health professionals involved in cancer care including GPs, a consultant medical oncologist, and a consultant palliative medicine physician.

MedEx MoveOn participants and non-participants were recruited via a verbal invitation (to the whole group; n = 37) at the end of the final 10-week exercise block (Study 1). Delivery agents in WIT (instructor carrying out the intervention; n = 1) and DCU (coordinator of the programme at DCU (n = 1), and an individual carrying out research on the MedEx MoveOn programme (n = 1)), hospital-based oncology health care professionals (n = 2), and GPs (n = 2) in general community practice were recruited via written invitation. Information letters (Appendix 12, 15, 18, 21) were sent to interested participants. The letters included an informed consent form (Appendix 13, 16, 19, 22) seeking consent to participate in the study. All interested participants consented to participate in the study.

5.6.4 Sampling method

The 15 interviewees were selected using purposive sampling from four key defined sample groups: (1) participants in the MedEx MoveOn programme; (2) non-participants in the MedEx MoveOn programme; (3) agents delivering the MedEx programme in both WIT and DCU; and (4) health care professionals involved in cancer care, including oncologists and community GPs. Participants were selected because of their knowledge of the intervention and the implementation process in both WIT and DCU. The purpose of the interviews was to: (1) identify the effects of the MedEx MoveOn programme on its participants; (2) identify barriers and facilitators for implementation of a research-based exercise trial in a community-based setting that could inform future scale-up of the MedEx chronic illness rehabilitation programme; and (3) explore how key stakeholders experience MedEx MoveOn in practice.

5.6.5 Setting, data collection methods, and procedures

Thematic analysis as described by Braun & Clarke (2006) was used to develop a coding frame, which was then applied to the entire data set as described in detail in Chapter 4 Section 4.4.7.

5.6.5.1 Data collection methods

5.6.5.1.2 Interview schedule

All participants were invited to take part in a semi-structured face-to-face interview, but were offered a semi-structured telephone interview if they preferred. Although face-to-face interviews are deemed the gold standard for qualitative data collection, telephone interviews may produce comparable results (Holt, 2010; Miller, 1995; Opdenakker, 2006; Sturges & Hanrahan, 2004; Vogl, 2013) and allow a wider geographical range for respondents (Adams, Khan, Raeside, & White, 2007; Glogowska, Young, & Lockyer, 2011; Holt, 2010; Knox & Burkard, 2009). Moreover, when dealing with health care professionals who have busy schedules and time restrictions, telephone interviews represent an ideal method for collecting qualitative when trying to engage populations that are hard to reach (Tausig & Freeman, 1988) Interviews were conducted by the principal investigator (P.S.), digitally recorded with each participant's consent, and transcribed verbatim. Interviews lasted for between 20 and 60 min.

5.6.5.2 Data collection procedure

All 15 participants were contacted via phone or email to invite them to participate in the study. An information leaflet and inform consent declaration were then forwarded to each participant via email or post. Although all interviewees were offered face-to-face interviews, all opted for a telephone interview. Reasons included time constraints and a preference to communicate via telephone. Consent forms were signed and returned to the investigator (P.S.) prior to interviews. Before initiating the interviews, the investigator explained the purpose of the study and the topics to be discussed, emphasising the importance of sharing as much information as possible. The researcher explained the data confidentiality protocol and asked for permission to audio-tape the interview. A variety of broad, open-ended questions regarding the study objectives were used and the participants were encouraged to provide answers using as much detail as possible. This was achieved by repeating what the participant had said to ensure that the respondent's meaning was understood, asking for further information if necessary (Britten, 1995). The interviewer briefly paraphrased the participant's answer to each question to ensure that the information provided was complete, and allowed the participant to add more information if applicable. Each interview was audio-taped, transcribed verbatim using Microsoft Word 2010, anonymised, coded, and analysed by the investigator soon after the interview took place. Table 5.1 lists the interview domains used in the study.

Table 5.1: Interview domains for each separate interview

Participants in MedEx MoveOn	**Non-participants in MedEx MoveOn**	**Agents delivering MedEx MoveOn in WIT**	**Agent delivering MedEx MoveOn in DCU**	**Health care professionals**
• Experiences of taking part in MedEx MoveOn • Reasons for taking part in MedEx MoveOn • Intervention location and setting • Facilitators and barriers to participation • Satisfaction with the programme • Satisfaction with the delivery agent • Programme effect • Most valued components • Expectations for the programme	• Reasons for not taking part in MedEx MoveOn • Barriers to participation • Ways to influence uptake of an exercise programme	• Experiences of delivering MedEx Move On • Implementation issues • Barriers and facilitators to implementation • Programme being implemented as planned • Level of expertise of delivering agent • Self-efficacy level when working with cancer survivors	• Programme strengths (peer support, multidisciplinary team • Programme barriers and challenges (uptake, location, travel, cost) • Challenges in implementing and scaling up a programme outside a city like Dublin • Barriers or issues faced when collaborating with health care professionals • Facilitators when scaling up a programme • Important facilitators for collaboration • Improvements to reach the target population • Level of change required to existing policies and practices to accelerate translation of an exercise programme such as MedEx MoveOn into cancer patient care • Key individuals in implementing and scaling up the programme • Factors needed to ensure fidelity	• Reasons for/not referring participants • Collaboration experience • Concerns about the programme • Barriers and facilitators encountered • Challenges/barriers to referral • Recommendations to improve the referral pathway

5.6.6 Topic guides

Outcomes were collected via semi-structured interviews. Separate interview guides were used for MedEx MoveOn participants, non-participants of MedEx MoveOn, health care professionals, and delivery agents (Appendix 14, 23, 17, 20). Questions were identified after referring to various papers on exercise oncology and rehabilitation (Pinto, Waldemore, & Rosen, 2014; Spence et al., 2011). Table 5.2 lists sample broad, open-ended questions that were used in the interviews according to a predetermined framework. Probing questions were also used to allow for the emergence of further themes.

Table 5.2: Sample broad, open-ended questions for interviews

Health professionals	**MedEx MoveOn participants**	**MedEx MoveOn non-participants**	**Delivery agents in WIT**	**Delivery agent in DCU**
• What are the barriers to referral to the MedEx MoveOn programme? • What are the facilitators for referral to the MedEx MoveOn programme?	• What were the most valued components of the programme? • Was there anything better, worse, different, or worrying you experienced on transfer from the research study to the MedEx MoveOn programme in terms of the instructor or setting?	• Why did you decide not to take part in MedEx MoveOn? • Could anything have been done to make you want to take part in MedEx MoveOn?	• Did you feel you have an adequate level of expertise to deliver the programme? • What were the implementation issues experienced? • What could be done better to enhance the implementation of the programme?	• What are the challenges faced when implementing this type of programme outside a city like Dublin? • What are the challenges faced when scaling up this type of programme outside a city like Dublin? • Who are the key individuals in scaling up the programme? • Do you think that the evidence on the fitness and QOL benefits is enough to change clinical oncology practice to make exercise programmes an essential component of cancer care? • Are any actions needed by management or coordinators to ensure long-term fidelity when setting up programmes outside the hub in Dublin?

5.6.7 Programme design

The 10-week intervention stemmed from work carried out by the investigator in Study 1. Workouts were slightly different in that resistance training was added, for which clients used both machine and free weights. Once a week, group exercise sessions were held in WIT Arena under the supervision of an exercised professional trained to deliver the intervention.

5.6.8 Data analysis

Interviews were digitally recorded on two devices and downloaded onto the secure computer network in WIT and transcribed before being erased from the recording devices. Interviews were analysed using thematic analysis (Braun & Clarke, 2006), as described in detail in Chapter 4 (Section 4.4.7). Interviewees were offered the opportunity to view the transcript of their interview.

5.7 Results

5.7.1 Findings

A number of key themes emerged from the qualitative data that shed light on factors that influence the implementation of cancer-specific exercise rehabilitation programmes such as MedEx MoveOn; what can be done for a more integrated and collaborative approach when implementing exercise programmes for cancer patients in practice; the level of change needed to incorporate exercise into routine care for Irish cancer patients; what is needed to ensure fidelity of a programme; and the challenges and barriers to scaling up the MedEx MoveOn programme outside Dublin.

5.7.2 Type of setting needed for successful implementation

When discussing the ideal setting for successful implementation of the MedEx MoveOn programme, many subthemes emerged (Table 5.3).

Table 5.3: Summary of subthemes identified when participants discussed the ideal setting for successful implementation of the MedEx MoveOn programme

Theme	**Subthemes**
Target setting	• Space • Facilities • Facility and programme run by professionals • Located outside a clinical setting • No preconceived idea of what participants are like at baseline • Supportive environment • Participants seen as the same as all gym-goers • Instructors invested and interested in participants • Time to train instructors

Participants noted that a space with suitable facilities and experienced instructors to carry out the programme were important, and felt that WIT Arena "*has the facilities and the instructors to do this" ID3* (MedEx participant). The facility was identified as a *"safe environment" ID2* where they liked to exercise. The GPs who were interviewed also commented on a safe environment as an important factor for successful implementation.

They mentioned that by "*being completely supervised it is very safe for patients who would be quite vulnerable post cancer treatment" ID12* (GP). On account of this *"I would have no concerns at all for referring to MedEx. I think it is an excellent initiative and it is definitely something that should be utilised more" ID12* (GP).

Others were impressed with how well the programme at the facility was being run. They stated that health care professionals were more likely to refer their cancer patients to a programme at a facility run by professionals:

"I was very impressed by the facility, when something is being very well run by professionals you are more likely to use the service" ID11 (GP).

The fact that the MedEx MoveOn programme is run outside a clinical setting, which is often associated with negative feelings, and that those associated with the programme did not have any preconceived ideas about participants before the programme started were identified as positives for programme implementation.

"I think rather than it being a hospital-based programme where people identify 'This is where I was having my treatment. I was well, then I went through all of this, and this place, kind of, it was through here that did it'. Doing it outside of that was important and ye had no preconceived idea what these people were like beforehand, so they were new to ye starting with this baseline" ID14 (consultant medical oncologist).

The MedEx programme *"has a very strong social interaction social support element" ID9* (delivery agent DCU). The MedEx MoveOn participants highlighted the support they received at the facility as an important factor for successful implementation. They appreciated that even though they preferred being in a cancer-specific group and liked to exercise with other cancer patients, they also really valued that they were *"treated as just one of the clients" ID3* (MedEx participant) as opposed to having a cancer identity. They did not feel any different from other members of the facility: *"We walk in the door of our gym with our little bottle of water and our towel and we are greeted at the front desk as actual just clients of the gym. Now we are very loved down there in the WIT Arena" ID3.* The MedEx MoveOn participants valued the fact that *"You and our instructor and your team leaders I would imagine you are interested in our care"* and *"They [instructors at WIT] have invested in us and we have become part of their lives" ID3*, which they felt was an important feature for the success of programme implementation.

Instructors at the facility also regarded training as an important feature for successful implementation of the programme. Instructors mentioned that the training they received had prepared them well and increased their confidence when dealing with a cancer cohort: *"What I was learning from you, Patricia, I was becoming more and more confident" ID15* (delivery agent at WIT). The training also taught them "*… how to adjust the exercises to cancer recovering patients and now obviously I am aware of the different medications, so therefore I know how to modify the exercise" ID15.* They realised they "*… needed to know that. So that was a huge help to me, because I wasn't aware of that"* and "*… was the most important thing to know before I began the training of these individuals" ID15.* Instructors also mentioned that for success to be maintained in a safe manner, continuous training and professional development are essential. Instructors welcomed the fact that they need to *"… constantly update my knowledge, so I would definitely appreciate any help from ye, you know, to gain as much knowledge as I can to lead my group in a safe way, so definitely updating my knowledge" ID15.*

5.7.3 Programme structure

Numerous key factors and features of the programme structure were identified as important for successful implementation of MedEx MoveOn (Table 5.4).

Table 5.4: Summary of subthemes identified when participants discussed the programme structure.

Theme	Subthemes
Programme structure	• Group format • Cancer-specific • Involves exercise professionals and specialists • Considers the social aspect • Considers the community aspect • Involves a multidisciplinary team • Has a leader who key stakeholders have formed links with • Incorporation of a local champion • Structured programme involving and educational element • A need for funding

5.7.3.1 Group format

The participants unanimously acknowledged and valued the importance of a group format for the MedEx MoveOn programme. All the participants felt that a one-to-one class basis would not work:

"I am afraid a one-to-one would not work. It wouldn't work for me, anyway" ID1.

Participants stated that the group format allowed them to form relationships and friendships and stressed the importance of group camaraderie. They also felt that the group format gave them something to look forward, to as they valued anticipating meeting the others in the group:

"We have relationships there between us that we will never forget, like, the camaraderie, like. It is so important to do it as a group, I think, because I personally look forward to meeting those people again" ID1.

One participant acknowledged that coming together with others who had been through the same experiences was moving them beyond their cancer:

"I think the coming together is probably equally as important; you see, you are meeting other people and we go beyond the cancer" ID3.

Others highlighted that being with a diverse group of participants of varying ages and both sexes was valuable:

"I loved it. I loved the cross-section of people, all the people I met, they were varying in age groups, different sexes, I thought it was great" ID4.

Participants also felt that a group format was important as it created group cohesion, which enabled the participants to encourage and motivate one another:

"Together you can help each other through it, you encourage each other and egg each other on and the groups brings the whole lot along" ID4.

In addition, participants reported that the group format created an environment in which they could receive the social support they needed, which they appreciated:

"I think, like, the support there, like, and the support of the other people in the group as a whole, you know, has been fantastic" ID5.

One participant noted that they were naturally shy and reserved, but felt that they gained more confidence in being part of a group:

"The group was good because I got to meet other people, but being somebody who is kind of reserved and kind of a quitter person, I wouldn't be the really social person out there talking to everybody. I would only be talking to the people I would know, so for me that was great. It kind of brought me out of myself, you know" ID5.

While all the participants identified the importance of a group format, they also all stated that it was essential that the group was specifically made up of a cancer only cohort. They felt this created an environment in which everyone had a cancer diagnosis in common, and even though their cancer was not necessarily spoken about all of the time, they still had that shared common factor:

"I think that having it cancer-specific, everybody kind of knows what it was like or what you went through, your emotion things, and even if we don't talk about it an awful lot, everybody was there and it was the common factor that everybody was the same, like" ID5.

5.7.3.2 Cancer-specific

Being in a cancer-specific group meant that participants were less likely to feel vulnerable or self-conscious in one another's company. In fact, it made them feel stronger for each other, with one participant stating:

"We are all cancer-specific, Patricia. I think that is the best thing because none of us are feeling vulnerable, no one is going in thinking 'Oh she is after having breast cancer' looking at her kind of funny, or 'He is after having prostate, he has a bag, I am going to look at him funny.' There is none of that because we are all vulnerable in our own little way, whereas in the group we are actually strong for one another" ID2.

Participants mentioned that the cancer-specific group format enabled others to empathise with them as they were with likeminded individuals, and even though there were times when they felt unable to do things, the others encouraged them to carry on because of this mutual empathy:

"You were with likeminded people. You were with people who could empathise with how you felt, and if you weren't able to do something you didn't feel like 'OMG I have to keep

going with it' and they encouraged you to keep going when you felt like you couldn't, so I thought the group setting was great" ID4.

The cancer-specific group structure was also identified as an essential factor for implementation, as participants reported that it gave them an opportunity to seek reassurance that others were also experiencing some of the issues they were going through:

"I think it is very important that people know that you are not the only one, that there are other people going through this" ID4.

MedEx MoveOn participants acknowledged that *"having a professional there is very important" ID2.* Another added, *"It is very important that you have a professional supervising it, there is no doubt" ID4*, and this was a factor key to the success of programme implementation. Health professionals echoed this view, stating that the involvement of leaders and instructors in the programme who had a "*background as exercise specialists is a key to it" ID14* (consultant medical oncologist).

5.7.3.3 Considers the community perspective

Interviewees acknowledged that the community perspective was an important factor for successful implementation of the MedEx MoveOn programme. The instructor at WIT Arena stated that MedEx MoveOn *"is more of a community as opposed to just coming into the gym and training, like they always stay after the workout, they stay for the chat and they support each other as well" ID15.* She felt that this was an important factor to consider and one that could influence successful implementation. MedEx MoveOn participants also highlighted the importance of doing activities together outside of the arena, spreading what they were doing into the community and helping charities. One participant noted *"We have gone on the Greenway and we are trying to organise this Eco walking for the hospice, and that is in the next 2 weeks or so and we are doing it as a group" ID5.*

5.7.3.4 Multidisciplinary team

Having a collaborative multidisciplinary team comprising individuals from the Department of Sport & Exercise Science and the Department of Nursing and Health Care at WIT, as well as staff from WIT Arena, was also mentioned as a vital factor for successful implementation of the MedEx MoveOn programme:

"With the Arena it is a collaboration with the main campus, so I really believe that this collaboration definitely helps and they [WIT main campus] were obviously the ones who were offering the MedEx MoveOn programme to the public, so I believe it was through that collaboration with main campus that helped I guess" ID15 (delivery agent at WIT).

5.7.3.5 A leader

Whilst a multidisciplinary team was identified as important, having a leader of this team was also viewed as having a critical influence on successful implementation. Having an individual, that key stakeholders could identify with, or who have already created links with was identified as crucial. Those at DCU suggested what really helped them with their successful implementation was "*having Dr. Noel McCaffery because he is heavily involved in establishing links particularly in Beaumont and The Mater" ID10* (delivery agent DCU). Having a face to the programme was suggested as something that *"definitely plays a big role" ID10.* According to the delivery agent at DCU, *"from our experience what has been helpful when trying to make that link with the health care professionals, is to have a face to put to the name to build up that relationship with that person initially maybe, and then to follow up with communications over email or letter" ID10.*

The DCU delivery agent stated *"It is a programme which, I suppose, we have, let's call it medical leadership, which is something that is valued by the participants and by the referring physicians and also by the other staff, so I suppose that is a strength" ID9*, which in turn influences successful implementation of the programme. The interviewee did *"think the medical leadership helps the people who are referring. The fact that there is a doctor involved, even though it is not necessary to be honest, it is a little boost" ID9.*

When scaling up the programme to other centres such as WIT, *"Each centre around the country will need a local champion, and without it, it will struggle" ID9,* which is another factor that can influence whether or not MedEx MoveOn is successfully implemented. Essential characteristics of a successful leader for the programme included a person with *"a bit of drive and commitment, enthusiasm ,and I suppose passion" ID9*.

5.7.3.6 Structured programme involving an educational element

The structured approach with a strong educational element was viewed as an important feature in MedEx MoveOn implementation. The health care professionals welcomed the teaching points on the importance of exercise and how to exercise properly. Inclusion of this educational element in the programme helped to reduce any concerns that health care professionals may have had in the programme. The clinical medical oncologist interviewed valued the implementation of *"the structured approach that you have to it. Teaching them that it is OK to feel short of breath, it is OK to feel their heart rate beat. The programme is exactly what is needed to get them into the frame of mind for exercise and recognising the benefits" ID14.* In addition, "T*aking the approach ye took about explaining what is involved, the introduction to exercise"* was important because *"maybe some of these people had never done any form of formal exercise" ID14.* She went on to state that because of the structured approached and the educational element, she has *"no concerns about the programme" ID14.*

5.7.4 Research design

Research design factors were also identified as having an influence on successful MedEx Move implementation (Table 5.5).

Table 5.5: Summary of subthemes identified when participants discussed the influence of the research design on implementation

Theme	**Subthemes**
Research design	• Inclusive programme (all cancer types, all abilities) • Excludes other cancer stages (during treatment, palliative) • Having the right person to implement the programme

MedEx MoveOn participants mentioned that *"Cancer doesn't discriminate, so I don't see why a rehabilitation programme should discriminate. People that have cancer and are undergoing treatment from cancer, the chemo therapy is sickening for everybody, it is damaging for everybody. The radiotherapy has its own side effects, it doesn't matter what kind of cancer you have, you are equally as sick. You are equally as tired, so I would be of the opinion that that should be expanded to include all cancer survivors" ID4.* This highlights the importance of having an inclusive programme that did not exclude anybody. A programme that was inclusive of all cancer types and abilities meant that more participants were reached and they did not feel as though they did not have the ability to take part. An inclusive programme also reduced the barrier of patient suitability issues for GPs:

"When I went I saw that you were so inclusive. You are inclusive of age, inclusive of ability, and from the positive stories I felt that you could work with almost anybody. So the barrier of patient suitability, I was a lot more better informed about that" ID11 (GP).

Health care professionals noted that although the programme included participants with all cancer types and abilities, it was targeted at post-treatment cancer patients only. They suggested that more cancer cohorts could potentially benefit from this programme. The consultant medical oncologist commented that the programme should be *"not just for cancer survivors, but for another group of women or for another group of people if they are well enough, and some of them are. And this is people who are living with cancer, so maybe some with secondaries or metastatic [disease], some of them are quite well" ID14*. This was echoed by the consultant palliative medicine physician, who recommended that the programme should be *"for all patients, for those who have gone beyond curative treatment and even those who are undergoing palliative treatment" ID13.*

Participants also highlighted that having the right investigator involved in MedEx MoveOn was crucial for its successful implementation. *"You have to have the right person there to do that, Trish, you have the right person who will not only have the belief that this is helpful, but that this can actually give people back their lives. To overcome that fatigue you have to have someone with the enthusiasm and the empathy that you will go in there and you will take it upon yourself to encourage these people, not only as a group but individually as well. So that is so important that you get the right person to do that" ID4*. Having the right person to implement the programme was also played a factor for its maintenance and sustainability, as one participant commented that by having the right person she "*fully intend to continue with this" ID4.*

5.7.5 Intervention characteristics

A further theme that emerged when discussing what could potentially influence translation and implementation of MedEx MoveOn into practice in a community setting was the intervention characteristics (Table 5.6).

Table 5.6: Summary of subthemes identified when participants discussed intervention characteristics that could influence MedEx MoveOn implementation

Theme	**Subthemes**
Intervention characteristics	• Fun and varied • Focus of intervention is on being active • Supervised by a professional • Membership package • Adaptable to the needs of cancer survivors • Include other programme options • Location/distance • Cost • Lack of reimbursement • Social element • Sense of connectedness

5.7.5.1 Fun and varied

Having a programme that was fun and varied was an important intervention characteristic. Participants valued that in *"the current MedEx programme we do something different every week we are in the gym. One week, if the sun is out we do our exercises outside, we are in the studio another week. So it is not that you are going to the same old, same old. You are doing the exercises, but in a different kind of format in a different venue [WIT Arena] or a different setting, so you don't get bored by it" ID4* (MedEx MoveOn participant). Because *"the exercise programme is fun, they do want to come here" ID15* (delivery agent WIT). Because the programme involves variety and fun, *"there is sort of a sense of adventure attached to it" ID4.*

5.7.5.2 Focus of the intervention is on being active

Interviewees mentioned that the intervention focus was on being active as opposed to sitting down and talking about their problems. The intervention involved active engagement, which was identified as a key characteristic for implementation. Active engagement led to empowerment of the participants. The consultant clinical medical Oncologist stated, *"The beauty of your programme is it is about being active instead of sitting down and talking".* She felt that "*sitting down and talking can be rehashing, whereas this is active, get going, and it is empowering them."* She went on to say that *"the key to this programme is that exercise" ID14.*

Features of the membership package, including access to other facilities and classes at WIT Arena, were highlighted as factors that influenced successful MedEx MoveOn implementation. Participants appreciated that as well as access to their cancer-specific class, their membership allowed them access to the Edge gym where they could carry out their workout programme on other days. One participant commented, *"I go down on the Tuesday, but I can go any other day if I want to and ID15 has done out a little programme and I can work away with that" ID5.*

5.7.5.3 Adaptable to the needs of cancer survivors

Participants highlighted the importance of having a programme that was adaptable to their needs as cancer survivors as a vital characteristic. Participants appreciated "*how simply the programme is adapted, there is ID4 [endometrial cancer], there is myself [oesophageal cancer], there is ID1 [prostate and bladder cancer], there are different people who have different cancers" ID3.* They felt that the intervention was always carried out in a manner that "*wasn't anyway intrusive or invasive or anything like that, always done within the parameters of how well you were able to do whatever you were asked, so great consideration taken and still done within your ability" ID4.*

5.7.5.4 Location and distance

Those interviewed also discussed various barriers and challenges regarding intervention characteristics that could influence implementation of the programme. An interviewee who initially showed interest in the programme but did not participate said *"It was mainly the distance [from Wexford]" ID7* (MedEx MoveOn non-participant). They suggested that *"If you had an alternative location" ID7,* they would consider joining the programme. Health care professionals who wanted to refer suitable patients to the programme also saw the distance involved as problematic. One GP felt that because her practice was not based in Waterford, she felt that participants would not travel. Even though she *"would refer in a heartbeat, you know I would"*, she highlighted that *"the problem for me is that I am not it Waterford. There are patients I know that would engage in the programme but they wouldn't have transport to Waterford, so that would be a problem" ID12.*

A solution to the distance issue was *"to have another option for people who can't travel, but who could maybe come and meet us once every 3 months for an assessment just to check in and see how everything is going, but maybe exercise independently at home using a manual or a YouTube channel or something like that. Where they can exercise independently but still have a touch base" ID10* (delivery agent DCU).

Other solutions that were mentioned included requesting *"funding for a bus or something to bring people say from Clonmel or bring people from Wexford once a week for set times" ID12* (GP). Possible funding sources identified included "*Tipperary Sports Partnership or Wexford Sports Partnerships" ID12.* The GP felt that this was something these organisations would fund. She also mentioned that "*the HSE would be interested in that, but also the sports partnerships as well, definitely would be great people to look for some funding because they are great to support projects like this" ID12.*

5.7.5.5 Cost

Cost was a theme that emerged when discussing challenges to successful implementation of the programme. Participants felt that cost was an issue for some in terms of MedEx MoveOn uptake. One participant mentioned *"There are people that we are aware of that can't afford the fee" ID3.* One individual who showed an interest in participating but did not join stated that a factor was *"the financial part of it" ID8*. In other words, one reason for not participating was that they could not afford to, even though they wanted to take part. Delivery agents of the programme that they *"have to be conscious of that" ID9*, in terms of reaching others.

Participants who had health care insurance mentioned lack of reimbursement as a factor. They felt that their health care policy excluded them from a lot that was on offer to others without insurance. One participant noted that *"because I am a private patient there are a lot of doors closed to me, like the special 6 week programme that they do about diet and* *exercise foot care, all these things. I am excluded from all of that because I have private health care medical insurance" ID3*.

When discussing what could be done for those who could not afford the programme but wanted to join, one participant stated that *"There should be money there, there should be funding" ID3* to give access to those who could not afford it. Another said *"If you can't afford to pay for that MedEx, I would fully endorse that anybody who would have a medical card that that would be part of their treatment, absolutely" ID4*. There was a strong feeling that the programme should be subsidised in some way by the government: "*Let them have it at a cheaper price or half the price, or let them have it as part of their treatment" ID8* (MedEx MoveOn non-participant), and *"… some sort of subsidisation like that for people with medical cards, and even if they don't have medical cards" ID7* (MedEx MoveOn non-participant). Another option would be *"to liase with companies like that (health insurance) there might be something they could provide like" ID7.*

The consultant palliative medicine physician noted that the National Cancer Strategy could be relevant in terms of funding: *"The Irish Cancer Strategy that was recently published for the next 10 years, while it doesn't mention cancer rehab specifically, it does talk about rehabilitation. That word is used, it talks about psychosocial and physical support for those after treatment, and in that it looks at cancer support centres. But I think you could use that to certainly infer that it relates to this as well, MedEx and those types of things, you know, and they are talking about bringing these things mainstream in as part of the health care flow sheet or algorithm" ID13*.

5.7.5.6 Time of day

The time of day when classes were held also emerged as a factor that could influence the success of MedEx MoveOn implementation. One participant said that *"the amount of people who have made contact with me and have enquired and unfortunately the programme doesn't suit being a Tuesday morning" ID3*. In other words, potential suitable clients were not being reached because of the class times. In addition, with some individuals returning to work or life roles such as motherhood, morning classes were seen as unsuitable for some potential programme candidates. One participant commented that *"the barriers I have experienced from people is number one, a morning class doesn't suit those who have returned to work because having cancer is a very expensive illness"* and noted, *"people probably can't get the time off work" ID3.* They felt strongly that *"most* *jobs, the jobs that I am familiar with, they allow you the time off to attend your clinics and your continuous assessment, and this is seen as part of your betterment and your recovery. Why isn't this on prescription, this, what I have been saying, why isn't this on prescription?" ID3.* They firmly believed that employees should allow cancer survivors time off work to attend their rehabilitation and that exercise is something that should be prescribed. They were of the opinion that MedEx Move On could be *"part of your recovery programme I mean you are given medication and you are time off work to go to appointments and stuff like that but I know now employers would probably go mad but maybe people should be given an hour to be able to go to an exercise programme" ID5*.

Delivery agents appreciated that "*people returning to work is a problem at the moment" ID15* (delivery agent WIT). This was echoed by those in DCU, who noted that "*people are getting back to work, so if there are daytime classes they are challenging" ID9.* Another comment was that cancer populations included people who *"are young and they have young families, so childcare and pick up runs for school can be a significant issue" ID9*. To address this issue affecting the uptake of morning classes, the introduction of evening classes was suggested as a solution: "it *would definitely be a good idea to add on, because at the moment we only have morning classes" ID15.*

5.7.5.7 Considering the social element

Participants discussed the importance of considering the social element when implementing cancer-specific programmes such as MedEx MoveOn. They appreciated the time spent over a cup of tea or coffee afterwards, and viewed this as an important element. A Medex MoveOn participant noted that *"we have the coffee when we finish, you know, and we have a chat and that is lovely, that is when the laughter comes in and the hard workouts are soon forgotten, and that is very important I think" ID1.* When asked why this was so important, he suggested that it was "*just meeting, and you are coming down from a high cos you are really perspiring at this stage [laughing] and emm you get time, you know, to chat between us and how we fared".* The interviewee said that the cup of tea afterwards is *"exceptionally important of, course it is … sometimes we hang on there for an hour or maybe longer, depending on if they are free, of course they will stay on" ID1*. This helped to foster an environment in which participants felt safe and secure and could chat, share concerns and information, and reflect. Participants also mentioned that without this element, they would not have had an opportunity to socialise with one another: "*[If] they went out of our class every single week and just went home, there would be none of the chat that goes on downstairs" ID3*, highlighting the importance of this factor for MedEx MoveOn implementation and its key role in the success.

Another participant mentioned that the cup of tea afterwards was just as important as the exercise programme. It gave those who could not exercise due to illness an opportunity to still meet up and be part of the group after class:

"For example, ID1 came last week for the cuppa because he was unable to do the exercise because of illness, but he came for the cup of tea and that wasn't just for him, that was for all of us because we were worried about him … it is worth its weight in gold" ID3.

5.7.5.8 Connectedness

For some MedEx MoveOn participants, a sense of connectedness and integration back into the community was an important characteristic of the programme. One participant said she felt that she was reconnected back with the general population and had returned to the real world: *"I think the fact of putting us into the general stream, we are now back with everybody else, we are back in the real world" ID3*.

5.7.6 Health care factors

A number of subthemes emerged when discussing health care factors that might influence the implementation of a cancer-specific exercise rehabilitation programme such as MedEx MoveOn (Table 5.7).

Table 5.7: Summary of subthemes identified when participants discussed health care factors that might influence implementation of the MedEx MoveOn programme

Theme	**Subthemes**
Health care factors	• Time • Lack of resources regarding PA and cancer • Lack of knowledge regarding PA and cancer • Lack of available programmes • Methods for contacting health care professionals to advise them of the programme • Gaining the confidence of physiotherapists • Key individuals to target in terms of informing patients about the programme • Endorsement by clinicians • Addressing the concerns of health care professionals regarding patient referral • Ease of referral

5.7.6.1 Time

Health care professionals agreed that time restrictions were an issue in discussing exercise with their cancer patients. One GP noted that they only discussed exercise "*when time allows; the biggest barrier for me is time"* because *"consultation times are limited and short, we generally aim for about 12 mins" ID12.* Besides the time factor, the DCU delivery agent pointed out the *"lack of resources around PA, so education materials and leaflets" ID10* are not readily available for health care professionals. Hence, *"the lack of knowledge of PA prescription for cancer survivors" ID10* may be attributed to a lack of resources for health care professionals in relation to PA and cancer. Although GPs highlighted time as an issue in discussing exercise, MedEx Move On participants felt that *"It is not good enough to say that you are cancer-free" ID4.* They felt that they should be informed about the importance of post-treatment exercise, and that health care professionals need to be educated:

The GPs and the oncologist need to be educated about the benefits of it [exercise]".

“*[I have] spoken about this programme to my GP and one of my oncologists and I have asked why they don’t have the information in their surgeries and why they are not sending their patients forward, why they are not informing them about it” ID4*

This was considered an essential factor that needs to be addressed to reach suitable cancer patients for the programme and achieve successful implementation.

5.7.6.2 Methods used to contact health care professionals to advise them of the programme

While health care professionals raised concerns regarding the lack of community-based programmes for their patients, informing health care professionals in the correct manner was also a challenge. Health care professionals suggested that letters are not the most efficient approach. According to one GP:

“As a GP, like, I am not a fan of letters, I am not a fan of surveys that are sent out, because we have so much post every day. If it is not important, it is put in different piles.”

“*[Letters] wouldn’t be the most efficient way in my opinion to invite GPs, because I think they are less likely to attend if they are letters. I mean we get letters for study days and things and we don’t go to most of them, you know” ID11.*

This GP suggested a more efficient engagement strategy:

“*… talk to them one on one about the programme or talk to them collectively in a group. Because I think if they could talk to you and actually listen to what you have to say, it impacts more on them. They can’t put it into a different pile, you know, engaging with them face to face would be a better way of promoting the programme” ID11*

Another GP confirmed that this approach would be more suitable for informing GPs about the programme and involving them in the patient referral pathway:

“We are doing everything right in terms of scaling up this project, but certainly by talking face to face with GPs, I think that that is definitely a good start” ID12.

5.7.6.3 Gaining the confidence of physiotherapists

In terms of engaging other health care professionals, the delivery agent at DCU felt that “*there is an issue of gaining the confidence from physiotherapy colleagues”* because *"sometimes they might feel that sometimes we might be a bit too cavalier in accepting everybody and to be more careful" ID9.*

5.7.6.4 Key individuals to target in terms of informing patients about the programme

When discussing the key individuals in the referral of patients to the MedEx MoveOn programme, the consultant palliative medicine physician suggested we should be *"looking at the liaison nurses, looking at the cancer specialists"ID13.* In terms of connecting with these key individuals, the following was suggested:

"*We could come in for 10 minutes at the end of an MDT. I don't know if you are familiar with the term 'the elevator pitch', you might not get the hour, so you have 10 minutes. So this is what we do, and you say we are supported by the medical oncologists, and some of the palliative care leads were involved in this. They endorse it, they are happy to have their names associated with supporting it, and could you think about this for your patients. And you have kind of got at the clinical leads then, and what you have to do then, with the support of that group then, is can we meet with your clinical nurse specialists. Because I think they are the people who spend most time with the patients and will actually be the effective referrers. And what you want is the clinical leads knowing about it and supportive of it, but the doers, the nurses, that they are actually the ones that you can spend a little bit more time with and make the referral pathway as easy as possible for them. That may mean meeting up with them a few times a year to ask 'Do you have any questions, so, for me?' That is probably where it is." ID13*

These individuals were considered the key people to target in terms of referral because "*they will get the timing right" ID13*. This was believed to be "*important because there is no point in somebody being diagnosed and you sending them a referral before they have had their treatment. So for me, it is those liaison nurses and nurse specialists, and then we have one advanced nurse practitioner, but with the endorsement of the clinicians, that is personally how I would do it" ID13.*

Endorsement by clinicians also emerged as an important factor that could influence successful implementation of the MedEx MoveOn programme:

"… seen as something that is an extension. I am not saying it is part of the health care but is an extension of their medical care rather and, is endorsed by all of their oncologists

and surgeons and GP's and palliative care physicians. That it is immersive and endorsed by them and looked after by reputable people who are accredited with training"
"… to show that legitimacy and that this isn't a pie in the sky thing that it is an appropriate treatment" ID13.

Endorsement would provide health care professionals with a sense of confidence in the programme: "*… the cancer centre endorses it and you; it has got that credibility both for participants and for referrals" ID13.* This was considered an important factor that could potentially influence successful implementation of the MedEx MoveOn programme.

5.7.6.5 Addressing the concerns of health care professionals regarding referral of patients

A main concern mentioned by the consultant palliative medicine physician was *"just knowledge, what you want to know when you are talking to a patient, or a patient is asking you 'Is it legitimate?' So it is about awareness and understanding what it is. That there are properly qualified sensible professional people"* ID13.

According to the GPs interviewed, the main concerns were in relation to the qualifications of staff and the professionalism of the programme:
"*… how professionally it is being run, like reassurance that those doing the programme are well trained, that they come from a professional background, the checks are done, and that it does not cause harm to the participants."*
"A*t least if it is done in a professional environment, which it is, that would be reassuring" ID11.*

GPs would also want the programme to respect confidentiality and to place no pressure on participants to commit to the full 10-week programme:

"*There could be vulnerable participants in it, so just the people that they are being referred to are professional and, you know, perhaps that there is no obligation."*
"S*omeone I referred to it could kind of try it and then drop out" [ID11]*

Allowing participants the options of *"a trial of it or something like that" [ID11]* was suggested as something that could be included in the programme structure, as it might influence a GP's decision on whether or not to refer patients.

5.7.6.6 Ease of referral

A theme that emerged among health care professionals throughout the interviews was the need for the referral pathway to be easy. Along with not liking to be informed about programmes such as MedEx MoveOn via letter, GPs do not like filling out forms: *"In terms of referring patients to MedEx, it needs to be simple. It needs to be a simple referral pathway" ID12* (GP). They also noted that a lot of their time is spent writing letters and filling in forms they would prefer to avoid: "*… because it is taking up most of our day outside of patient care, it is paperwork, you know. It isn't ideal, so it needs to be simple" ID12.*

The method used to obtain GP clearance for our study was identified as a barrier: *"Because, you know, there are so many forms coming in every day, be it from boxing clubs, swimming clubs, and a lot of the feelings amongst the GPs is 'Why the hell am I doing this, it is just so annoying', and I do see it as a barrier" ID12.*

While the GP admitted that *"It is a great programme, and I think that every GP you will talk to will know that and recognise that" ID12*, if MedEx MoveOn is to be successfully implemented and reach the most suitable candidates, "*ease of referral, I think, would probably be the main thing" ID12.*

When discussing how such barriers could be overcome to make the referral pathway easier for GPs, interviewees suggested it would be easier if:

"… they are all online. So if I never find the form in my office, I can just go to breastcare.ie and I can download the referral form. What we were doing now in our practices, we are all computerised and our referral forms go into a forms section. So the practice managers scan the referral forms in, so if I want to refer to prostate, I just go into the forms section, click prostate, and download that "ID11.

It was also suggested that the MedEx website have "*a section for professionals, you gave a summary of the exercise expectations that was there, or something like that, and please find the referral form to be printed" ID11.* A comparison to the hospital system was also made:

"*There is electronic referral in the hospital. That would make it easier, like, rather than writing a letter. If you could do it electronically through their software package, through our Healthlink, which is where all our electronic referrals go to, it would be so much easier. That way the medications and everything would automatically go into the referral* *computer package. We just press a button and say 'Off you go', so it is about actually integrating that into a system" ID12.*

5.7.7 Collaboration among key stakeholders

The collaboration between key stakeholders including participants, health care professionals, delivery agents, and academics was discussed and identified as a factor that could influence to MedEx MoveOn implementation. Several subthemes emerged throughout the discussions with interviewees (Table 5.8).

Table 5.8: Summary of subthemes identified when participants discussed the influence of collaboration among key stakeholders on implementation

Theme	**Subthemes**
Collaboration among key stakeholders	• Need for a multidisciplinary team • Coordinated communication between various centres • Use of participants as role models and champions • Include pharmaceutical companies as a means of recognition for the programme • Collaboration with other cancer care providers • Government-owned structures

5.7.7.1 Need for a multidisciplinary team

The consultant palliative medicine physician noted that if exercise programmes such as MedEx MoveOn are being implemented then, *"It is an MDT type of input you need rather than me just telling people that you need to exercise" ID13.*

5.7.7.2 Coordinated communication between various centres

Collaboration between the various centres running the MedEx Move programmes was identified as an important factor. Communication between the centres should ensure that the programme is carried out in a coordinated fashion, as noted by the delivery agent in DCU:

"Communication between the two teams is hugely important, and to make sure that you are both kind of singing from the same hymn sheet and that the service delivery team are very much in the loop about what is going on from a research perspective" ID13.

This approach "*leads to translate, you know, kind of professionally to the participants that both are on the same page, and that this is kind of like a co-delivery as opposed to it being one or the other" ID10.*

5.7.7.3 Use of participants as role models and champions

MedEx MoveOn participants were also identified as key collaborative partners in the implementation of the programme. One participant suggested that we should "*have even, you know, kind of the mascots for the MedEx, go out and have a talk while people are having their chemo. That would be no problem, it would be brilliant … use the MedEx group as a tool" ID2* to reach other suitable candidates for the programme. A role for those who have experienced the programme first hand is an important factor for implementation, as *"feedback from the initial participants was very positive, so people went back to their consultants and expressed a positive satisfaction and warmth of how it went" ID9* (delivery agent DCU). Because of this feedback, *"the word spread" ID9* about the programme.

5.7.7.4 Pharmaceutical companies

Collaboration with local pharmaceutical companies was identified as a means of publicising the programme and in turn reaching more participants. It was suggested that, *"even if one of the drug companies or the prosthetic companies or, I mean there are so many of the companies around now, like, even making the chemo drugs in town, or the companies who make the Freddy lines, if they came on board, you know, get the recognition to this" ID2* MedEx MoveOn participant).

5.7.7.5 Collaboration between other cancer care providers

Collaboration with other cancer care providers was identified as a factor in translation of the MedEx MoveOn programme into practice. Those delivering the programme is DCU commented that they *"had actually developed a very close relationship with the Irish Cancer Society and they would be very close partners of ours. So that would be a very positive thing. We also work closely with Arc so within the network of support groups we would be well known and well respected" ID9.* Owing to the connections and links made within these organisations, "*one thing feeds into the next. There is great feedback among colleagues in the hospitals, in the oncologists, and the surgeons. These are people who are key" ID9.* This highlights the importance of including other care providers in the collaboration network when implementing such programmes, to create a feedback loop that covers the whole caner care continuum.

5.7.7.6 Other stakeholders

Other stakeholders identified were local state-owned gyms who could potentially offer the programme from their facility: *"Up here we are starting to roll out into Dublin into the local state-owned leisure centres, which is fantastic as well" ID9* (delivery agent DCU). The news of this idea generated *"a huge positivity around that from the government-owned structures, who see themselves of having a role in this as well" ID9.* This means that the programme spills out into the wider community, leading to greater accessibility and adoption of the programme by those who need it most.

5.7.8 Recommendations for a more integrated or collaborative approach

When discussing how the various centres running MedEx MoveOn could apply a more integrated ore collaborative approach when implementing the programme, several subthemes emerged (Table 5.9).

Table 5.9: Summary of subthemes identified when participants discussed recommendations for a more integrated or more collaborative approach

Theme	Subthemes
Recommendations for a more integrated or collaborative approach	• Linking partners • Same programme in all centres • Advantages of one coherent project • Spill out into the wider community • Ensuring fidelity

5.7.8.1 Linking partners

Linking partners emerged as a key strategy for a more integrated or collaborative approach when implementing the MedEx MoveOn programme. Linking the centres would be beneficial: "*Say somebody comes up from Waterford and they meet their* *consultant in Dublin, and then they come to visit MedEx and we can link them with Waterford" ID9* (delivery agent SCU). By linking the centres' data systems to one another, *"You can see their file electronically from what we have done and look at their test outcomes or their 6 min time trial and all that" ID9,* and centres could help each other to deliver the programme. This in turn would facilitate scale-up of the entire programme to reach more people. In addition, if individuals were away on holidays or working in a different location for a few days, "*we can help you deliver it to one of your patients when they are up here temporarily or on holiday, so that way of linking in all the partners in a seamless way" ID9.*

5.7.8.2 Same programme in all centres

For linkage of the centres to be successful, the same programme has to be implemented in all centres. There needs to be *"one coherent, branded, trusted project that everybody knew about and had confidence in" ID9* (delivery agent DCU). Within a coherent programme, *"the cost structure is the same, the content is the same, the ethos is the same the data handling system is the same" ID9* for successful implementation. This vision of a coherent and branded programme would mean that more people would be likely to use it. Many advantages of a coherent project emerged in the discussions. It was suggested that as part of a single coherent project, each centre could help with the delivery of a home-based programme for those who could not attend the supervised classes. Therefore, more people could be reached and the programme could be further scaled up. The delivery agent at DCU suggested that "*each centre around the country could become a little hub for the local home programme, and people can drop in and out to that centre and their occasional face-to-face contact element of the home programme" ID9.*

5.7.9 Exercise programmes need to be embedded in cancer care

Throughout the discussions with all interviewees, the need for programmes such as MedEx MoveOn to be embedded in cancer care was a theme that repeatedly emerged (Table 5.10).

Table 5.10: Summary of subthemes identified when participants discussed the need to embed exercise in cancer care

Theme	**Subthemes**
Need to embed exercise in cancer care	• The next phase in cancer treatment • Exercise should be prescribed regardless of baseline function

5.7.9.1 Next phase in the treatment of cancer

One MedEx MoveOn participant could not understand why exercise is not included in cancer care for rehabilitation, just as screening is for prevention. She highlighted the fact that *"there is cervical cancer screening, there is breast cancer screening, there is prostate screening, there is retinal screening, there is all these government programmes, why can't they put in an exercise programme for everything" ID3.* Another participant felt strongly *"that it should be automatically part of your treatment. When you get to the end of this phase, and this phase, this is the next phase, the get-your-life-back phase" ID4*. Another suggested that just as medication is prescribed to treat cancer, exercise should be prescribed in the recovery phase: *"I think it is important to try and get it into the recovery of people, as a medication for people, and I think exercise should be part of the recovery. It should be essential" ID5*.

5.7.9.2 Exercise should be prescribed regardless of baseline function

Interviewees felt passionately that exercise should be prescribed regardless of a patient's condition or their stage in their cancer journey. The DCU delivery agent stated, "*The bottom line is exercise should be recommended to everybody, full stop. You can maintain wellness during periods where you might have disimproved, like sometimes during chemotherapy. You could improve wellness preoperatively, postoperatively and post-treatment … It should become part of mainstream policy to document physical activity, to measure functional capacity and to prescribe on the basis of observed deficits" ID9*. The interviewee felt that exercise should be normalised and part of routine practice, no matter how fit or unfit an individual is: *"The whole psychological wellness piece is fundamentally based on exercise. So I mean, it should become routine prescription for* *everybody to measure their current level, provide advice and support to enable them to participate no matter what their baseline function is" ID9.*

5.7.10 Level of change needed to implement MedEx MoveOn in the routine care of cancer patients

To embed programmes such as MedEx MoveOn in the care of cancer patients, a certain level of change will be needed. In discussions on this issue, three subthemes emerged (Table 5.11).

Table 5.11: Summary of subthemes identified when participants discussed the level of change needed to implement MedEx MoveOn in the routine care of cancer patients

Theme	**Subthemes**
Level of change needed	• Part of mainstream policy • Pressure from key stakeholders • Evaluation of cost effectiveness

5.7.10.1 Part of mainstream policy

Interviewees noted that for change to happen, exercise and PA *"should become part of mainstream policy"* and "*should be recommended to everybody, full stop" ID9* (delivery agent DCU).

5.7.10.2 Pressure from key stakeholders

If change is to happen, interviewees noted that the HSE and the government *"need pressure from stakeholders and patients and physicians, and the likes of ourselves who are running it. The HSE needs to be put under pressure, and the government" ID9* (delivery agent DCU). It was noted that "*the evidence is now there from the evaluation from the MedEx programme funded by the HSE"* and "*based on the findings of the evidence that is now there … this is worth doing" ID9.* The delivery agent also hoped that support from the HSE "*will come in in a practical way and support delivery as opposed to research, and I think that that is important"* if full implementation and scale-up of the programme are to be achieved.

5.7.10.3 Evaluation of cost effectiveness

Evaluation of the cost effectiveness of the MedEx MoveOn programme was identified as a essential if it is to be included in the routine care of cancer patients. However, providing solid evidence of cost effectiveness is not without challenges: *"[It] is a huge project, and that is a difficult thing to actually do … The HSE should embrace the responsibility for doing that in itself, which is just a bigger project; it takes a bigger study to demonstrate cost effectiveness than the one we carried out" ID9* (delivery agent DCU).

5.7.11 Ensuring fidelity

For scaling up the MedEx MoveOn programme outside DCU, a single, branded, coherent programme was identified as being essential. To achieve this, the fidelity of the programme structure needs to be maintained across all delivery centres (Table 5.12).

Table 5.12: Summary of subthemes identified when participants discussed strategies to ensure the fidelity of the programme

Theme	**Subthemes**
Ensuring fidelity	• Structures to ensure fidelity • Listen to and understand clinicians

5.7.11.1 Structures to ensure fidelity

When discussing the support structures needed to ensure fidelity, a number of factors were identified. A minimum qualification of a BA degree for which exercise science was a key component was recognised as essential for implementation of the programme, as well as standard procedures and compliance:

"We need to apply a standard about what people should be instructing. So currently it is a BA in those standards, minimum, and that somebody in the room should be at that standard, but other people assisting need not be."

"There are standards, well agreed, and you know they are not disputed a whole lot. It doesn't take a lot for people to buy into the importance to comply with them. I think then once that it is done, then it is quite easy to support other centres."

"Ratios need to consistently adhered to … there is a consistency around content of class content."

"We share our learning. So we have SOPs that we have drawn up over many years and we know what we would like to see done in terms of the whole induction process and the referral process and communicate them back" ID9 (delivery agent DCU).

5.7.11.2 Listen to and understand clinicians

At the level of management and coordination, the DCU delivery agent noted that programme fidelity requires that "*everybody involved in running these programmes needs to be fundamentally willing to listen to the clinicians in the hospitals and do what they say and also to not do what they say not to do"*, because *"they are the experts" ID9.*

5.7.12 Challenges to scaling up the programme outside of an urban centre

For scaling up the programme outside an urban centre, many challenges were identified (Table 5.13).

Table 5.13: Summary of subthemes identified when participants discussed the challenges to scaling up the MedEx MoveOn programme outside an urban centre

Theme	**Subthemes**
Challenges to scaling up the programme outside Dublin	• Embedded within the broader service • Making up numbers • Travel • Coherent data systems • Consistency in programme structure across all centres • Commitment and support from the HSE

For successful programme scale-up, the DCU deliver agent identified a number of factors: "*First of all, it needs to be embedded within the broader service."* Other *"challenges making it work is making up numbers."* However, a solution would be *"one identity instead of numerous separate ones" ID9* to achieve credibility in the programme. Travel to centres was also identified as a challenged to scaling up the programme outside Dublin: *"The other challenge outside of Dublin is going to be travel" ID9.* A solution suggested was "*the idea of a home programme option is important."ID9.* This is something that

DCU *"are working on, so that people can attend from a distance or attend infrequently. That it is done from home" ID9.*

The need for consistency in the programme structure across all centres was mentioned: "*Having a coherent data management system that the different partner centres can share. There needs to be consistency with approach, maybe with things like pricing structure if you are going to brand something and run it around the country. It should be consistently run in some way" ID9*. Another *"big challenge is going to be trying to get the HSE to commit to helping"ID9.* This is something the delivery agent in DCU felt *"needs to happen, I am hoping it will happen in due course, but it has not happened yet" ID9*

5.8 Discussion

5.8.1 Introduction

Many oncology organisations have identified the need to incorporate exercise in cancer care (Denlinger et al., 2014; Rock et al., 2012; Schmitz et al., 2010). Similar to our findings, cancer patients in other studies have expressed a desire to participate in appropriately designed programmes that are specific to the needs of cancer cohorts (Blaney, Lowe-Strong, Rankin-Watt, Campbell, & Gracey, 2013; Jones & Courneya, 2002b). The primary aim of this feasibility study was to examine the factors that influence the initial implementation stage of an exercise programme such as MedEx MoveOn in practice. A secondary aim was to develop a model of best practice to incorporate exercise and PA into cancer care in Ireland using the data gathered from the interviews.

This study used the active implementation frameworks (Fixsen et al., 2005) and the RE-AIM framework (Glasgow, Vogt, & Boles, 1999) to elucidate what implementation methods are effective and recommend how they can improved. These data contributed to the development of a model of best practice for incorporating exercise and PA into cancer care in Ireland.

The current study provides an insight into the factors that influence the implementation of exercise rehabilitation programmes for cancer survivors and an understanding of the level of change needed to implement a programme such as MedEx MoveOn in routine care for Irish cancer patients. In addition, it identifies the challenges and barriers in scaling up the MedEx MoveOn programme outside Dublin. Finally, it highlights what strategies need to be implemented to ensure the fidelity of the MedEx MoveOn programme. The study findings add to previous research among cancer survivors by identifying factors that influence the implementation of exercise rehabilitation programmes for cancer survivors in practice. They may also benefit programme developers by providing information on more integrated and collaborative approaches for implementing exercise programmes for cancer survivors and how to ensure fidelity.

Linking the formula for success to active implementation frameworks indicates that effective implementation methods involve implementation teams (who), implementation stages (when), implementation drivers (how), and improvement cycles (how) (Fixsen et al., 2005; NIRN, 2013). The last variable in the formula is an enabling context. A context (environment) that is enabling is essential so that change is supported, results match the intended outcomes, and the successful programme is sustainable in the long term. The study results are discussed under the active implementation framework headings (Fixsen et al., 2005) of effective implementation methods and enabling contexts. The final section discusses a proposed model of best practice for incorporating exercise and PA into care in Ireland.

5.8.2 Effective implementation methods

5.8.2.1 Implementation teams

The initial implementation stage begins when the new programme is first being put into practice. As the MedEx MoveOn programme was in its first year of implementation, it was recognised as being in the initial implementation stage. Having a multidisciplinary team comprising individuals from the Department of Sport & Exercise Science and the Department of Nursing and Health Care at WIT and staff in the WIT Arena was mentioned as a critical factor in successful implementation of the MedEx MoveOn programme. The professional implementation team for MedEx MoveOn at WIT consisted of a leadership team and WIT Arena staff who were actively involved on a daily basis in ensuring effective use of the programme. Besides a multidisciplinary team, having a leader of this team was mentioned as being crucial to implementation. A leader is an individual who motivates people to work collaboratively to achieve targets. While managers mobilise individuals and resources to reach goals, leaders set the direction and purpose for an organisation for the short and long term. A leader knows how to set goals, run meetings, identify mentors, understand and apply research, create a team, and negotiate conflict. The delivery agent at DCU identified having a leader as crucial to the programme success. The success of the MedEx MoveOn programme in DCU was also attributed to the presence of a leader. A leader provides other key stakeholders with a point of contact for building a strong relationship when trying to create further links with additional key individuals and possible partners. Fixsen and colleagues highlighted the importance of incorporating a leadership driver (NIRN, 2013). Such a driver can enhance the ability to create a more hospitable structural environment. To date, there is no implementation leader in place at WIT. This role needs to be institutionalised in WIT to ensure that the intended outcomes of the MedEx MoveOn programme are achieved.

Change champions have been identified as key individuals in implementation teams to ensure that new innovations move through the phases of commencement, development, and implementation. Santa Mina et al. (2015) reported that a steadfast champion who gathered support from physicians and patient advocates continuously complemented successful programme initiation. The DCU delivery agent felt that a local champion is essential if the programme is to be successfully implemented and scaled up to other institutions and sites across the country. Key characteristics of a local champion identified by interviewees for driving quality improvement efforts by other members of the implementation team were drive, passion, commitment, and enthusiasm. According to previous research, charisma alone can only get a change champion so far (Nutting et al., 2010), and facilitative leadership qualities are also required. These include an ability to empower staff and to create safe and respectful environments to bring about change (Nutting et al., 2010). WIT has a local champion for the programme who has all of the characteristics listed above and has created strong links and partnerships with the oncology unit at University Hospital Waterford, cancer support centres, local media, and staff at WIT Arena. Because of the links the local champion has created, greater commitment and buy-in from further stakeholders has been achieved.

5.8.2.2 Health care system factors to consider for effective implementation

Consistent with previous research (Din, Moore, Murphy, Wilkinson, & Williams, 2015; Graham, Dugdill, & Cable, 2005; Laws et al., 2008), health care professionals interviewed in our study identified time restrictions as a barrier to discussing exercise with their patients. If health care providers do not have the time or skills to prescribe exercise for their patients, knowing what programmes to refer their patients to is vital. Policies need to be put in place to ensure that GPs prescribe exercise just as they prescribe medication. The need for health care providers to direct cancer survivors to appropriate rehabilitation programmes such as MedEx MoveOn cannot be overemphasised. Action area 3 of The National Physical Activity Plan for Ireland highlights the important role that health care professionals play in promoting PA and exercise, and notes that PA should be seen as part of the remedy to a patient’s condition (Get Ireland Active, 2016). The use of third level institutions to provide training on the role of PA for all health care professionals is also proposed in the plan (Get Ireland Active, 2016). This action is needed to ensure that health care professionals have the skills and knowledge to prescribe exercise. A recent study revealed that only 16.4% of oncology nurses and 8% of physiotherapists received undergraduate education on the use of exercise in cancer cohorts (O’Hanlon & Kennedy, 2014). Hence, it is imperative that health care professionals receive training to ensure they have the skills and knowledge to promote and prescribe PA and exercise. This training should highlight the structured programmes that are in place to raise awareness of MedEx MoveOn and similar programmes.

When the MedEx Move On programme was launched in April 2017, more than 100 invitation letters were sent to GPs in the South East. None of the GPs invited actually attended the launch. Interviews revealed that letters were not the best approach to engage and inform GPs about programmes such as MedEx MoveOn. GPs interviewed in our study suggested that the best way to provide this information is by meeting them face to face. Although this could be time-consuming, one suggestion was to meet GPs collectively in group. What is needed to attract GPs is a hook, something so attractive that they find it hard to refuse. A recent Exercise is Medicine seminar in the University of Limerick attracted 80 physicians. This level of success in attracting physicians may have been due in part to the inclusion of an American expert speaker. Another option could be to set up a professional development workshop on exercise and cancer for GPs and other health care professionals for which they could earn continuing professional development points**.**

Similar to previous research (Din et al., 2015), concern regarding patient safety was identified as a barrier to referral. Health care professionals stated that the main barrier to referral would be the safety of the programme. However, endorsement of the programme by oncologists and a cancer care centre was identified as a facilitator in reducing such concerns.

While GPs were identified as key individuals to target in terms of referring patients to the programme, they are not the only health care professionals that should be targeted. Other key individuals identified as important in the referral pathway were liaison nurses and cancer specialists. Clinical nurse specialists spend the most time with the target population and were highlighted as effective referrers. Training should be provided to these key individuals on the importance of exercise and cancer, This is another issue the MedEx MoveOn implementation team could improve on and explore further to reach greater numbers of cancer survivors and scale up the programme.

The level of paperwork was identified as a barrier to engagement in exercise referral, consistent with previous research (Din et al., 2015). GPs noted that the time required for filling out clearance forms was a major barrier to successful implementation of the programme. Suggestions to improve the ease of referral included an online option, with clearance forms available on the MedEx MoveOn website and a connection to the Healthlink software used by health care professionals. Healthlink, which has been in operation since 1995, is a web-based messaging service for secure transmission of patient data between hospitals, GPs, and health care agencies. It is fully compliant with the HIQA National GP Messaging Standards.

Consistent with previous research (Din et al., 2015), health professionals pointed to concerns that patients would be either unable or unwilling to travel to WIT Arena to avail of the facilities because of its location and the travel distance involved for some patients. A home-based programme could mitigate this problem. Seeking funding for a bus to transport participants to WIT Arena was also suggested as a way to achieve full implementation and reach more participants in scaling up the programme. The South East Radiotherapy Trust provides free transport for cancer patients living in the South East of Ireland who require radiotherapy. The MedEx MoveOn implementation team at WIT should consider approaching key organisations such as local sports partnerships (as identified by interviewees in the study) for funding for a similar service for individuals requiring cancer rehabilitation.

5.8.2.3 Programme structure

Some elements of the MedEx MoveOn programme structure identified as crucial implementation methods have been discussed elsewhere in this chapter. These included the group format, cancer-specific cohort, need for funding, multidisciplinary team, and a leader and local champion.

Failure to consider the community perspective in developing intervention strategies has also been identified as a factor that can influence successful programme implementation. According to Glasgow & Emmons (2007), including the community perspective (cancer survivors and health care professionals involved in cancer care) is critical. From study commencement, the principal investigator ensured that the perspective of the study participants (cancer survivors) and the health care professionals (oncologists and cancer centres in the South East) involved in their care was taken into consideration. This allowed the identification and application of effective implementation methods to ensure successful implementation of the MedEx Move On programme in practice.

5.8.2.4 Intervention characteristics

Fixsen et al. (2005) reported that in addition to specific content, purpose, and structure, other characteristics of programmes appear to influence implementation success. Similar to our findings, fun and variation have been reported as key factors in implementing exercise programmes for cancer survivors (L. Smith et al., 2017). Participants in our study suggested that the fun and variation involved in the MedEx MoveOn programme motivated them to attend the classes and exercise. Motivation is crucial in supporting sustained exercise, which in turn is linked to important health outcomes (Teixeira, Carraça, Markland, Silva, & Ryan, 2012). Therefore, it is essential for programmes such as MedEx MoveOn to ensure that the intervention being carried out is fun and varied.

The focus of the programme on participating in an activity (exercise) as opposed to sitting down and talking (e.g. counselling) was identified as an effective implementation feature by the health care professionals interviewed. Similar to the motto of the Men’s Shed association (“Men don’t talk face to face, they talk shoulder to shoulder”), this suggests that cancer survivors are more likely to talk when the setting is right, such as participating in an activity they enjoy in the company of similar individuals. As highlighted by the participants in the study described in Chapter 4, they were not talking, as they did not want to feel like they were ungrateful. In a previous study, participants also stated that they were not interested in sitting down and talking about their issues (Hefferon, Murphy, McLeod, Mutrie, & Campbell, 2013) and considered participation in an exercise programme a better alternative. When in an environment in which they feel safe, cancer survivors are more likely to open up and feel comfortable talking about their worries.

5.8.2.5 Considers the social element

Social support is an important factor that influences health outcomes (Berkman et al., 2000; Holt-Lunstad, Smith, & Layton, 2010). Considering the social element of the intervention by including a cup of tea or coffee after the classes was identified as a major effective implementation method in the MedEx MoveOn programme. Participants valued this time for interacting with the group that allowed them to continue conversations, share information, create a sense of camaraderie, and reflect on the work done during their exercise class. Some noted that without this, they would not have had the time to interact with the other participants. This feature also gave participants who were not be able to exercise due to illness an opportunity to still meet and interact with the other group members, which led to a sense of inclusion. Even if participants could not take part in the exercise session, they could still meet up and chat over a cup of tea or coffee with the others. This reassured the group members that the individual who could not exercise was okay. Because of its benefits, this social element was identified as an effective implementation method in the MedEx MoveOn programme.

5.8.3 Ensuring fidelity

Interventions shown to be effective in clinical trials may not impact health at a population level if they are not delivered with fidelity (Fixsen et al., 2005; Mihalic, 2004). Implementation fidelity is vital in achieving successful outcomes. Many factors were identified as important to ensuring fidelity of the MedEx MoveOn programme. These included coordinated communication between various centres; linking centres; the same coherent project carried out at all centres; having a minimum qualification of a BA degree for which exercise science was a key component; well-agreed standards; sharing of information and learning between centres; and listening to and understanding cancer clinicians, as they are the experts. At present, the programmes differ between WIT and DCU. At the time when this research was carried out, participants in the MedEx MoveOn programme at WIT were being offered one supervised class per week for 10 weeks (10 sessions), whereas MedEx MoveOn in DCU involved two classes per week for 12 weeks (24 sessions). The DCU programme also included an induction session, whereas the programme implemented at WIT did not. The pricing structure also differed: subscription to the programme at WIT costs €90 for the 10-week programme, while the cost at DCU is €50 per month, which comes to €150 for the 12-week programme. To achieve programme scalability, its fidelity needs to be ensured, which is not the case at present.

5.8.4 Level of change needed to implement exercise in routine cancer care

Implementation teams cannot address and overcome all the challenges. Solutions will require input from policy makers and other key individuals in the health care system. When discussing the level of change needed to implement the MedEx Move On programme in routine care for Irish cancer patients, the main factor cited was that key MedEx MoveOn stakeholders (patients, physicians, delivery agents) should put pressure on those who have the power to bring about change, such as the government and HSE. This could be achieved via channels such as The National Physical Activity Plan

(Department of Health, 2016) and The National Cancer Strategy 2017–2026 (Department of Health, 2017).

Consistent with the Clinical Oncology Society of Australia position statement on exercise in cancer care (Cormie et al., 2018) participants in our study felt strongly about having exercise embedded in the care of all Irish cancer survivors. They stated that it should be the next step in cancer treatment and should be viewed as key therapy in the rehabilitation stage of a person’s cancer journey. Just as medication is used to treat the disease, exercise should be used to rehabilitate the individual to help in reducing the burden of common side effects and improve the overall QOL of cancer survivors. They called for all members of the cancer care continuum to recommend and refer patients to the MedEx MoveOn programme and could not understand why such programmes do not have the same status as current cancer prevention programmes such as the Cervical Check and Breast Check national screening programmes. In addition, the health care professionals interviewed noted that regardless of disease stage or baseline function, exercise should be prescribed for all individuals as part of their treatment plan. It was highlighted that this is important because exercise has positive physical and mental health effects for all levels of baseline functions.

5.8.5 Challenges to scaling up the MedEx MoveOn programme outside of a major urban centre

Scalability has been defined as “The ability of a health intervention shown to be efficacious on a small scale and or under controlled conditions to be expanded under real world conditions to reach a greater proportion of the eligible population, while retaining effectiveness” (Milat, King, Bauman, & Redman, 2013, p. 289). Challenges to scaling up the programme outside a major urban centre cited in the interviews included having the programme embedded in the broader health system; access to the target population; synchronised and coherent data systems; a consistent programme structure across all centres; travel; and obtaining commitment from government bodies such as the HSE. Consistent with these findings, Reis et al. (2016) reported that scale-up can only be considered successful if the research setting is embedded in a health care system. This is turn will ensure that the programme is sustainable and can be maintained. Unfortunately, this approach is not yet applied in Irish health care systems and thus is itself a barrier to scale-up of the MedEx MoveOn programme.

5.8.6 Enabling context

According to the World Health Organisation (WHO) health systems framework, every "building block" in a health care system needs to have an enabling environment to ensure that services are successful and effective (WHO, 2017). An enabling context is part of the formula for success. Implementation teams also play an active role in creating a welcoming and sociable environment that represents an enabling context and supports those who are trying to make the programme work. Creating an enabling environment for MedEx MoveOn was a crucial factor when developing and implementing the programme. When discussing the MedEx MoveOn environment, many factors were identified by the interviewees.

MedEx MoveOn participants and health care professionals interviewed mentioned the safe and supportive environment both at the WIT Arena and in the MedEx MoveOn programme as crucial to the intervention success. This was achieved via a supervised programme, trained professional personnel both at the facility and the instructor delivering the programme, and the resources available at the WIT Arena. The use of professionals for every step of the programme meant that the health care professionals interviewed had no concerns about referring patients. This indicates that key individuals in the referral pathway should have no concerns when recommending the programme to the target population. Our findings highlight the importance of including professional staff in the delivery of an exercise rehabilitation programme to ensure that the target cohort is being reached and referred to the intervention.

According to the Maslow (1954) hierarchy of need, a sense of belonging is crucial to an individual's health. The MedEx MoveOn participants continually mentioned how welcoming and supportive the staff at WIT Arena were. They gained a sense of normality, and felt just like any other member of the facility, as opposed to a marginalised and vulnerable group. The inclusive environment enhanced their self-confidence and sense of belonging. This is in agreement with a study in which subjects gained a sense of normality by participating in a cancer-specific exercise rehabilitation programme (Korstjens et al., 2008).

The research design, which involved inclusion of all cancer types and a programme designed to meet the specific needs and abilities of all participants, was another factor identified by the MedEx MoveOn participants as having a positive effect that contributed to the success of the programme. The design led to an environment in which participants felt safe. Of the participants who discussed this in their interview, most reported a desire to exercise with other cancer survivors to feel a sense of connection with individuals who were in the same situation. An environment that they felt was designed specifically for their needs provided a space where they felt safe in discussing issues with others who were experiencing the same problems. This gave them an opportunity to seek reassurance and thus helped them in reducing their anxiety about the issues and in moving beyond their cancer by increasing their confidence.

While participants mentioned how inclusive the environment felt, it must be noted that the MedEx MoveOn programme at WIT involved a fee to participate and only included patients who were post-treatment, which is a limitation of the research design. Unlike other programmes on offer to cancer patients in the USA, which are historically offered free of charge or at a low cost (Irwin et al., 2017), the MedEx MoveOn programme involves a cost of €90 that is not subsidised in any way or reimbursed by health insurance companies. The fee involved was identified as a barrier for many individuals who were interested in the programme but could not afford it (MedEx MoveOn non-participants interviewed). Results from the study outlined in Chapter 4 indicate that a cancer diagnosis imposes a huge financial burden on many cancer patients and their families. Many are faced with extra costs such as fees for GP visits and medications to alleviate the side effects of cancer and its treatment. In addition, many patients and families incur fees for parking at hospitals and have to pay for fuel to travel to treatment and follow-up appointments. Patients recovering from cancer spend more time at home, and therefore utility bills are often higher. Moreover, as discussed in earlier chapters, many patients do not return to work because of side effects such as persistent severe CrF. Among those who are out of work, many do not receive sick pay from their employer. A reduction in income may have a wide range of consequences for both cancer patients and their families. Therefore, offering a rehabilitation programme that involves a cost may reduce the likelihood that participants who are under financial pressure will take part, which could limit the reach and scalability of the programme.

Limited reimbursement for cancer rehabilitation and expenses not covered by insurance companies may also deter cancer patients from taking part in programmes such as MedEx Move On. Similar to previous studies (Alfano, Ganz, et al., 2012), the cost involved and lack of insurance cover were identified as a barrier to uptake for some individuals in our study. Limited reimbursement could directly affect the availability and sustainability of the MedEx MoveOn programme. The cost for participating also reduces the reach of the programme, and is an issue that needs to be considered by the implementation team.

Exercise programmes for cancer survivors must reflect the diversity of their needs. The MedEx MoveOn programme currently being run at WIT is supervised and only involves morning classes. Those interviewed mentioned that morning-only classes are not suitable for those who have returned to work or have childcare issues. In addition, the location and travel distance to the facility were identified as barriers. Solutions to these problems identified by the interviewees were the addition of evening classes and a home-based option. Some individuals may face barriers that make exercise difficult or even unsafe in an unsupervised setting. Hence, they may need to be part of a structured and supervised cancer rehabilitation programme before they can advance to a home-based intervention (Stull, Snyder, & Demark-Wahnefried, 2007). Ther are many logistic, resource, and preference issues for this growing and vulnerable group. Although the MedEx MoveOn participants reported that they preferred being part of a supervised exercise programme, others, such as those who have returned to life roles or cannot commit to certain class times, might be interested in home-based programmes. It is clear from our study results that cancer survivors need wider availability of a range of options to meet their needs. To meet these needs, the inclusion of options such as evening classes and home-based programmes would enhance the reach and uptake of such interventions. In turn, this could enhance the overall health outcomes for cancer survivors on a greater scale.

If MedEx MoveOn at WIT is to be scaled up, the cost issue and inclusion of all individuals with a cancer diagnosis (during and after treatment and in the palliative setting) need to be considered, as well as the incorporation of a home-based option. Health care professionals also highlighted an interest in programmes that included patients during treatment and those in palliative care. High costs, programmes that are not adaptable to the needs of cancer survivors, and participants who are unwilling to travel to cancer centres have been identified as barriers to successful implementation in previous studies (Alfano, Ganz, Rowland, & Hahn, 2012; Irwin, 2009; Santa Mina et al., 2012).

The Cancer Foundation for Life (CFFL) runs a non-profit community-based exercise programme designed to improve the QOL of cancer patients. In 2010, CFFL had almost 3000 referrals and 66,000 patient encounters (Haas & Kimmel, 2011). This success in reaching so many patients who took part in the programme could be attributable to the lack of cost involved, inclusion of all individuals with cancer regardless of the type or stage, and incorporation of a home-based programme. Funding is obtained from oncologists, other health care providers, foundations, and philanthropists. Each member of the foundation donates $75,000 over a 3-year period. The programme is also supported by a small grant from the Lance Armstrong Foundation. No funding is currently in place for the MedEx MoveOn programme at WIT. The reach and adoption of the programme could be improved by targeting key funding opportunities within the local community. This could enhance the sustainability of the programme. Sourcing funding and donations from organisations within the community could also help to offset the costs of running the programme at WIT Arena.

The literature suggests that individuals lacking social connectedness experience poorer physical and mental health, including a higher risk of depression (Cruwys, Haslam, Dingle, Haslam, & Jetten, 2014), and die earlier than those who feel socially connected (Holt-Lunstad et al., 2010). Participants in Study 2 often mentioned how disconnected, isolated, and lonely they felt following their cancer diagnosis. Use of a community setting that was outside the clinical setting was mentioned as an important factor in creating an enabling environment in which the MedEx Move On participants felt they could reconnect with the real world again, which enhanced their sense of connectedness. Health care professionals also discussed the importance of having an environment outside the clinical setting. They mentioned that this was a more positive environment for cancer survivors, as patients associate the clinical setting with negative feelings.

5.8.7 Model of best practice for incorporating exercise and PA into care in Ireland

Embedding an exercise programme such as MedEx MoveOn into oncology practice as a standard of care for Irish cancer patients to achieve lifelong behaviour change is challenging. Patients with cancer are often intimidated, lack confidence, and fear exercise, as evidenced by the results for the studies described in Chapters 3 and 4. Hence, a programme specifically designed to meet the various needs and abilities of participants at all stages of their cancer journey (before surgery, during and after treatment, and in palliative care) is essential. The programme also needs to involve an enabled environment that is safe, supportive, welcoming, and inclusive for all participants. The intervention itself needs to be fun, varied, and attractive to the target population, and include social and educational elements. Where possible, a group-based supervised programme specific to cancer populations should be implemented. This environment seems to provide a superior benefit and outcomes in terms of side effects (e.g. CrF, as observed in the study described in Chapter 3), QOL, physical and psychological functions, and physical fitness. However, other options (e.g. home-based exercise and evening classes) should be on offer to reach those who may have returned to work and life roles, or who are living too far from the programme location. Those running the programme need to be professional, enthusiastic, and passionate. The implementation team should have a local champion as a point of contact for key stakeholders. The local champion should exhibit passion, determination, drive, and enthusiasm, and needs to have facilitative skills to empower staff and create a safe, supportive, and respectful environment to bring about change (Nutting et al., 2010). Engaging the wider community should be a priority of the MedEx MoveOn programme via collaborative connections with cancer patients and their families and health care professionals involved in their care; the local media should be included as partners in the project. The implementation of strategies to ease the burden of referral and create an easy referral pathway for health care professionals is also important because of the time restraints identified by GPs. Costs also need to be considered, so funding and commitment from appropriate agencies needs to be targeted to ensure that those who cannot afford the service can still have access. Cost-effectiveness studies are needed to ensure that the programme is sustainable and can be maintained. A coherent programme that involves the same cost, components, and structure should be implemented across all centres.

5.8.8 Study limitations

Limitations include the fact that many of the participants involved in the interviews were advocates and endorsers of the programme therefore; their views may not be representative of all cancer survivors, and health care professionals.

Assessor bias cannot be ruled out as the same investigator who facilitated educational seminars in the MedEx MoveOn programme also carried this feasibility study and is an advocate of the programme.

This study did not involve any measure of cost effectiveness. However this programme was in the initial stage of implementation therefore, long-term cost effectiveness was outside the scope of this study.

5.8.9 Study strengths

Though limitations did exist these were offset by strengths of the study. External validity of the programme is supported by its implementation in a community setting. This was further enhanced by the “the real world” administration of the programme. Evaluation tools such as the RE-AIM framework and Active Implementation Frameworks also guided evaluation of the programme.

5.9 Conclusion

This study set out to examine what factors influence the implementation of an exercise programme for cancer survivors in practice. Implementation appears to be most successful where an enabled environment is created, a collaborative multidisciplinary team are involved, champions exist in recruitment settings and an overall programme leader exists to co-ordinate. Barriers and challenges to programme scale up outside of a major urban centre included accessibility to the target population and financial support from relevant agencies. The cost involved, lack of reimbursement, time of day for classes, and location were also identified as possible barriers to the scalability and reach of the programme. The implementation team need to consider the possibility of funding via organisations such as local sports partnerships, health care units, and possibly local pharmaceutical companies who manufacture cancer drugs and treatments. Addition of a home-based programme and evening classes could also help those who cannot access the facility or attend morning classes. The programme could also be more inclusive, as only post-treatment patients were included. Individuals who need rehabilitation before surgery (prehabilitation), during treatment and in palliative care could all benefit from exercise. This in turn would affect the reach and scalability of the programme.

Exercise programmes for cancer survivors are suitable for delivery in community settings. There is a need to embed exercise rehabilitation in the care of Irish cancer patients. To achieve this aim, future cost effectiveness research needs to be undertaken. In addition, key programme stakeholders (patients, physicians, delivery agents) will need to put pressure on those who have the power to bring about change, by lobbying the government and HSE.

CHAPTER 6.

RECOMMENDATIONS

Chapter 6: Recommendations

6.1 Introduction

The recommendations presented below are based on an integrated analysis of the findings of the previous three research chapters and serve to draw the various strands of this thesis together. The recommendations are organised under recommendations for health care practice and future research.

6.2 Recommendations (R) for Health Care Practice

R. 1: That cancer patients are provided with the knowledge, skills and guidance to enhance their self-management behaviours prior to completing treatment

CrF is a major problem for cancer survivors and persists for years following treatment. Results would suggest that CrF not only affects cancer survivors physically, it affects them mentally, socially and financially. Participants cited that they felt a sense of abandonment following their treatment with very little follow up. They also stated that they were not provided with the knowledge or skills to cope with the transition from patient to survivor. This they felt was a void in their treatment. As the number of cancer survivors continues to increase, it is essential that they be provided with the knowledge, skills and guidance to enhance their self-management behaviours prior to completing treatment. This would then improve their overall QOL and reduce their risk of other chronic illnesses that often occur in this patient group.

R. 2: Education on fatigue needs to be included in the curricula for health care professionals

Participants mentioned that their health care team, family and friends misunderstood their CrF contributing to their sense of isolation and loneliness. If CrF is to be treated correctly, health care professionals involved in the care of cancer patients need to be aware of how serious and debilitating this condition is, and the impact it has on sufferers' QOL. Education on this condition needs to be included in the curricula for health care professionals, particularly oncology health care professionals and general practitioners.

R. 3: Exercise should be **the** major component of efforts to treat cancer-related fatigue and associated problems

In survivors with documented fatigue, progressive exercise training has beneficial effects of on fatigue, physical fitness and other QOL outcomes beyond those attributable to peer support and investigator attention. The net change in fatigue over the 10 week intervention period was 4 times the recognised CID for the FACT-F. The intervention effect size (Cohen's d) was 1.38. This was the first intervention that we know of, specifically designed for fatigued individuals as we recruited only fatigued individuals. Though this was not a definitive trial our findings are very promising. We achieved results of considerably greater magnitude than those achieved in other studies, we had 100% retention to 10 weeks, and no adverse events. Changes were sustained to 26 weeks and possibly beyond. The intervention effect on fatigue in the EXG was largely achieved by week 4 and changes were carried through to 26 weeks. Due to the decreases in fatigue, participants reported feeling healthier than ever with some returning to work full-time. The intervention had a clinically important increase in 6MWT distance. The beneficial effects on survivors' physical fitness enhanced ability to carry out activities of daily living. By engaging in activities of daily living, survivors are more willing and able to engage in social activities with family and friends. Participants in the qualitative study suggested that having the energy to return to life roles and engage in family activities enhanced their sense of connectedness by decreasing their sense of isolation and loneliness, which was often mentioned as an issue. This highlights the importance of exercise rehabilitation and it should be the major component of the treatment for fatigue.

Exercise training also has beneficial effects on associated problems of cancer such as insomnia and reduced cognitive function. Participants in the qualitative study reported that they were sleeping better and that the tiredness they felt was a genuine tiredness as opposed to fatigue. Others reported better cognitive functioning noting the "fuzziness" had alleviated. Insomnia and cognitive dysfunction have a major impact on the daily lives of cancer patients and impact on a patient's ability to return to work, with a negative knock-on effect on their self-esteem. The exercise intervention effect on insomnia severity also exceeded the CID. There is evidence in our data that the reductions in CrF and insomnia were related. There was a large positive intervention effect on cognitive function in the EXG, and the improvement was sustained at follow-up. Exercise has beneficial effects on fatigue, sleep, and cognitive function, which are common effects of cancer and its treatment, and exercise should be acknowledged as a primary treatment.

Exercise also has beneficial effects on physical function, role function, social function and global QOL. Engaging in the exercise intervention increased participants' social function due to the social support, interaction, engagement and feelings of connectedness and the sense of belonging experienced. Participants in the qualitative study commented that the programme had not only saved them, it had given a family back its mother, wife, sister and friend. The physical and psychological benefits participants gained from the exercise meant that they felt well enough and had the energy to return to work and life roles. Enhancing a survivor's ability to return to work will also help improve the financial burden a cancer diagnosis brings. With survivorship set to increase, a person's QOL is vital. Preserving and enhancing physical, social and role functional status is essential in improving long-term health outcomes and QOL in cancer survivors. This can be achieved through progressive exercise training. Exercise should be the major component of efforts to treat cancer-related fatigue and associated problems.

R. 4: Exercise programmes for cancer survivors are suitable for delivery in community settings.

Exercise programmes for cancer survivors are suitable for delivery in community settings as long as they provide a safe, supportive and social environment. Although the involvement of oncologists and other health care professionals is imperative, the inclusion of exercise specialists in the care of cancer patients could ease the burden on an already strained health system. Creating an enabling environment is a key component for successful implementation of a programme. A community setting was identified as a key setting for the delivery of an exercise programme for cancer survivors. The use of a community setting that is outside of the clinical setting was identified as an important factor to create an enabling environment. This creates an environment where cancer survivors feel reconnected with the real world, enhancing their sense of connectedness and normality. Health care professionals highlighted the importance of having an environment outside of a clinical setting. They identified the community setting as a more positive environment for cancer survivors to be part of, whereas in a clinical setting, patients identify with feelings of negativity. Providing a safe, supportive and social environment for cancer survivors allows participants to feel more comfortable sharing their experiences and information, gaining information and seeking reassurance from those who are in the same boat. It also provides an opportunity for social and peer support as mentioned. Numerous factors must be considered for the successful implementation of an exercise programme in a community setting. The environment is enabling when a collaborative multidisciplinary team are involved, champions exist in recruitment settings and an overall programme leader exists to co-ordinate.

R. 5: Exercise-based rehabilitation should be incorporated into health services programmes, budgets and treatment plans

Exercise based rehabilitation was identified as a missing link in cancer care. Health and cancer services need to make provision for survivor-tailored structured exercise rehabilitation that will greatly enhance QOL, and assist in a return to work. It is essential that exercise rehabilitation be identified as the next step in the care of cancer patients. The cost involved to participate in community based rehabilitation programme is a barrier to participation as identified in the feasibility study. It is imperative that nobody is discriminated against in having access to such programmes. Cancer patients need exercise medicine support. Provisions need to be put in place for those who cannot afford to pay. This could be done via channels such as lobbying government, having cancer rehabilitation free of charge for cancer sufferers (seeing it as a further treatment in their cancer journey) and creating partnerships with health insurance companies by having cancer rehabilitation included or subsidised by their cover.

6.3 Recommendations for future research

R. 6: Exercise oncology and exercise oncology translational research is in its infancy and there is a need to prioritise research funding for this field

6.3.1 Trials to investigate dose response issues related to exercise and CrF

The dose–response relationship for exercise and fatigue is still unknown. Our results indicate that the intervention effect on fatigue in the EXG was largely achieved by week 4. No study to date has examined the minimum dose required to positively affect fatigue in cancer survivors with documented fatigue. Assessment of the lowest PA dose necessary to achieve beneficial effects warrants investigation in future studies. Knowing how much exercise is needed for a positive dose response would allow correct management and treatment of CrF.

The interaction of acute and chronic exercise should also be investigated. It is important to understand the changes in fatigue and sleep quality that occur in the aftermath of single exercise sessions so as not to overload the fatigued participant in the early stages of training. It is possible that the effects of regular exercise on fatigue and sleep relate to multiple acute effects.

6.3.2 The inclusion of follow up to determine the medium-term effects on CrF, PA, fitness, and other QOL indicators

The inclusion of a follow up enabled the investigation team in our study to observe if fatigue returns to pre-intervention levels when supervised exercise ceases and the participant's physical activity is entirely self-directed. Though our results suggest that the effects of a supervised exercise programme extend to 16 weeks post-intervention, longer follow up durations of 12-24 months warrant further investigation. If health services are to invest in community based exercise programmes for cancer survivors they need to know that the positive health benefits are sustained in the long term as a result of participation in the programme.

6.3.3 Investigate the interrelationships between pain, sleep quality, and fatigue, and the effects of exercise on pain in fatigued cancer survivors

Our results suggest interrelationships between fatigue, insomnia and cognitive function. This evidence suggests a symptom cluster exists. Exercise had beneficial effects on all three outcomes in our study. Pain is an additional problem also reported by cancer survivors. Although pain was not an outcome measure included in this study, interrelationships between pain, sleep quality, cognitive function and fatigue, and the effects of exercise on pain in fatigued cancer survivors warrant further investigation. Future studies should include participants who are experiencing this specific symptom cluster and investigate the changes with exercise. A larger sample would be needed for such a correlational study to be carried out.

Sleep quality and cognitive function were measured subjectively. The self-report instruments did not capture night-time awakenings or daytime napping. Increases in daytime napping as a result of an increased night-time awakenings due to pain, anxiety, hot flushes, increased need to urinate and the impact of illness and medications, is often reported among cancer patients and survivors. This leads to poor sleep quality. There is a need for future studies to capture such data via a sleep diary and/or a wearable device. Additionally, objective measures of cognitive function are needed. Objective measures would allow a more comprehensive assessment of the interrelationships between sleep quality, cognitive function and fatigue.

6.3.4 Investigate the effect of reducing sedentary time of CrF and QOL

Reducing sedentary time has been shown to influence disease risk and health outcomes for other conditions. Targeting sedentary time may be an alternative acceptable approach to getting participants out of the armchair at regular intervals.

6.3.5 Investigate how to create awareness of community based exercise rehabilitation programs among health care professionals and, how to gain the trust of health care professionals to refer cancer patients to community based exercise rehabilitation programmes

Creating awareness of the exercise programme and gaining the trust of health care professionals to refer cancer patients to the exercise programme were identified as potential barriers to programme success. Referral from clinical practices is not only needed in terms of reaching the target population but also in terms of the scaling up and sustainability of the programme. If any programme is to last, it needs participants. Though certain factors were identified in our study, specific studies should investigate how to create awareness and gain the trust of health care professionals, so that they refer cancer patients. This needs to be undertaken on a larger sample of healthcare professionals including a wider variety of practitioners involved in the care of cancer patients, not just general practitioners and oncologists.

6.3.6 Cost effectiveness study

Cost effectiveness was not measured in our study. If the government and health care services are to embed exercise into the routine care of cancer patients they need to know that the programme is cost effective. The aim of future studies should be to evaluate the cost effectiveness of community-based rehabilitation programmes. Where multiple sites are involved, a national level economic evaluation should be undertaken. Such evaluations may provide the evidence-base and justification for community based exercise rehabilitation programmes to be established nationwide to enhance the QOL of cancer cohorts at population level.

6.4 Contributions (C) to knowledge

C. 1: The effect of exercise on CrF is considerably greater than has been previously reported as the result of exercise *per se*.

Though more a feasibility study, the results outlined in chapter 3, if confirmed in a definitive trial, indicate an exercise effect on CrF that is of considerable magnitude, equivalent to four times the clinical important difference. In addition, we can attribute the between group changes in fatigue to exercise *per se* rather than to peer group support and investigator attention.

C. 2: The effect of exercise is evident at 4 weeks.

Even though the dose–response relationship for exercise and fatigue is still unknown, the results in chapter 3 indicate that the beneficial effects of exercise on fatigue may be evident at 4 weeks. This observation is corroborated by the qualitative results in chapter 4, where many reported not feeling the effects right away but, rather after a few weeks.

C. 4: Exercise can be targeted at individuals with CrF.

The results observed in both chapter 3 and 4 confirm that exercise is feasible and safe, and can be targeted at individuals with documented CrF. Specific programmes tailored to individuals with fatigue are necessary.

C. 5: Cancer related fatigue affects cancer survivors physically, mentally, socially, and financially reducing their overall quality of life.

The results outlined in Chapter 4 confirm that CrF has a negative impact on cancer survivor's physical, psychological, social, and role function, reducing their overall quality of life. The qualitative results indicate that specific exercise programmes designed to the needs of individuals with CrF, can have a multitude of physical, psychological, social and educational benefits which can greatly improve their overall quality of life.

C. 6: Cancer survivors with CrF are faced with many barriers to exercise. Many facilitators can be implemented into a specifically designed programme to overcome such barriers.

Results in Chapter 4 elucidate the barriers, facilitators, preferences, and motives to exercise among fatigued cancer survivors. The key barriers include, fatigue, fear, and lack of information. The key facilitators include, cancer specific class in the company of other cancer survivors that are individually tailored, inclusion of an exercise professional, and the implementation of informal teaching and instruction. Knowing these can facilitate enhanced development and implementation of exercise interventions to meet the needs of cancer populations suffering from CrF. Furthermore, the findings confirm that exercise rehabilitation is missing and needed in the overall care of cancer patients.

C. 7: Exercise-based cancer rehabilitation programmes can be delivered in a community setting, though careful consideration is needed of a range of factors that relate to successful implementation

The results outlined in chapter 5 capture the factors that influence the successful implementation of an exercise intervention targeted at cancer survivors, in a community setting. These results provide further knowledge regarding the suitability of a community setting for implementing cancer rehabilitation programmes. Barriers and challenges to programme scale up outside of a major urban centre include, accessibility to the target population, as well as financial support from relevant agencies. On the contrary, implementation appears most successful when a collaborative multidisciplinary team are involved, and an overall programme leader exists to co-ordinate the programme.

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Appendix 1

Foirfe chun fónaimh

Date: ________________________

Code (for office use):________________________

We are interested in you and your health. Please answer all questions. There are no "right" or "wrong" answers. Any information gathered from the following questionnaire will be treated in the strictest confidence

If, after completing these questions, you want to add some more information, then please use the space provided. All information will remain confidential to the research team.

☐ **I do not wish to complete this questionnaire, and am returning it to you uncompleted.**

SECTION A: PERSONAL INFORMATION

Name: ____

Telephone Number: ____

Email:____

Date of birth: ____

Menopausal Status: ☐ Peri-menopausal ☐ Menopausal ☐ Post- Menopausal

What is your current marital status?

Single (never married) ☐
Cohabiting ☐
Married ☐
Separated ☐
Divorced ☐
Widowed ☐

Do you have a medical card?

Yes, full medical card ☐
Yes, GP only card ☐
No ☐

Education to date:

No formal education ☐
Primary education ☐
Secondary education ☐
Higher Certificate ☐
National Diploma ☐
Honours Bachelor Degree ☐
Postgraduate Diploma or Degree ☐
Doctorate (PhD) or Higher ☐
Other (please Specify) _______________

SECTION B: FATIGUE

Below is a list of statements that other people with your illness have said are important.

Please circle or mark one number per line to indicate your response as it applies to the past SEVEN days

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
1. I feel fatigued	0	1	2	3	4
2. I feel weak all over	0	1	2	3	4
3. I feel listless ("washed out")	0	1	2	3	4
4. I feel tired	0	1	2	3	4
5. I have trouble starting things because I am tired	0	1	2	3	4
6. I have trouble finishing things because I am tired	0	1	2	3	4
7. I have energy	0	1	2	3	4
8. I am able to do my usual activities	0	1	2	3	4
9. I need to sleep during the day	0	1	2	3	4
10. I am too tired to eat	0	1	2	3	4
11. I need help doing my usual activities	0	1	2	3	4

12. I am frustrated by being too tired to do the things I want to do	0	1	2	3	4
13. I have to limit my social activity because I am tired	0	1	2	3	4

SECTION C: QUALITY OF LIFE

Please circle or mark one number per line to indicate your response

	Not at all	**A little**	**Quite a bit**	**Very Much**
14. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
15. Do you have any trouble taking a long walk?	1	2	3	4
16. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
17. Do you need to stay in bed or a chair during the day?	1	2	3	4
18. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

Please circle or mark one number per line to indicate your response

DURING THE PAST WEEK	**Not at all**	**A little**	**Quite a bit**	**Very Much**
19. Were you limited in doing either your work or other daily activities?	1	2	3	4
20. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4

21. Were you short of breath?	1	2	3	4
22. Have you had pain?	1	2	3	4
23. Did you need to rest?	1	2	3	4
24. Have you had trouble sleeping?	1	2	3	4

DURING THE PAST WEEK (Continued)	**Not at all**	**A little**	**Quite a bit**	**Very Much**
25. Have you felt weak?	1	2	3	4
26. Have you lacked appetite?	1	2	3	4
27. Have you felt nauseated?	1	2	3	4
28. Have you vomited?	1	2	3	4
29. Have you been constipated?	1	2	3	4
30. Have you had diarrhoea?	1	2	3	4
31. Were you tired?	1	2	3	4
32. Did pain interfere with your daily activities?	1	2	3	4
33. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
34. Did you feel tense?	1	2	3	4
35. Did you worry?	1	2	3	4
36. Did you feel irritable?	1	2	3	4

37. Did you feel depressed?	1	2	3	4
38. Have you had difficulty remembering things?	1	2	3	4
39. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
40. Has your physical condition or medical treatment interfered with your social activities	1	2	3	4
41. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

Please circle or mark one number per line to indicate your response

For the following questions please circle the number between 1 and 7 that best applies to you.							
	Very Poor						**Excellent**
42. How would you rate your overall health during the past week?	1	2	3	4	5	6	7
43. How would you rate your overall quality of life during the past week?	1	2	3	4	5	6	7

SECTION D: SLEEP HYGEINE

Please put an X in <u>one</u> of the boxes to the right of each item that best matches how you feel

Please rate the current (i.e., last 2 weeks) SEVERITY of your insomnia problems					
	(0) **None**	**(1)** **Mild**	**(2)** **Moderate**	**(3)** **Severe**	**(4)** **Very Severe**
44. Difficulty falling asleep					
45. Difficulty staying asleep					
46. Problem waking up early					

For the following questions please circle the number between 0 and 4 that best applies to you	
	Very Satisfied ... **Very Dissatisfied**

47. How SATISFIED / dissatisfied are you with your current sleep pattern?	0	1	2	3	4
	Not at all interfering	**A little**	**Some what**	**Much**	**Very Much**
48. To what extent do you consider your sleep problem to INTERFERE WITH YOUR DAILY Functioning (e.g. daytime fatigue, ability to function at work / daily chores, concentration, memory, mood, etc.)	0	1	2	3	4
	Not at all noticeable	**Barely**	**Some what**	**Much**	**Very Much**
49. How NOTICABLE to others do you think your sleeping problem is in terms of impairing the quality of your life?	0	1	2	3	4

	Not at all	**A little**	**Some what**	**Much**	**Very Much**
50. How WORRIED distressed are you about your current sleep problem?	0	1	2	3	4

SECTION E: CANCER & ACTIVITY / EXERCISE

I am concerned about participating in physical activity and/or exercise because……

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
51. Of the side effects of cancer treatment					
52. Of my cancer symptoms					
53. My body cannot do what it could before my cancer					
54. Of my overall health since my cancer					
55. Physical activity/exercise might cause new symptoms					

56. Of causing or increasing hot flashes					
57. Of causing or increasing cancer-related fatigue					
58. I might be too tired afterwards to do my daily activities					
59.Physical activity/exercise may be too strenuous					
60. Of causing or increasing pain					
61. I might injure myself					
62. Pain from physical activity/exercise means I am harming myself					
I am concerned about participating in physical activity and/or exercise because……					
	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
63. Of causing or increasing lymphedema					
64.Of causing or increasing the tenderness in one or both of my arms					
65. One or both of my arms feels numb					
66. Of the stiffness in one or both of my arms					
67. Of the poor amount of movement in one or both of my arms					
68. Of the physical changes in my body since my cancer					
69.Of how people might see my body					
70.Physical activity/exercise may make my cancer come back					
71. Physical activity/exercise is unsafe					

72. I am unsure about what type of physical activity/exercise I should or should not do					
73. A health care professional told me not to strain one or both of my arms.					

SECTION F: HEALTH MANAGEMENT

Please answer the following questions indicating with an X the statement which you feel describes how you feel

	Strongly Agree	**Agree**	**Uncertain**	**Disagree**	**Strongly Disagree**
74. I handle myself well with respect to my health					
75. No matter how hard I try, my health just doesn't turn out the way I would like.					
76. It is difficult for me to find effective solutions to the health problems that come my way.					
77. I succeed in the projects I undertake to improve my health.					
78. I'm generally able to accomplish my goals with respect to my health.					
79. I find my efforts to change things I don't like about my health are ineffective.					
80. Typically, my plans for my health don't work out well.					

81. I am able to do things for my health as well as most other people.					

Additional information:

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You Have Now Reached the End of the Survey

Your Participation is Greatly Appreciated

Thank You!

Patricia Sheehan

Appendix 2

Testing protocols

Questionnaire Introduction:

The questionnaire consisted of six sections in total for breast cancer survivors: section A – personal information, section B assessed fatigue, section C- QOL, and section D – sleep hygiene, section E – cancer & activity / exercise and section F – health management (Appendix). There were 81 questions in total and it took approximately 20 minutes to administer. Section E was eliminated for cancers other than breast therefore, consisted of only 58 questions. Fatigue the primary outcome was measured using the FACT-F (Yellen et al., 1997), QOL using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire –C30 (EORTC QLQ-C30) (Aaronson et al., 1993), fear of PA using Fear of Physical Activity and Exercise in Survivors of Breast Cancer (FAPX-B) questionnaire *(Sander et al., 2011)*, sleep difficulties using Insomnia Severity Index (Morin, 1993) and perceived health competency using Perceived Health Competency (PHCS) questionnaire *(Smith et al., 1995)*. The full questionnaire was administered at three time points; pre, post and 6MFU.

Fatigue (FACT-F) (Yellen et al., 1997)

The FACT-F was used to asses fatigue and is a 13-item fatigue scale of the FACT measurement method which is specifically developed for cancer populations. For the purpose of this study the scoring method used was developed by Downie, Mar Fan, Houédé-Tchen, Yi & Tannock (2006). Scores range 0–52 the total fatigue scores were classified as: > 45 = normal, 33–45 = mild, 20–32 = moderate, < 20 = severe fatigue. Participants were only included in the study if they had a score of < 45. Fatigue was measured at baseline, week 4, week 8, post intervention and at 6 month follow up (6MFU).

Quality of Life (EORTC QLQ – C30 questionnaire) *(Aaronson et al., 1993)*

Quality of life was assessed using the EORTC QLQ C-30 version 3.0. It is a 30-item scale comprising of 5 functional (physical, role, emotional, social and cognitive) and three symptom (fatigue, pain, nausea and vomiting) scales. Additionally, there are six singles items which assess further symptoms often mentioned by cancer patients. The questionnaire has been validated and tested cross culturally across a variety of cancer populations (Sprangers et al., 1996). The present study considered dimensions of fatigue, global QOL and cognitive functioning. Each element of the EORTC QLQ C-30 takes a score between 0 and 100 which were calculated with the use of the scoring manual which was provided by the EORTC.31. Higher scores for global quality of life and cognitive functioning represent a good quality of life whereas, higher scores for symptom scales such as fatigue represent a high level of issues (Aaranson et al., 1993).

Fear of Physical Activity and Exercise in Survivors of Breast Cancer (FAPX-B) questionnaire *(Sander et al., 2011)*

Fear of PA was assessed using the FAPX-B questionnaire among breast cancer survivors only. This is a 23-item scale measuring pain and other factors specific to breast cancer that may influence a person decision whether or not to exercise. The scale was scored by totalling the individual item scores, whereby higher scores signify more fear of PA.

Sleep Difficulties questionnaire (Insomnia Severity Index) (ISI) (*Morin, 1993)*

The ISI was used to assess sleep difficulties among the participants. This is a 7-item scale which assess the nature, severity and impact of insomnia (Bastien, Vallières & Morin, 2001; Morin, 1993) using a 5 point Likert scale. Items are scored 0-4 and totalised giving a range between 0 and 28. Scores between 0-7 = no sleep impairment, 8-14 = sleep impairment, 15-21 moderate sleep impairment and 22-28 severe sleep impairment. An ISI scores of between 15 and 28 is classified as clinically significant insomnia.

Perceived Health Competency questionnaire (PHCS) *(Smith et al., 1995)*

Self-efficacy in general health management was measured using the 8-item PHCS questionnaire which is often used to predict health outcomes and behaviours. A higher PHCS score with a possible range of between 8 – 40, suggests greater health competence and higher self-efficacy beliefs by performing behaviours to achieve desired health outcomes (Smith, Wallston & Smith, 1995).

Demographics and health status

Demographic characteristics were gathered via an administered questionnaire at the baseline visit. Health status including cancer stage, type of treatment, and time since diagnoses, treatment dates, contraindications for exercise present, and physical/ mental and psychological health history via a medical clearance form which was administered by the participant's general practitioner (GP). Height and weight, blood pressure (BP) and heart rate (HR) were measured at baseline, post intervention and 6 months using a digital scale, stadiometer and Omron blood pressure monitor. Height and weight were used to determine the body mass index (BMI).

Physical fitness and physical activity measures

Physical fitness tests and physical activity measures were taken at baseline, post intervention and 6 months. PA was measured using the International Physical Activity Questionnaire (IPAQ). All participants were asked to wear a pedometer from when they woke up until they went to bed and night. Participants were asked to record the number of steps they took in their step diary once they went to bed. The pedometer was then reset for the next day. Pedometers measurements were only noted for the duration of the 10 week exercise intervention.

6 minute walk test (6MWT)

The 6-minute walk test was performed as a measure of physical function. The test is a measure of distance in meters an individual can cover in 6 minutes. It is performed on a flat surface with a marked out predetermined distance. Though this study stuck rigidly to the guidelines implemented but the American Thoracic Society (ATS) (Crapo et al., 2002) it did adjust the layout of the walkway though not modifying the distance (30m). In the case if this study it was 10m X 5m X 10m X 5m (marked every 2.5m) due to the lack of suitable indoor space of 30m in length. It would seem this is a limitation for many studies using the 6MWT to date with many modification of the 6MWT protocol walkway length being utilised. A recent systematic review with meta-analysis on the protocol variations and 6MWT performance in stroke survivors noted that only 27 of the 127 studies included, reported using indoor 30m walkways in accordance to the ATS guidelines (Dunn et al., 2014).

Participants were instructed walk as far as they could during the 6 minutes, at a self-determined walking speed, stopping to rest if needed. Participants were allowed to stop the test at any time if the felt pain, dizziness or shortness of breath. The subject's heart rate was recorded along with fatigue, rate of perceived exertion (RPE) and dyspnoea using the BORG scale pre and post-test. The total walking distance covered during the 6 minutes was measured and recorded.

Six minute walk tests range from 400 to 700m among healthy individuals, improvements of 70 m+ is considered to be of clinical importance (CI) to the patient (Enright, 2003).

Standard Sit-and-reach Test

Since reduced mobility is often reported following treatment it was decided to use the standard sit and reach test. This test is the most commonly used flexibility test in fitness testing batteries. The test requires a sit-and-reach box consisting of distance scale with centimetre gradations on top of a box approximately 40cm high with an overhang of 26cm.

Procedure

- The subject was instructed to sit down on a mat on the floor with legs straight and the soles of their feet (minus shoes) against the sit-and-reach box
- The subject was then instructed to smoothly and slowly reach as far forward as possible along the top of the box and hold this position for 2 seconds, keeping their knees straight, feet against the box and bum on the floor
- After a short break the procedure was repeated twice more and the researcher recorded all three score and an average of the three attempts was used as the sit-and-reach score

The 30 second sit to stand chair test

This test is used as a predictor for leg strength and endurance. The 30 second sit to stand chair test has demonstrated excellent test-retest reliability among cancer cohorts (ICC = 0.901-0.960) and it is recommended as a reliable measurement tool with cancer patients A chair with a straight back without arm rests and a stopwatch are needed to carry out the test.

Procedure

- Subject instructed to sit in the middle of the chair
- The subject was then instructed to place hands on opposite shoulder crossed at the wrists
- Feet were to be kept flat on the floor
- Back was to be kept straight and arms against chest
- The subjects were then informed on the word “GO” to rise to a full standing position and sit back down again
- This was repeated for 30 seconds

- The number of times the subject came to a full standing position in 30 seconds was counted

Pulse Wave Velocity (PWV)

PWV is the speed at which the forward pressure wave is diffused via the vascular tree (Inaba, Chen & Bergmann, 2010; Jatoi, Mahmud, Bennett & Feely, 2009) Carotid-femoral PWV represents the aortoilliac route and deemed the ‘‘gold standard’’ measurement of arterial stiffness (Laurent et al., 2009). As noted previously, PWV has been seen to increase during treatment (Chaosuwannakit, et al., 2010; Dafts et al., 2013).

Appendix 3

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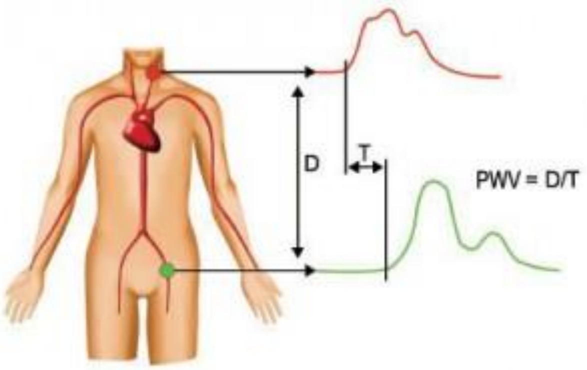
Protocol for Pulse Wave Velocity Test

Pulse Wave Velocity (PWV) is the speed at which the pulse wave travels on an arterial segment. In elastic arteries, the pulse wave travels slowly. However, in stiff arteries the pulse wave travels faster.

Carotid-femoral PWV is measured from the distance D and the transit time T between the carotid and femoral arteries.



PWV = carotid-femoral distance / transit time

1. Patient lies flat on examination table and relaxes in order to stabilise the heart rate and blood pressure while the Complior Analyse software is being launched.
2. Enter the patients' details (name, age, sex etc…).
3. Locate the carotid and femoral arteries and mark the point where carotid and femoral pressure will be measured.
4. Measure the distance between the carotid and femoral artery and enter it on the Complior Analyse software.

5. Cuff blood pressure is measured and entered on Complior Analyse software then signal acquisition is launched
6. Position the carotid sensor with the help of its specific holder

7. Hold the femoral sensor on the femoral artery. When software indicator turns green, stops the acquisition.

8. The Complior Analyse software displays the pulse wave velocity and the central (carotid) pressure waveform analysis.

Appendix 4

Waterford Institute *of* Technology
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GENERAL INFORMATION LEAFLET

Evaluation of a Sustainable Intervention using Exercise - for Cancer Fatigue (ESIE-CF Trial)

Researchers from the School of Health Science at Waterford Institute of Technology in collaboration with the medical team at UHW are undertaking a study to examine the value of exercise in reducing fatigue in individuals who are experiencing cancer-related fatigue. We are hoping that you might consider participating in this study.

Who is eligible?
You are eligible to participate if:

- You have had treatment (surgery, chemotherapy or radiotherapy) for breast, colon or prostate cancer and you are at least 6 weeks post-treatment
- You are experiencing fatigue (tiredness)

What will the study involve?
Participants will be allocated to either an exercise group or a health education group for a 10 week period. You must be willing to be allocated to either group to participate. At the end of the 10 weeks, those allocated to the health education group initially will be able (if they wish) to enter the exercise arm of the study for another 10 weeks.

What commitment is involved?

- Participation in the exercise arm of the study will involve 2 exercise sessions per week for 10 weeks. We will try to schedule group exercise classes to suit participants and supplement group classes with home-based exercise. The exercise will be gentle and you will be free to push yourself or not during the classes. You will be free to bring an exercise buddy with you to all classes. Classes will be at WIT but we can try to schedule classes in other locations if there is demand.
- Participation in the health education arm of the study will involve 1 health education session per week for 10 weeks.
- We will ask you to fill out some questionnaires and do some simple fitness tests at the start and end of study to measure the exercise and health education effects.

More information
For more information contact Patricia Sheehan on (087) 9670735

Patricia will also be in attendance at hospital clinics to meet potential participants if they want further information.

Appendix 5

Waterford Institute of Technology

RESEARCH STUDY

EXERCISE GROUP INFORMED CONSENT FORM

You have shown interest in participating in this study and have been randomly allocated to the exercise intervention. Before you sign your consent form, please read the following information carefully. Please feel free to ask if anything is not clear or if you would like more information.

I. Project Title: **E**valuation of a **S**ustainable Intervention using **E**xercise - for Cancer Fatigue (ESIE-CF Trial)

II. Introduction to this study:

Fatigue is one of the most common and significant side effects for breast cancer survivors with overwhelming impacts on quality of life. Such side effects can persist for months and years following the completion of successful treatment. Exercise rehabilitation is used for survivors of cancer and may reduce this fatigue. However, few examples exist of exercise interventions, specifically for survivors with fatigue

III. You are being asked to participate in this research study. The study has the following purposes:

1. To develop an exercise intervention specifically for cancer survivors with fatigue that will also empower participants to exercise when the supervised element of the intervention is finished
2. To evaluate the effects of the intervention on fatigue and in self-confidence for exercise

IV. This research study will take place at Waterford Institute of Technology.

V. This is what will happen during the research study:

1. You have been randomly allocated to the exercise for a 10 week intervention. You will fill out questionnaires before and after the 10 week intervention period to assess fatigue, fear of exercise, quality of sleep and quality of life. Your fitness and the stiffness of your arteries (measure of cardiovascular health) will also be measured. A blood and saliva sample will be taken to measure inflammatory markers that are believed to influence fatigue.
2. You will undertake 2 sessions of exercise weekly for the first 5 weeks reducing to once per week for the remaining 5. The exercise bouts will be both gentle and short to begin with and we will assist you in gradually increasing exercise intensity and duration as the 12 weeks progress. The programme combines both group-based and home-based exercise and we will discuss exercise venues and suitable combinations of group and home-based exercise with you. You are free to bring an exercise buddy with you to all classes.
3. You will be followed up 6 months after the exercise intervention is finished to reassess quality of life, fatigue and exercise.

VI. Sometimes there may be side effects from performing exercise and having blood drawn. These side effects are often called risks, and for this project, the risks are:

1. Exercise testing and participation carries small risks, even in non-cancer groups, including a very small risk of heart problems. You are required to get clearance from

your GP in order to participate in the exercise intervention. If you feel unwell at any stage during the exercise, you must let us know immediately.
2. In cancer survivor groups, there may be specific issues that complicate exercise including loss of sensation in feet, hot flushes, suppressed immune system and lymphedema. The exercise professional is knowledgeable of these and will discuss your particular exercise complications and side-effects with you as the study progresses and suggest practical solutions. You must let us know of any side effects and complications that arise as a result of the exercise programme. In some circumstances, we may need to take you off the programme briefly and refer you back to your GP before continuing with the exercise.
3. You may experience additional fatigue later in the day on exercise days. This is likely to subside as the programme progresses.
4. You may feel a slight pain when the needle is inserted for the blood sample and you may develop a bruise where the blood sample is obtained. The pain and bruising is usually mild and a person trained in blood drawing will obtain your blood.

VII. There may be benefits from your participation in this study. These are:

1. You and your exercise buddy will receive 12 weeks of exercise (~24 sessions), free of charge.
2. You will be part of a network of individuals with similar health issues and you may find the peer support beneficial.
3. You will get a copy of your personal results including changes in your fatigue and fitness profile upon request.

VIII. Your confidentiality will be guarded:

Waterford Institute of Technology will protect all the information about you and your part in this study. Your identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications.

IX. If you have questions about the research project, you are free to call Dr. Michael Harrison (051-302161) or Dr. Suzanne Denieffe (051-302743):

X. Taking part in this study is your decision.

If you do agree to take part in the study, you may withdraw at any point. Your medical treatment will not be affected in any way by taking part, refusing to take part or withdrawing from the study.

XI. Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project entitled: *“**E**valuation of a **S**ustainable Intervention using **E**xercise - for Cancer Fatigue (ESIE-CF Trial)”*

Signed: ____

Date: ____

Appendix 6

Waterford Institute *of* Technology

RESEARCH STUDY

HEALTH EDUCATION GROUP INFORMED CONSENT FORM

You have shown interest in participating in this study and have been randomly allocated to the health education group. Before you sign your consent form, please read the following information carefully. Please feel free to ask if anything is not clear or if you would like more information.

I. Project Title: **E**valuation of a **S**ustainable Intervention using **E**xercise - for Cancer Fatigue (ESIE-CF Trial)

II. Introduction to this study:

Fatigue is one of the most common and significant side effects for breast cancer survivors with overwhelming impacts on quality of life. Such side effects can persist for months and years following the completion of successful treatment. Exercise rehabilitation is used for survivors of cancer and may reduce this fatigue. However, few examples exist of exercise interventions, specifically for survivors with fatigue

III. You are being asked to participate in this research study. The study has the following purposes:

1. To develop an exercise intervention specifically for cancer survivors with fatigue that will also empower participants to exercise when the supervised element of the intervention is finished
2. To evaluate the effects of the intervention on fatigue and in self-confidence for exercise

IV. This research study will take place at Waterford Institute of Technology.

V. This is what will happen during the research study:

1. You have been randomly allocated to the health education group for a 12 week intervention. At the end of this period, you will be able to undertake the exercise arm of the study if they so wish.
2. You will fill out questionnaires before and after the 12 week intervention period to assess fatigue, fear of exercise, quality of sleep and quality of life. Your fitness and the stiffness of your arteries (measure of cardiovascular health) will also be measured. A blood and saliva sample will be taken to measure inflammatory markers that are believed to influence fatigue.
3. You will meet once weekly for 12 weeks.
4. You will be followed up 6 months after the exercise intervention is finished to reassess quality of life and fatigue.

VI. Sometimes there may be side effects from having blood drawn. These side effects are often called risks, and for this project, the risks are:

You may feel a slight pain when the needle is inserted for the blood sample and you may develop a bruise where the blood sample is obtained. The pain and bruising is usually mild and a person trained in blood drawing will obtain your blood.

VII. <u>There may be benefits from your participation in this study. These are:</u>

1. You will receive 10 weeks of health education (~10 sessions), free of charge, with the option of availing of the exercise intervention once completed.
2. You will be part of a network of individuals with similar health issues and you may find the peer support beneficial.
3. You will get a copy of your personal results including changes in your upon request.

VIII. <u>Your confidentiality will be guarded:</u>

Waterford Institute of Technology will protect all the information about you and your part in this study. Your identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications.

IX. <u>If you have questions about the research project, you are free to call Dr. Michael Harrison (051-302161) or Dr. Suzanne Denieffe (051-302743):</u>

X. <u>Taking part in this study is your decision</u>.

If you do agree to take part in the study, you may withdraw at any point. Your medical treatment will not be affected in any way by taking part, refusing to take part or withdrawing from the study.

XI. <u>Signature:</u>

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project entitled: *“**E**valuation of a **S**ustainable Intervention using **E**xercise - for Cancer Fatigue (ESIE-CF Trial)”*

Signed: ____

Date: ____

Appendix 7

Waterford Institute *of* Technology
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EXERCISE GROUP INFORMATION LEAFLET

Evaluation of a Sustainable Intervention using Exercise - for Cancer Fatigue (ESIE-CF Trial)

You have shown interest in participating in this study and have been randomly allocated to the exercise. Before you sign your consent form, please read the following information carefully. Please feel free to ask if anything is not clear or if you would like more information.

What will the study involve?

You have been randomly allocated to the exercise group for a 10 week period. You will undertake 2 sessions of exercise weekly for the first 5 weeks reducing to once per week for the remaining 5. The exercise bouts will be both gentle and short to begin with and we will assist you in gradually increasing exercise intensity and duration as the 10 weeks progress. The programme combines both group-based and home-based exercise and we will discuss exercise venues and suitable combinations of group and home-based exercise with you. You are free to bring an exercise buddy with you to all classes.

What commitment is involved?

- The programme involve 2 sessions of exercise weekly for the first 5 weeks reducing to once per week for the remaining 5. We will try to schedule group exercise classes to suit participants and supplement group classes with home-based exercise. The exercise will be gentle and you will be free to push yourself or not during the classes. You will be free to bring an exercise buddy with you to all classes. Classes will be at WIT but we can try to schedule classes in other locations if there is demand.
- We will ask you to fill out some questionnaires, do some simple fitness tests and have a blood sample taken at the start and end of study to measure the effects of the exercise training.

More information

For more information contact Patricia Sheehan on (087) 9670735

Patricia will also be in attendance at hospital clinics to meet potential participants if they want further information

Appendix 8

Waterford Institute *of* Technology
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HEALTH EDUCATION GROUP INFORMATION LEAFLET

Evaluation of a Sustainable Intervention using Exercise - for Cancer Fatigue (ESIE-CF Trial)

You have shown interest in participating in this study and have been randomly allocated to the health education group. Before you sign your consent form, please read the following information carefully. Please feel free to ask if anything is not clear or if you would like more information

What will the study involve?

You have been randomly allocated to the health education group for a 10 week period. At the end of the 10 weeks, you will be able (if you wish) to enter the exercise arm of the study for another 10 weeks.

What commitment is involved?

- Participation in the health education arm of the study will involve 1 health education session per week for 10 weeks.
- We will ask you to fill out some questionnaires, do some simple fitness tests and have a blood sample taken at the start and end of study to measure the effects of the health education initiative.

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More information

For more information contact Patricia Sheehan on (087) 9670735

Patricia will also be in attendance at hospital clinics to meet potential participants if they want further information

Appendix 9

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Section **Page No**

1. Course Details

2. Programme Syllabus and schedule

Section 1 – Course Details

1.1 Health education module in the fight against cancer related fatigue

1.2 Aim

The aim of the program is to provide post treatment cancer survivors (6weeks +) the knowledge, understanding and skills needed to cope, manage, and reduce the burden of cancer related fatigue.

1.3 Programme Objectives

1. To develop participant’s knowledge and understanding of cancer related fatigue

2. To develop participant’s knowledge and understanding of basic nutrition

4. To develop participant’s knowledge of the benefits of healthy eating

5. To enable participants to develop plans for making healthier lifestyle choices

6. To develop strategies to overcome possible barriers to healthy eating

7. To develop participant’s knowledge and understanding of sleep hygiene

8. To develop participant’s knowledge and understanding of proper sleep

9. To develop strategies to overcome poor sleeping habits

1.4 Programme Content

- Food and Nutrition
- Goal setting
- Healthy meal planning
- Identifying barriers
- Achieving success through healthy eating
- Sleep Hygiene
- Cognitive Behaviour Therapy

1.5 Length of the Programme

10 hours

1.6 Target Population

This programme is aimed at post treatment cancer survivors (6 weeks+) with documented fatigue. The programme is hoped to provide the participants with the knowledge, understanding and skills needed for coping, managing, and reducing the burden of cancer related fatigue.

1.7 Inclusion Criteria

- Women and men
- Aged 18 years +
- Breast, colorectal and prostate cancer survivors
- At least 6 weeks but not more than 10 years following the completion of surgery, radiotherapy and chemotherapy (to allow for stabilization of fatigue following treatment) but not excluding those on ongoing hormonal therapy
- Ongoing fatigue (FACT-F score <45)

1.8 Exclusion Criteria

- Inability to travel to Waterford Institute of Technology for testing and to group exercise sites twice weekly

- GP unwilling to provide medical clearance for moderate intensity exercise
- Unwilling to be randomized to health education arm first
- Orthopaedic limitations that render participant unable to participate in a class-based moderate intensity exercise programme
- Currently undertaking 90 min or more of moderate intensity exercise weekly

Section 2: Programme Syllabus and Schedule

2.1 Health education module in the fight against cancer related fatigue

2.1.1 Aim

The aim of the program is to provide post treatment cancer survivors (6weeks+) the knowledge, understanding and skills needed to cope, manage, and reduce the effects of cancer related fatigue.

2.1.2 Programme Objectives

1. To develop participant's knowledge and understanding of cancer related fatigue

2. To develop participant's knowledge and understanding of basic nutrition

4. To develop participant's knowledge of the benefits of healthy eating

5. To enable participants to develop plans for making healthier lifestyle choices

6. To develop strategies to overcome possible barriers to healthy eating

7. To develop participant's knowledge and understanding of sleep hygiene

8. To develop participant's knowledge and understanding of proper sleep

9. To develop strategies to overcome poor sleeping habits

Units

1. Cancer related fatigue
2. Diet, nutrition and cancer survivorship
3. Sleep Hygiene
4. Cognitive Behaviour Therapy

2.2 Extended Syllabus

Unit 1 – Cancer related fatigue (1 hour)

Aim

To provide participants, the knowledge and understanding of cancer related fatigue.

Learning outcomes:

On completion of Unit 1 the participant will be able to:

- Define cancer related fatigue
- Recognise what causes cancer related fatigue
- Identify how common cancer related fatigue is
- Identify behaviours which cause them to feel more or less exhausted
- List how cancer related fatigue makes them feel
- Explain the importance of vegetables and fruit in the diet
- Understand the importance of keeping a daily fatigue journal

Content

- What is cancer related fatigue?
- How common is cancer related fatigue?
- What causes cancer related fatigue?
- How fatigue makes you feel?
- Keeping a daily fatigue journal

Unit 2 – Food and Nutrition (4 hours)

Aim

To provide participants, the knowledge, understanding and skills of healthier food choices, enabling them to implement same into their daily lives.

Learning outcomes:

On completion of Unit 2 the participant will be able to:

- Identify the main nutrients found in food
- Classify food into groups
- Outline the importance of the different types of food
- Explain factors that influence food habits
- List the factors that form food habits
- Explain what is meant by a balanced diet
- Explain the importance of vegetables and fruit in the diet
- Identify barriers to eating healthy
- Outline the disadvantages of processed foods
- List foods that are minimally processed
- List foods that are extremely processed
- Appreciate the importance of portion sizes
- Compare personal eating and drinking habits
- Prepare meals to make them a healthier option
- Prepare healthy meals while on a budget

- Choose healthier foods when eating out
- Explain the importance of hydration
- List tips for keeping food safe
- Identify strategies to reduce salt intake in the diet
- Understand the conditions that bring about food spoilage
- Understand safer food procedures when choosing, storing and handling food

Content

- Nutrients found in food
- Food groups
- The importance of food
- The importance of fruit and vegetables in diets / easy ways to eat more fruit and veg/ fruit and veg shopping tips/ preparing and cooking fruit and veg/ seasonal guide to fruit and veg
- A balanced diet
- Factors influencing food habits and the effects of food habits on individuals health
- Barriers to eating healthy
- Disadvantages of processed foods / how to reduce convenience foods in the diet
- Potion Size
- Food Diary
- Meal planning; making meals healthier
- Eating healthy on a budget
- The importance of hydration
- Food Hygiene & Safety
- Salt reduction intake
- Whole grains
- Omega 3
- Good Fat V Bad Fat – A guide to fats and oils
- Making Sense of food labelling

Unit 3 – Cognitive Behaviour Therapy (3 hours)

Aim

To provide participants, the knowledge, understanding and skills of cognitive behaviour therapy for coping, managing and aiding the reduction of cancer related fatigue.

Learning outcomes:

On completion of Unit 3 the learner will be able to:

- Explain what is meant by cognitive behaviour therapy
- Understand how and why problems develop and what makes them worse
- Identify difficulties they are experiencing since having cancer
- Convert problems into goals

- Plan activity and rest is to try to stop the Circle of Tiredness
- Understand the impact of negative thinking
- Appreciate the importance of keeping a thought diary
- Understand the importance of recognising and challenging your negative thoughts
- Identify strategies for forward planning and problem solving

Content

- What is cognitive behaviour therapy?
- Problems and goals
- Activity, rest, and tiredness
- Negative thinking
- Thought diary
- Challenging negative thoughts
- Forward planning and problem solving
- Problem focused coping
- Building self-confidence
- Self-monitoring and self-regulation

Unit 4 – Sleep hygiene – healthy sleeping habits (2 hours)

Aim

To provide participants, the knowledge, understanding and skills of healthy sleeping habits.

Learning outcomes:

On completion of Unit 4 the participant will be able to:

- Identify problems with falling asleep, staying asleep, or early morning awakenings
- Identify strategies for the management of sleep disturbances
- Identify strategies to prevent excessive monitoring or worrying about getting enough sleep
- Modify the sleep environment to decrease sleep disruption
- List actions or interventions that may promote rest
- Change the goal from “need to sleep” to “just relax”
- List some habits that may lead to poor sleep hygiene

Content

- Problems with falling asleep, staying asleep, or early morning awakenings
- Management of sleep disturbance
- Preventing monitoring about getting enough sleep
- Promoting rest
- Goal setting
- Sleep habits

2.3 Course Schedule

2.3.1 Proposed Programme Timetable

Session Number	Duration	Unit	Topic
1	1 hour	1	Understanding CRF
2	1 hour	1	Introduction to nutrition, Food & Nutrition, Barriers to eating healthy
3	1 hour	1	Processed foods & Portion Size, Hydration & Salt reduction intake
4	1 hour	1	Food Diary, Food safety, Meal planning; making meals healthier, eating healthy on a low cost budget
5	1 hour	1	Whole Grains, Omega 3, Good fat/Bad Fat
6	1 hour	1	Introduction to CBT, Identifying problems and goal setting
7	1 hour	1	Activity, rest & tiredness
8	1 hour	1	Negative thinking
9	1 hour	1	Healthy Vs Unhealthy Sleeping habits
10	1 hour	1	Strategies to healthier sleeping habits

Appendix 10

Waterford Institute *of* Technology
INSTITIÚID TEICNEOLAÍOCHTA PHORT LÁIRGE

FACT-F QUESTIONNAIRE

Below is a list of statements that other people with your illness have said are important.

Please circle or mark one number per line to indicate your response as it applies to the past SEVEN days

	Not at all	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
1. I feel fatigued	0	1	2	3	4
2. I feel weak all over	0	1	2	3	4
3. I feel listless ("washed out")	0	1	2	3	4
4. I feel tired	0	1	2	3	4
5. I have trouble starting things because I am tired	0	1	2	3	4
6. I have trouble finishing things because I am tired	0	1	2	3	4
7. I have energy	0	1	2	3	4
8. I am able to do my usual activities	0	1	2	3	4
9. I need to sleep during the day	0	1	2	3	4
10. I am too tired to eat	0	1	2	3	4
11. I need help doing my usual activities	0	1	2	3	4
12. I am frustrated by being too tired to do the things I want to do	0	1	2	3	4
13. I have to limit my social activity because I am tired	0	1	2	3	4

Appendix 11

Topic guide

Running the focus group sessions:

- Refer to notes before the group meet to refresh memory
- Takes notes during session
- Try to get everyone involved in the discussion
- Make sure everyone is comfortable and can see one and other

Informed Consent:

Today is a once off interview and there will be no follow up after this. The interview will be recorded and you are under no obligation to talk or answer questions and you can leave at any stage during the interview. Therefore, by taking part in the focus group discussion, you have consented to be part of the research.

Confidentiality statement:

Opinions expressed shall be treated in confidence among the research team with all responses remaining anonymous. Confidentiality is of utmost importance your names will only be seen by the researcher and the researcher's supervisor.

Ensure there are no objections to the use of a recording device; then go ahead and switch on device.

Start by repeating the reason of the meeting:

Thank you all so much for taking the time to talk to me about your experiences of being a participant in my research study to date. |Today I want to concentrate on discussing......

Please note there are no wrong opinions, so please feel comfortable saying what you have to say and how you really feel.

Sample broad open/ended questions:

What was standing in your way of participation?
What were your reasons for taking part in this programme?
What motivated you to exercise?
What was the main benefit of the exercise programme?

Sample probing questions:

Had you ever received any information on cancer related fatigue?
Had you been given any advice on how to manage your fatigue?
Were you ever told the exercise guidelines you should be following after your treatment had finished?
Were you ever prescribed exercise as a treatment for your fatigue?
What were the issues that were most relevant to your post-treatment experience?
Was fatigue something you would have experienced daily?
What type of exercise are you now most interested in?
Were you happy with the location of the programme?
If this was to continue in the long term where would you prefer the exercise intervention take place?
How would you like to receive information on future exercise programmes for cancer survivors?
What do you feel were the factors that facilitated your participation in the programme?
What have you learned from being part of this study?
Are you passing on the information you have gained since starting the study
How do you think the intervention was implemented?
How do you feel now that the intervention has finished?
Did you enjoy the buddy system? Who would you prefer to exercise with?
Have you made new friends because of taking part of this research?
What do you think needs to be done to ensure you continue exercising?
How do you think the programme could be adapted to reach more people?
Was there anything you would change about the programme?

<u>Prompts to help:</u>

- Tell me more about that ……………
- So what you're saying is ……………….
- Yea, really ……………
- It sounds as if you ………………

Participants' names and time, date and location

Appendix 12

Information form for MedEx MoveOn Participants

“Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting”

Introduction to this study: Fatigue is one of the most common and significant side effects for breast cancer survivors with overwhelming impacts on quality of life. Such side effects can persist for months and years following the completion of successful treatment. Exercise rehabilitation is used for survivors of cancer and may reduce this fatigue. However, few examples exist of exercise interventions, specifically for survivors with fatigue. Furthermore, few are translated into practice to impact on individuals at a population level.

What is involved? You are asked to take part in a 60-minute group interview discussion with a researcher in Waterford Institute of Technology. With your permission, an audio recording of the discussion will be made.

How do I take part? You can contact Patricia Sheehan (details below). You are asked to sign the Consent Form to take part. If you do agree to take part in the study, you may withdraw at any point.

What is the information used for? The information from the group discussion will be used to support the implementation and translation of exercise rehabilitation programmes for cancer survivors. With your permission, we would also like to use sections the recorded group discussion in a later stage of this study. By knowing your views and personal experiences are extremely valuable and your input will aid the researcher in the implementation of exercise programmes specific to cancer survivors.

Your confidentiality will be guarded: Waterford Institute of Technology will protect all the information about you and your part in this study. Your identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications. Though, other participants will be asked to respect your confidentiality, your identity will be known to other focus group participants and the researchers cannot guarantee that others in this group will respect the confidentiality of the group.

Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project entitled: ***“Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting”***

Signed: ______________________________ Date:_____________________

Research Team Contact Details: Patricia Sheehan (Research Student), Department of Sport & Exercise Science, WIT. Phone: (087) 9670735 patricia.sheehan@postgrad.wit.ie

Appendix 13

Consent form for MedEx Move On participants

“Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting”

PLEASE NOTE PARTICIPATION IS STRICTLY VOLUNTARY.

Please tick EACH box and sign your name in the space below

1. I confirm that I have read the document entitled ‘Information form for participants who transferred from ESIE-CF trial to MedEx Move On Programme” and have had the opportunity to ask questions ☐
2. I am satisfied that I understand the information provided and have had enough time to digest the information ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any stage throughout the study without reason and without my legal rights being affected ☐
4. I understand that Waterford Institute of Technology will protect all the information about me and my part in this study. My identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications. Though, other participants will be asked to respect my confidentiality, my identity will be known to other focus group participants and the researchers cannot guarantee that others in this group will respect the confidentiality of the group
5. I agree to take part in the study entitled “Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting” ☐

Name: ______________________________________ (Please use block capitals)

Signature: ________________________________ Date: ______ / ______ / _____

Appendix 14

Topic guide for MedEx Move On Programme Paricipants

"Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting"

Running the focus group sessions:

- Refer to notes before the group meet to refresh memory
- Takes notes during session
- Try to get everyone involved in the discussion
- Make sure everyone is comfortable and can see one and other
- Ensure participants have been issued the Participant Information Form prior to interview day.
- Allow time for questions prior to interview commencement.
- The participant will provide the informed consent form

Informed Consent:

Today is a once off interview and there will be no follow up after this. The interview will be recorded and you are under no obligation to talk or answer questions and you can leave at any stage during the interview. Therefore, by taking part in the focus group discussion, you have consented to be part of the research.

Confidentiality statement:

Confidentiality is of utmost importance your names will only be seen by the researcher and the researcher's supervisor on the informed consent form. Opinions expressed shall be treated in confidence among the research team with all responses remaining anonymous. Though, other participants will be asked to respect your confidentiality, your identity will be known to other focus group participants and the researchers cannot guarantee that others in this group will respect the confidentiality of the group.

Ensure there are no objections to the use of a recording device; then go ahead and switch on device.

Start by repeating the reason of the meeting:

The purpose of the interview is to discuss your personal experiences of being part of the "**E**valuation of a **S**ustainable Intervention using **E**xercise - for Cancer Fatigue (ESIE-CF Trial) and the MedEx Move On Programme.

Thank you for taking time for being part of this discussion. You has been invited to participate because your view is very important to us. We know that you are very busy and we greatly appreciate your contribution to this study. Please note there are no wrong answers, so please feel comfortable saying what you want and how you really feel. Remember, we are very interested in what you think and feel and we really want to know your opinion.

Sample questions:

What were the most valued components of the programme?
What improvements or changes have you noticed since starting the programme?
What have you enjoyed most about the MedEx Prgramme?
What have you least enjoyed about the MedEx Programme?
What influence has the programme had on your quality of life?
Do you think you would have been willing or able to do a similar programme during treatment?
When do you think the best time to start a programme like this is?
Would you have preferred a different type of exercise programme- for example: gym based, treadmills/weights, swimming, and water aerobics? If yes, what?
What were your experiences of the group format?
Would you have preferred a one to one (individual) setting? Why/ why not?
Would you have preferred a group with people recovering from various health problems? Why/ why not?
Would you have preferred a group of the general population? Why/why not?
Would you have preferred to do the exercise at home and alone and whenever was convenient without the help of a professional? If not: How much contact? What type of contact?
GENERAL QUESTIONS:
Would you recommend a similar programme to others going through chemo? Why/why not?
Was there anything better/worse/ different /worrying that you experienced from transferring from the ESIE-CF to the MedEx Move On Programme? Instructor/setting
Is there anything about the programme that you think we could improve or that we should change?
Is there anything else you would like to tell us about your experience in the programme?
Do you plan to exercise on your own now that you have finished the program? If yes: What do you plan to do?

Appendix 15

Information form for health care professionals

"Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting"

Introduction to this study: Fatigue is one of the most common and significant side effects for breast cancer survivors with overwhelming impacts on quality of life. Such side effects can persist for months and years following the completion of successful treatment. Exercise rehabilitation is used for survivors of cancer and may reduce this fatigue. However, few examples exist of exercise interventions, specifically for survivors with fatigue. Furthermore, few are translated into practice to impact on individuals at a population level.

What is involved? You are asked to take part in a 15-minute telephone interview with a researcher on a day and time of your choosing. With your permission, an audio recording of the discussion will be made.

How do I take part? You can contact Patricia Sheehan (details below). You are asked to sign the Consent Form to take part. If you do agree to take part in the study, you may withdraw at any point.

What is the information used for? The information from the telephone interview will be used to support the implementation and translation of exercise rehabilitation programmes for cancer survivors. With your permission, we would also like to use sections of the recorded interview in a later stage of this study. By knowing your views and personal experiences are extremely valuable and your input will aid the researcher in the implementation of exercise programmes specific to cancer survivors.

Your confidentiality will be guarded: Waterford Institute of Technology will protect all the information about you and your part in this study. Your identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications.

Signature:
I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project entitled: ***"Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting"***

Signed: ____________________________ Date:____________________

Research Team Contact Details: Patricia Sheehan (Research Student), Department of Sport & Exercise Science, WIT. Phone: (087) 9670735 patricia.sheehan@postgrad.wit.ie

Appendix 16

Consent form for healthcare professionals

"Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting"

PLEASE NOTE PARTICIPATION IS STRICTLY VOLUNTARY.

Please tick EACH box and sign your name in the space below

1. I confirm that I have read the document entitled 'Information form for health care professionals" and have had the opportunity to ask questions ☐

2. I am satisfied that I understand the information provided and have had enough time to digest the information ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any stage throughout the study without reason and without my legal rights being affected ☐

4. I understand that Waterford Institute of Technology will protect all the information about me and my part in this study. My identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications. ☐

5. I agree to take part in the study entitled "Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting" ☐

Name: ______________________________________ (Please use block capitals)

Signature: _________________________________ Date: ______ / ______ / ______

Appendix 17

Topic guide for health care professionals

“Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting”

Running the telephone interviews:

- Takes notes during interviews
- Ensure participants have been issued the correct Information Form prior to interview day.
- Allow time for questions prior to interview commencement.
- The participant will provide the informed consent form

Informed Consent:

Today is a once off interview and there will be no follow up after this. The interview will be recorded and you are under no obligation to talk or answer questions and you can leave at any stage during the interview. Therefore, by taking part in the telephone interview, you have consented to be part of the research.

Confidentiality statement:

Confidentiality is of utmost importance your name will only be seen by the researcher and the researcher’s supervisor on the informed consent form. Opinions expressed shall be treated in confidence among the research team with all responses remaining anonymous.

Start by repeating the reason of the meeting:

The purpose of the interview is to discuss your personal collaboration experiences with Waterford Institute of Technology on the “**E**valuation of a **S**ustainable Intervention using **E**xercise - for Cancer Fatigue (ESIE-CF Trial) and the MedEx Move On Programme.

Thank you for taking this telephone interview. You has been invited to participate because your view is very important to us. We know that you are very busy and we greatly appreciate your contribution to this study. Please note there are no wrong answers, so please feel comfortable saying what you want and how you really feel. Remember, we are very interested in what you think and feel and we really want to know your opinions.

Sample questions:

Do you take time to discuss exercise programming with your patients?
What were your concerns about involvement with the MedEx Programme?
What were the barriers to collaboration?
What were the most important facilitators?
What could the researchers have done better to facilitate the collaboration?
What would influence further decisions to partnerships?
What are your reasons for/not referring participants?

Appendix 18

Information form for delivery agents of MedEx Move On Programme

"Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting"

Introduction to this study: Fatigue is one of the most common and significant side effects for breast cancer survivors with overwhelming impacts on quality of life. Such side effects can persist for months and years following the completion of successful treatment. Exercise rehabilitation is used for survivors of cancer and may reduce this fatigue. However, few examples exist of exercise interventions, specifically for survivors with fatigue. Furthermore, few are translated into practice to impact on individuals at a population level.

What is involved? You are asked to take part in a 40-minute interview with a researcher on a day and time of your choosing. With your permission, an audio recording of the discussion will be made.

How do I take part? You can contact Patricia Sheehan (details below). You are asked to sign the Consent Form to take part. If you do agree to take part in the study, you may withdraw at any point.

What is the information used for? The information from interview will be used to support the implementation and translation of exercise rehabilitation programmes for cancer survivors. With your permission, we would also like to use sections of the recorded interview in a later stage of this study. By knowing your views and personal experiences are extremely valuable and your input will aid the researcher in the implementation of exercise programmes specific to cancer survivors.

Your confidentiality will be guarded: Waterford Institute of Technology will protect all the information about you and your part in this study. Your identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications.

Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project entitled: ***"Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting"***

Signed: ____________________________ Date:____________________

Research Team Contact Details: Patricia Sheehan (Research Student), Department of Sport & Exercise Science, WIT. Phone: (087) 9670735 patricia.sheehan@postgrad.wit.ie

Appendix 19

Consent form for delivering agents of MedEx Move On Programme

“Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting”

PLEASE NOTE PARTICIPATION IS STRICTLY VOLUNTARY.

Please tick EACH box and sign your name in the space below

1. I confirm that I have read the document entitled ‘Information form delivering agents” and have had the opportunity to ask questions ☐

2. I am satisfied that I understand the information provided and have had enough time to digest the information ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any stage throughout the study without reason and without my legal rights being affected ☐

4. I understand that Waterford Institute of Technology will protect all the information about me and my part in this study. My identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications. ☐

5. I agree to take part in the study entitled “Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting” ☐

Name: ____________________________________ (Please use block capitals)

Signature: _________________________________Date: ______ / ______ / ______

Appendix 20

Topic guide for delivery agents on MedEx MoveOn Programme

“Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting”

Running the telephone interviews:

- Takes notes during interviews
- Ensure participants have been issued the correct Information Form prior to interview day.
- Allow time for questions prior to interview commencement.
- The participant will provide the informed consent form

Informed Consent:

Today is a once off interview and there will be no follow up after this. The interview will be recorded and you are under no obligation to talk or answer questions and you can leave at any stage during the interview. Therefore, by taking part in the telephone interview, you have consented to be part of the research.

Confidentiality statement:

Confidentiality is of utmost importance your name will only be seen by the researcher and the researcher’s supervisor on the informed consent form. Opinions expressed shall be treated in confidence among the research team with all responses remaining anonymous.

Start by repeating the reason of the meeting:

The purpose of the interview is to discuss your personal collaboration experiences with Waterford Institute of Technology on the “**E**valuation of a **S**ustainable Intervention using **E**xercise - for Cancer Fatigue (ESIE-CF Trial) and the MedEx Move On Programme.

Thank you for taking part in this interview. You has been invited to participate because your view is very important to us. We know that you are very busy and we greatly appreciate your contribution to this study. Please note there are no wrong answers, so please feel comfortable saying what you want and how you really feel. Remember, we are very interested in what you think and feel and we really want to know your opinion.

Sample questions and probing questions:

What were your concerns about involvement with the MedEx Programme?
What were the barriers to collaboration?
What were the most important facilitators to collaboration?
What could the researchers have done better to facilitate the collaboration?
What would influence further decisions to partnerships?
Did you feel you have an adequate level of expertise to deliver the programme?
How would you rate your level of self-efficacy when dealing with cancer survivors?
What were your experiences of the training delivered by the researcher?
What were the implementation issues experienced?
What improvements could be made to reach the target population
What could be done better to enhance the implementation of the programme

Appendix 21

Information form for non-participants of MedEx MoveOn Programme

"Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting"

Introduction to this study: Fatigue is one of the most common and significant side effects for breast cancer survivors with overwhelming impacts on quality of life. Such side effects can persist for months and years following the completion of successful treatment. Exercise rehabilitation is used for survivors of cancer and may reduce this fatigue. However, few examples exist of exercise interventions, specifically for survivors with fatigue. Furthermore, few are translated into practice to impact on individuals at a population level.

What is involved? You are asked to take part in a 15 minute telephone interview with a researcher on a day and time of your choosing. With your permission, an audio recording of the discussion will be made.

How do I take part? You can contact Patricia Sheehan (details below). You are asked to sign the Consent Form to take part. If you do agree to take part in the study, you may withdraw at any point.

What is the information used for? The information from the telephone interview will be used to support the implementation and translation of exercise rehabilitation programmes for cancer survivors. With your permission, we would also like to use sections of the recorded interview in a later stage of this study. By knowing your views and personal experiences are extremely valuable and your input will aid the researcher in the implementation of exercise programmes specific to cancer survivors.

Your confidentiality will be guarded: Waterford Institute of Technology will protect all the information about you and your part in this study. Your identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications.

Signature:
I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project entitled: *"Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting"*

Signed: ______________________________ Date:_____________________

Research Team Contact Details: Patricia Sheehan (Research Student), Department of Sport & Exercise Science, WIT. Phone: (087) 9670735 patricia.sheehan@postgrad.wit.ie

Appendix 22

Consent form for delivering agents of MedEx Move On Programme

“Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting”

PLEASE NOTE PARTICIPATION IS STRICTLY VOLUNTARY.

Please tick EACH box and sign your name in the space below

1. I confirm that I have read the document entitled ‘Information form delivering agents” and have had the opportunity to ask questions ☐

2. I am satisfied that I understand the information provided and have had enough time to digest the information ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any stage throughout the study without reason and without my legal rights being affected ☐

4. I understand that Waterford Institute of Technology will protect all the information about me and my part in this study. My identity or personal information will not be revealed, published or used in future studies. The study findings will form the basis for preparation of a postgraduate thesis, academic publications, conference papers and other scientific publications. ☐

5. I agree to take part in the study entitled “Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting” ☐

Name: ______________________________________ (Please use block capitals)

Signature: ___________________________________Date: ______ / ______ / ______

Appendix 23

Topic guide non-participants of the MedEx MoveOne Programme

"Translational formative evaluation of exercise intervention for cancer survivors delivered in a higher education fitness centre setting"

Running the telephone interviews:

- Takes notes during interviews
- Ensure participants have been issued the correct Information Form prior to interview day.
- Allow time for questions prior to interview commencement.
- The participant will provide the informed consent form

Informed Consent:

Today is a once off interview and there will be no follow up after this. The interview will be recorded and you are under no obligation to talk or answer questions and you can leave at any stage during the interview. Therefore, by taking part in the telephone interview, you have consented to be part of the research.

Confidentiality statement:

Confidentiality is of utmost importance your name will only be seen by the researcher and the researcher's supervisor on the informed consent form. Opinions expressed shall be treated in confidence among the research team with all responses remaining anonymous.

Start by repeating the reason of the meeting:

The purpose of the interview is to discuss your reasons for not transferring into the MedEx Move On Programme following completion of the ESIE-CF trial.

Thank you for taking this telephone interview. You has been invited to participate because your view is very important to us. We know that you are very busy and we greatly appreciate your contribution to this study. Please note there are no wrong answers, so please feel comfortable saying what want and how you really feel. Remember, we are very interested in what you think and feel and we really want to know your opinions.

Sample questions:

What were your concerns about involvement with the MedEx Programme?
What stopped you from joining the MedEx Programme?
What could be done to facilitate your decision to join an exercise rehabilitation programme such as the MedEx Move On Programme?

Appendix 24

Waterford Institute of Technology

Dear Doctor:___________________________

Your patient __________________________ wishes to take part an exercise programme to help with his fatigue.

I would be grateful if you could complete the attached questionnaire regarding your patient's history of cancer treatments and current state of health. I am collecting brief cancer treatment histories as different histories and treatments may moderate the fatigue response to exercise in final analyses. I am collecting current state of health data to assist with participant management and safety during exercise.

The 10 week exercise programme will emphasise aerobic exercise, commencing with exercise of low to moderate intensity. The duration of exercise bouts and the intensity of exercise will be increased gradually subject to participant tolerance. I am a PhD Scholarship student undertaking a project in the area of exercise and cancer related fatigue and also have a First Class Honours degree in Exercise and Health Studies and am a registered fitness professional.

I would be grateful if you would confirm your patient's medical suitability to participate in the programme. I would be more than happy to discuss this programme with you if you wish, and can be contacted at any time.

Thanking you

Yours sincerely

____

Patricia Sheehan,

PhD Scholarship Student,

(087) 9670735

patricia.sheehan@postgrad.wit.ie

Medical Clearance Form

Patient Name: ______________________________

Please Circle or provide detail as appropriate

Cancer Diagnosis

Date of Diagnosis: _________________________ (Month/Year)

Cancer site: Breast Prostate Colon Other _______________

Cancer Stage: I II III IV

Cancer Treatments

Surgery Yes No

Date of Surgery: __________________________ (Month/Year)

Site of Surgery: __________________________

Chemotherapy Yes No

Date of Completion: ______________________ (Month/Year)

Or

Still on Chemotherapy Yes No

Chemotherapy Regime

____

____

Radiation Therapy Yes No

Site of Radiation: __________________________

Duration of Radiation Treatment: __________________________(Weeks)

Date of Radiation Completion : __________________________(Month/Year)

Currently taking medication relating to cancer treatment e.g. anti-hormonal therapy

Yes No

Name of Medication: ____

The following are contraindications for exercise in cancer patients

- Low haemoglobin, white blood cells, neutrophils or platelet counts
- Fever
- Cachexia or loss of >35% pre-morbid weight
- Limiting dyspnoea with exertion
- Bone pain
- Severe nausea
- Ataxia

Are you satisfied that these contraindications are not present? Yes No

In order to assist in the safe management of the patient during exercise, please indicate if to your knowledge any of the following are present:

Shortness of breath	Yes	No
Lymphoedema	Yes	No
Joint pain/ stiffness	Yes	No
Fracture history	Yes	No
Myalgias	Yes	No
Muscle weakness	Yes	No
Neuropathy	Yes	No
Reduced cardiac function	Yes	No
Coronary heart disease	Yes	No
Hypertension	Yes	No
Diabetes	Yes	No

Has the patient any other physical/ mental/ psychological health issues that may render them unsuitable for the exercise programme?

Yes No

Are you satisfied for your patient to participate in the exercise programme?

Yes No

Additional comments:

____

____

Signature: ____ **Date:** ______

Print Name: _______________________________________

Appendix 25

CONFERENCE PRESENTATIONS

- ACSM 65th Annual Meeting 2018 (Minneapolis)
- FSEM Annual Scientific Conference 2017 (Royal College of Surgeons Ireland)
- The 'International Psycho-Oncology Society Congress' 2016 (Dublin)
- 3rd All Ireland Postgraduate Conference in Sport Sciences, Physical Activity and Physical Education 2016 (Waterford)
- Waterford Institute of Technology Research Day 2016
- University Hospital Waterford Research Day 2016, 2014

PUBLICATIONS

Sheehan, P., Denieffe, S., & Harrison, M. (2018). Exercise Is More Effective Than Health Education In Reducing Fatigue In Fatigued Cancer Survivors. *Medicine & Science in Sports & Exercise, 50*, 256-25. DOI:10.1249/01.mss.0000535930.11692.a2

Sheehan, P., Denieffe, S., & Harrison, M. (2016). Evaluation of a Sustainable Intervention using Exercise-for Cancer Fatigue (ESIE-CF Trial). *Psychooncology*, *25*, 183–184. http://doi.org/http://dx.doi.org/10.1002/pon.4272

Appendix 26

Summary of the studies included in the literature review

Study	Aim	Sample size	Gender	Mean age (years)	Cancer type	Intervention	Data collection	Analysis method
Groeneveld, de Boer, & Frings-Dresen, 2013	To explore cancer survivors' experiences with (1) return to work (RTW) and work performance; (2) a physical exercise program after treatment; and (3) the perceived link between physical exercise and work	10	M(1)+ F	56	Mixed	Group intervention twice a week for 12 weeks Cycle ergometer and weights; cardiovascular and resistance training	Semi-structured, individual interviews	Thematic
Fischer et al., 2015	Investigate the impact of a Nordic walking intervention on women's subjective wellbeing and shoulder functioning	28	F	54	Breast	10-weeks of structured Nordic walking; first 3 sessions used to educate participants on correct technique Upper body strength and conditioning	Focus groups	Inductive content analysis
Frensham, Zarnowiecki, Parfitt, King, & Dollman, 2014	Explore experiences of rural participants engaging in an online lifestyle intervention	8	F(6) + M	67	Mixed	6 weeks of online support for pedometer-based walking	Interviews	Content analysis
Hefferon et al., 2013	To study perceived barriers to exercise implementation 5 years after breast cancer diagnosis	83	F		Breast	Original study: Specially designed circuit classes (45 min) 6 days/week and two evenings a week at eight separate leisure centres across the city of Glasgow.	One-to-one semi-structured interview	Inductive Thematic
Korstjens, Mesters, Gijsen, & Van Den Borne, 2008	To explore patients' perspectives on how and to what extent a rehabilitation programme had met their needs and suggestions as to how the programme could be improved	23	M(2)+F	52	Mixed	Group intervention Twice a week for 3 months Cardiovascular and resistance training including psychosocial activities	Focus group interviews	Thematic

Luoma et al., 2014	To investigate how tailored exercise is experienced by cancer survivors	25	F	54	Breast	Group intervention once a week; supervised 3 times a week; home-based 12 months Cardiovascular exercise	Semi-structured focus group interviews	Phenomenological
McDonough, Sabiston, & Crocker, 2008	Explore women's experiences of changes in their body image and feelings of social support during a novice season of dragon boating	14	F	54	Breast	12 weeks (single season) of dragon boating	Interviews	Interpretative phenomenological analysis
McDonough, Sabiston, & Ullrich-French, 2011	Explore the development of social relationships, social support, and outcomes among women participating in a dragon boating program over two seasons	17	F	51	Breast	76-weeks (i.e., two season) of dragon boating	Interviews	Interpretative phenomenological analysis
Midtgaard et al., 2011	To describe post treatment cancer survivors' lived experience of long-term PA maintenance to gain an understanding of adherence-enhancing resources and strategies	23	M(6) + F	50	Mixed	Group intervention once a week 12 months High-intensity exercise including expert presentations and individual coaching	Semi-structured focus group interviews	Systematic text condensation
Parry, 2008	Understand how participation in dragon boating contributes to women's health throughout survivorship	11	F	Not stated	Breast	1 season of dragon boating	Interviews	Content analysis
Sabiston, McDonagh, & Crocker, 2008	Explore women's experiences of engaging in dragon boating	20	F	59	Breast	Dragon boating	Interviews	Content and thematic analysis
Sander, Wilson, Izzo, Mountford, & Hayes, 2012	To investigate factors affecting decisions on exercise and PA by breast cancer survivors	34	F	Not stated	Breast	Not a specific exercise programme; recruited breast cancer survivors who were currently exercising or had never exercised on a regular basis	Semi-structured interviews and focus groups	Triangulated with 2 quantitative studies

Spence, Heesch, & Brown, 2011	To understand participants' experiences in an exercise rehabilitation programme and their preferences for programme content and delivery	10	M(7) + F	58	Colorectal	Individual exercise 3 times/week 12 weeks Moderate- to high-intensity aerobic exercise	Semi-structured, individual interviews	Not stated
Wurz, St-Aubin, & Brunet, 2015	To explore the barriers and motives experienced by women attending an 8-week group-based PA program offered in the community following treatment for breast cancer	7	F	55	Breast	8 weeks of structured, group-based training	Interviews	Thematic analysis

Appendix 27

Key themes, subthemes, and sample quotes

Theme	**Subtheme**	**Reference**	**Sample quote**
Benefits and improvements	Physical	Luoma et al., 2014	*"I was in a really bad shape, somehow really tired. I feel so much better after I've started exercising. It really makes a difference."*
		Groeneveld, de Boer, & Frings-Dresen, 2013	*"By participating in exercise you realize that you are capable of doing things, and that, and you just get more energy and with that extra energy you feel like being active, because you don't get tired all the time."*
		Parry, 2008	*"I found [dragon boat racing] actually improved my physical condition. I used to have very severe osteoporosis, and I had lower back pain, and when I started paddling, because you use your whole body and you use your lower back, I was worried that it would cause too much strain on my back and it would be difficult, but it had the opposite effect. After a while, my back pain actually went away, so it was really beneficial."* *"I just felt so good, I felt like I was in great shape and I felt energetic and I felt positive."*
	Psychological	Spence, Heesch, & Brown, 2013	*"It builds confidence and shows that life can return to normal."* *"The ImPACT Programme helped me to think I was fit enough to go back to work which was very important to me."*
		Parry, 2008	*"... During that time it's hard to feel normal because everything has changed, but with dragon boat racing I just felt so, so normal. And from*

			my everyday life, that was so uncomfortable for so long, for this 2 hours that I'm with them [teammates], twice a week, it was a reprieve. It was 4 hours a week that made me feel normal, 4 hours a week that I felt so good and felt a little bit like I could cope. It's so important to feel normal [throughout breast cancer survivorship]. I think it helps you recover a lot faster and better. I think if I wasn't doing the dragon boat racing I think I would be in really bad shape emotionally. And no matter how bad I'm feeling physically, emotionally I feel really happy."
		Wurz, St-Aubin, & Brunet, 2015	*"…feel almost normal again … a great way to transition yourself from being an ill patient to a well person."*
		Korstjens et al., 2008	*"I do feel that it's easier for me to open up and tell other people that I had it myself."*
		Luoma et al., 2014	*"During the summer my physical condition was at its worst, but when you come here and see that you have the energy to do lots of stuff and are feeling well, that lifts your spirits. So carry on. When you notice that you are able to do more, so why not."*
	Social	Luoma et al., 2014	*"I'm so sick of everybody at work asking how am I doing. I can't forget it. This group doesn't ask me all the time how I'm doing. That's a really good thing. They know without asking how I'm doing."*
		Sabiston, McDonough, & Crocker, 2007	*"We support each other, we offer practical information about how to deal with what decisions we made and it's really comforting, to know that they*

			have had those things, dealing with fear and the unknown of whether you are going to live.”
	Return to work influenced by increase in fitness and/or energy	Groeneveld, de Boer, & Frings-Dresen, 2013	*“I think if I would not have participated in sports I would not have returned to work so fast because I would just have had much less energy.”*
Barriers	Physical appearance	Luoma et al., 2014	*“I hate to be the one that people look at. Or they try not to look, but they’ll look anyway. (Makes me always think how retarded people feel when people…) You know, when you walk by and you just notice that eyes are staring”.*
	Fear	Groeneveld, de Boer, & Frings-Dresen, 2013	*“I was a little frightened to start exercising myself, I mean, in the gym. […] Because you might overdo it and the next day everything hurts and you won’t feel like going again.”*
		Parry, 2008	*”I was worried that it would cause too much strain on my back and it would be difficult.”*
		Sander, Wilson, Izzo, Mountford, & Hayes, 2012	*“But I was also afraid of doing those exercises because of the fear ... of lymphedema ... So I think there's a piece of me that's always a little bit concerned about what I can do with my right side and what kinds of exercises I should be doing.”* *“Right after my surgery, I was afraid to pick up my grandbaby. Not that I was worried about dropping her, but I felt that she might have been too heavy for me.”*

	Isolation	Luoma et al., 2014	*"Then there was this funny thought I had when the treatments were over, that I didn't feel safe, thinking that now I'll be left on my own and alone with this scary thing."*
	Time of day/roles	Wurz et al., 2015	*"Unfortunately, I had to go back to work and because they [group-based PA classes] were during the day, when I had the day off I would go over to the exercise classes."* *"It's right in the middle of the day. Like it's fine if you're off work, but I see that being a big barrier for people who are working like me."*
	Social support	Sander, Wilson, Izzo, Mountford, & Hayes, 2012	*"My immediate family has become so concerned about me that they try to do things for me instead of letting me do them."*
	Fatigue	Sander, Wilson, Izzo, Mountford, & Hayes, 2012	*"Chemotherapy came and I did experience fatigue … so that stopped me from doing a lot of things."*
Facilitators	Social support	Sander, Wilson, Izzo, Mountford, & Hayes, 2012	*"I need a class. I need that social aspect to it."*
	Time of day	Sander, Wilson, Izzo, Mountford, & Hayes, 2012	*"I need a class that is at a nice time of the day for me to go."*
Preferences	Importance of exercising with other cancer patients	Korstjens, Mesters, Gijsen, & Van Den Borne, 2008	*"Mutual contacts with fellow patients … you don't have to explain the fear you felt, the uncertainty, the grief. Everyone felt the same. That really felt good."*

	Importance of professional instructors	Luoma et al., 2014	*"I felt it was really important that we are instructed to do exercises that suit us. I'm really careful about how my hand and spine works and moves. I didn't know how much strain I could put on it. And how much I can stretch it".*
	How long after treatment	Spence, Heesch, & Brown, 2011	*"Treat it as the next stage in treatment … you are generally on a high after finishing treatment and to keep momentum the programme should start just after treatment."*
	Considering an unsupervised programme	Spence, Heesch, & Brown, 2011	*"I wouldn't know how hard to push myself [without a supervising exercise physiologist]."*
Motivators	The instructor	Frensham, Zarnowiecki, Parfitt, King, & Dollman, 2014	*"I wasn't doing what I should do and you sort of were the motivation that got me up and going."*
	A cancer-specific programme	Frensham, Zarnowiecki, Parfitt, King, & Dollman, 2014	*"Especially when you have had cancer because it is so easy to just sit in a chair and read a book and this made me go out."*
	Social networking	Wurz et al., 2015	*"I like to participate and see the people and talk with them and get that dose of energy. It's very motivating. It really is. I have never done formal exercise class before and this is great."*
	Acquiring health benefits	Wurz et al., 2015	*"You never forget what you went through and you see the progress there and you get to the point where you feel even better than before you were sick."*

			“I find that I don’t have that much get-up-and-go when I don’t come to the exercise classes.”
	Being with similar individuals	Wurz et al., 2015	*“I really feel like although we’re all different people, with different cancer, different ages, different everything, that there’s that common basis and common reason for being there that just makes it a place where you want to be.”*
	Encouragement received	Wurz et al., 2015	*“We’re each others’ cheering partner!”*
	Programme played a key role in cancer recovery	Wurz et al., 2015	*“… more like a normal person and less like a cancer patient.”* *“It makes me feel like I am doing something about my own situation and that is something that is lacking when you finish your treatments. It is that feeling of doing something for yourself and your health.”* *“… this [group-based PA program] is medication for me.”*
	Reaching goals	Frensham, Zarnowiecki, Parfitt, King, & Dollman, 2014	*“If it got dark and I hadn’t had my number of steps I would make the effort to top-up.”*
	Personal fulfilment	Wurz et al., 2015	*“I have been pleasantly surprised when I realize how much I can actually do. I keep up better than I would’ve given myself credit for. There have just been too many limitations lately, so it feels good.”* *“I feel great after completing one [group-based PA class]. There is a sense of personal fulfilment. When I try new moves, and I realize how*

			simple they are. The accomplishment for me is wow, I can do these even at home."
	Positive affirmation of PA	Midtgaard et al., 2011	*"My feelings about exercise are due to my feeling that actually exercise saved my life. Even if it has been a very tough period some good things have also come about, and why would I and how could I give up what I believe keeps my healthy. I am convinced that everything will turn out well."*
	Reduced fear	Midtgaard et al., 2011	*"About the cancer coming back, I feel that it just doesn't happen as long as I stay active. Yes, that is how I feel about it. It is simply not a possibility".*
Experience of the programme	Relieved to be supervised	Groeneveld, de Boer, & Frings-Dresen, 2013	*"I was very glad that I had the opportunity to, eh, participate in supervised exercise."*
	Sharing and obtaining information	Sabiston, McDonough, & Crocker, 2007	*"We support each other, we offer practical information about how to deal with what the decision we made … and it's really comforting, to know that they have had those things, dealing with fear and the unknown of whether you are going to live."*
	Unique from other groups	Sabiston, McDonough, & Crocker, 2007	*"When you're in a support group … you're still very much into that 'I'm ill' treatment mode. Whereas now it's, we're getting on with life and aren't we lucky that we can do this. And we can laugh at our misshaped bodies and, not say, 'oh you poor thing.'"*

Value of an exercise programme	Importance of skilled instructor	Korstjens, Mesters, Gijsen, & Van Den Borne, 2008	*"I felt it was really important that we are instructed to do exercise that suit us. I'm really careful about how my hand and spine works and moves. I didn't know how much strain I could put on it. And how much I can stretch it"*
	Helped in gaining a sense of normality	Luoma et al., 2014	*"But you don't get the feeling that you are ill. I think it's really well planned. All the exercises and everybody know how fit they are and do everything according to how they feel that day."*
	Opportunity for extra medical care	Luoma et al., 2014	*"I knew that in that study they would do examinations I wouldn't otherwise go to. So I got tests done like bone density that wouldn't have been done on me otherwise. I thought it was great. They took all x-rays and all examinations. They took good care of me and I felt safe"*
Social support	Having an implicit understanding of the breast cancer experience	McDonough, Sabiston, & Crocker, 2008	*"People who have had breast cancer understand. There's a level of understanding that you can only have if you've done it. And so there's sort of unspoken things that you don't even have to talk about. You just know someone else's experience. You understand their fears. You understand their joy. You understand their attitude towards life".*
		Sabiston, McDonough, & Crocker, 2007	*"You don't have to fill in the blanks and create background. They all have the background, they've been in the blanks themselves, so you can cut right to the today. And they will know exactly how you are feeling. You don't have to explain it. You don't have to say a word. They would just*

			know how you are feeling…because you don't have to articulate anything, it's already in there".
	Sharing first-hand information about their experiences with breast cancer	McDonough, Sabiston, & Crocker, 2008	*"I had a mastectomy but I have not yet had reconstruction. So you can ask different people (at dragon boating), "Who did you go to? Did you like it? Was it worth it?"*
		Sabiston, McDonough, & Crocker, 2007	*"We support each other, we offer practical information about how to deal with what the decision we made … and it's really comforting, to know that they have had those things, dealing with fear and the unknown of whether you are going to live."*
	Unconditional support	Sabiston, McDonough, & Crocker, 2007	*"Everybody pitches in and that's another thing that belongs to the dragon boats, it's almost like an insurance policy."* *"The fact that it may come back, you may, it may reoccur, that you have women that you can talk to or will support you or you can be alone if you want to."*
	Opportunity to help	Sabiston, McDonough, & Crocker, 2007	*"It was nice being helped in the first year. It was even nicer to be able to help."*
	Unique from support groups	Sabiston, McDonough, & Crocker, 2007	*"Some of these other support groups are just sort of all sat around and say how terrible it was that [name] had died. Well, we all think that but at the same time we are getting on with living."*

			“When you’re in a support group … you’re still very much into that ‘I’m ill’ treatment mode. Whereas now it’s, we’re getting on with life and aren’t we lucky that we can do this. And we can laugh at our misshaped bodies and, not say, ‘oh you poor thing.’” *“That’s why it was so appealing, because it was an activity, it had everything a group had but without this overlay of too much navel gazing, too much whatever.”*
Reduction of fear	Miscellaneous	Midtgaard et al., 2011	*“About the cancer coming back, I feel that it just doesn't happen as long as I stay active. Yes, that is how I feel about it. It is simply not a possibility.”* *“But it is a paradox, isn't it. That you need someone to breathe down your neck, before you get your act together. It is like I needed to be reminded that there is an end to my life, before I started to live.”* *“It is my private space—and when I am there, I feel untouchable and invincible, and I am able to handle/face the whole world. Of course it doesn't last, but it gives security to know, that this private space exists for me.”*
	Inclusion of a psychologist or psychiatrist	Korstjens, Mesters, Gijsen, & Van Den Borne, 2008	*“I would have very much liked to see a psychologist or a psychiatrist as part of the programme … about the psychosocial effects of having cancer, about one’s personality before and after cancer, and how to get something*

Recommendations for improvements to the programme			*positive out of it. Some people say: having cancer and coming out of it positive, that's not possible. But it is! The question is: how?"*
	More coaching on life after cancer	Korstjens, Mesters, Gijsen, & Van Den Borne, 2008	*"When I got cancer, I spent a lot of time thinking about my life, and I discovered that I had done many things just because I'd been raised that way. Suddenly realized, I have to set boundaries, but because I'd never done that, it's something I have to learn. That's where coaching is needed, and that should be stressed more … with a psychologist whom you can ask things and who can advise you. Now, I had to find that out myself."*
	Offer unsupervised for those who missed supervised sessions, but ensure safety	Spence, Heesch, & Brown, 2011	*"Offer optional prescriptions for unsupervised sessions for participants who have to miss supervised sessions (e.g. due to work or family commitments), but ensure follow-up with participants to maintain the safety of the exercise prescription and optimise accountability."*
	Variety/alternatives	Spence, Heesch, & Brown, 2011	*"Provide choice of exercise modality to allow for exercise preferences (e.g. walking, running, bushwalking, swimming, dancing) and special requirements (e.g. colostomy bag, requiring close proximity to toilet facilities, existing injuries). Access to gym facilities may be important to overcome barriers such as weather or safe environments for exercise."*

APPENDIX 28

Week 1 – Education session (1 hour)

Aim

To provide participants, the knowledge, understanding and skills needed to exercise at the correct intensity to help with the management and treatment of CrF

Content

- What are the PA guidelines for cancer survivors
- What is moderate to vigorous PA
- How to measure exercise intensity
- How to measure blood pressure
- How to measure heart rate
- How should I feel when exercising at moderate and vigorous intensity
- Show how to use pedometer
- Give out and explain how to use step tracker (worksheet 1), daily fatigue diary (worksheet 2), and RPE scale (worksheet 3)

Worksheet 1: 10 week step tracker

Please attach pedometer first thing in the morning. When going to bed please take off pedometer and record total number of step on your tracker. Please then hit the reset button. Reattach pedometer when you get up each morning to track you steps taken throughout the whole day.

Week	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday	Weekly Total
Week 1								
Week 2								
Week 3								
Week 4								
Week 5								
Week 6								
Week 7								
Week 8								
Week 9								
Week 10								

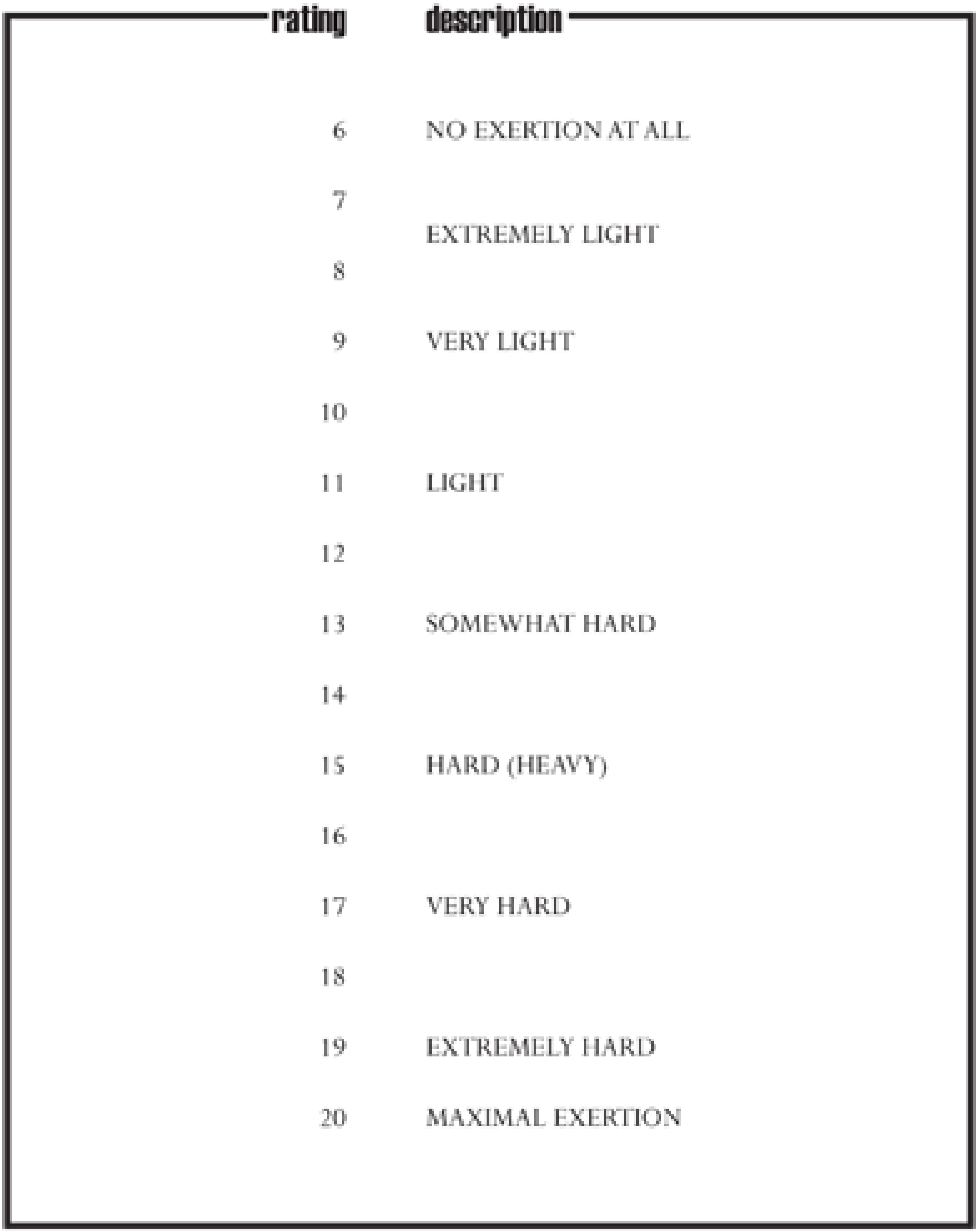
Worksheet 2: 10 week Fatigue Diary

Enter score at the end of the day as to how you felt all day overall

Rate your fatigue 0=not at all fatigued; 10 = as fatigued as I could be

Week	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Week 1							
Week 2							
Week 3							
Week 4							
Week 5							
Week 6							
Week 7							
Week 8							
Week 9							
Week 10							

Worksheet 3 – RPE Scale



rating	description
6	NO EXERTION AT ALL
7	EXTREMELY LIGHT
8	
9	VERY LIGHT
10	
11	LIGHT
12	
13	SOMEWHAT HARD
14	
15	HARD (HEAVY)
16	
17	VERY HARD
18	
19	EXTREMELY HARD
20	MAXIMAL EXERTION

Week 2 – Exercise session (1 hour)

Content

- Sign in participants
- Take blood pressure and heart rate measurements
- Review participant fatigue diary and step diary
- Identify any barriers to PA and come up with strategies to overcome barriers (behaviour change strategy Worksheet 4)
- Promote positive outcomes for PA (use of goal setting Worksheet 5, and review diaries)
- Provide participants with positive reinforcements

Exercise session

10 mins	• Dynamic warm up
6-8 mins	• Aerobic main phase • Group walking (if raining indoor adaptable circuits)
10 mins	• Cooldown
10 mins	• Post stretch including some mobility exercises

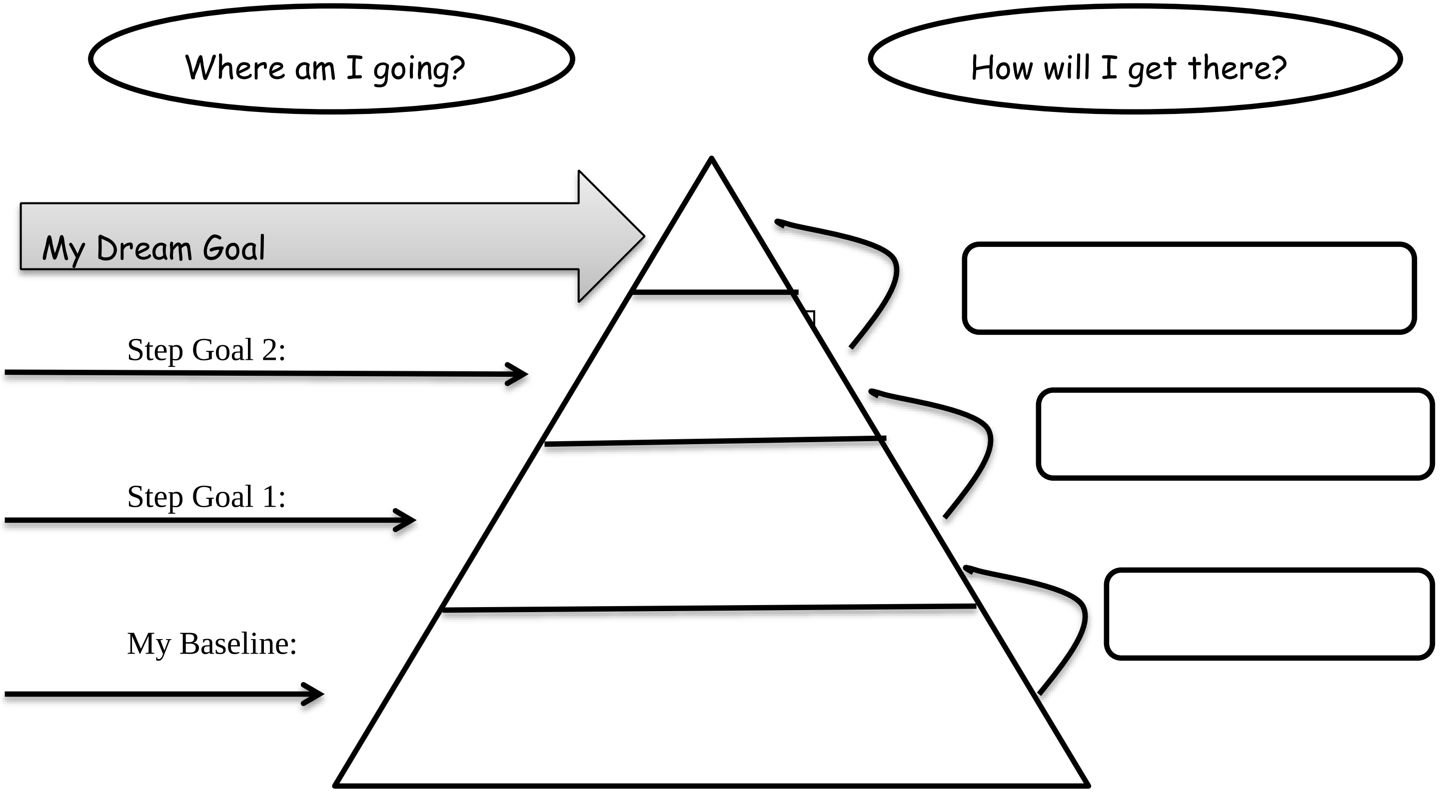
Worksheet 4 – Overcoming barriers

Overcoming Barriers

BARRIER	STRATEGIES TO OVERCOME

Worksheet 5 – Goalsetting

Getting to my Dream Goal: A goal-setting pyramid



Week 3 – Exercise session (1 hour)

Content

- Sign in participants
- Take blood pressure and heart rate measurements
- Review participant fatigue diary and step diary
- Identify any barriers to PA and come up with strategies to overcome barriers (behaviour change strategy Worksheet 4)
- Revisit goals to ensure participant is staying on track (be prepared for any relapse)
- Provide participants with Pro’s & Con’s of PA worksheets (behaviour change strategy Worksheet 6)

10 mins	• Dynamic warm up
8-10 mins	• Aerobic main phase • Group walking (if raining indoor adaptable circuits)
10 mins	• Cooldown
10 mins	• Post stretch including some mobility exercises

Worksheet 6 – Pros & Cons of PA

Fill in the pros and cons of changing and compare them, and ask yourself if the cons are worth it.

	Physical activity	**Inactivity**
PROS		
CONS		

It’s your choice. Now list the most important reasons why you want to change. You are the one who must choose what it will take to tip the scale in favour of change: ___

Week 4 – Exercise session (1 hour)

Content

- Assess fatigue (FACT-F)
- Sign in participants
- Take blood pressure and heart rate measurements
- Review participant fatigue diary and step diary
- Identify any barriers to PA and come up with strategies to overcome barriers (behaviour change strategy)
- Revisit goals to ensure participant is staying on track (be prepared for any relapse)
- Revise Pro's & Con's worksheet and identify if Pro's outweigh the Con's highlighting this to participants through positive reinforcements

10 mins	• Dynamic warm up
10 -12mins	• Aerobic main phase • Group walking (if raining indoor adaptable circuits)
10 mins	• Cooldown
10 mins	• Post stretch including some mobility exercises

Week 5 – Exercise session (1 hour)

Content

- Sign in participants
- Take blood pressure and heart rate measurements
- Review participant fatigue diary and step diary
- Identify any barriers to PA and come up with strategies to overcome barriers (behaviour change strategy)
- Revisit goals to ensure participant is staying on track (be prepared for any relapse)
- Identify Social Support to PA (behaviour change strategy Worksheet 7)

10 mins	• Dynamic warm up
12-14 mins	• Aerobic main phase • Group walking (if raining indoor adaptable circuits)
10 mins	• Cooldown
10 mins	• Post stretch including some mobility exercises

Worksheet 7 – Identifying Social Support to PA

List more than one person for each if possible! Make it a goal to speak to or see at least two people from this list every week during your physical activity journey

COMPANIONSHIP SUPPORT

Someone who will exercise with you and help you enjoy your activity. This might be a friend, roommate, or exercise group.

INSTRUMENTAL SUPPORT

Someone who provides tangible and practical assistance for your exercise goals such as: spotting you at the gym.

EMOTIONAL SUPPORT

Someone who is encouraging, caring, and empathetic that will give praise for your effort, encourage you to work harder, and understand when you are tired or sore.

____

____

____

INFORMATIONAL SUPPORT

Someone who can give you direction, advice, or suggestions about *how* to exercise. This can be a friend, trainer, teacher, or doctor.

____

____

____

VALIDATION

Someone who can confirm that your thoughts and feelings about activity are normal or can help you gauge your progress.

____

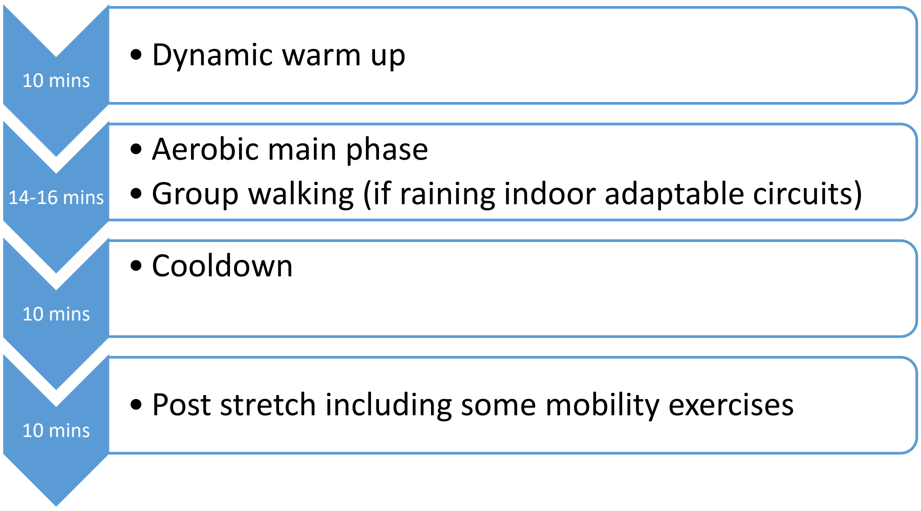
____

____

Week 6 – Exercise session (1 hour)

Content

- Sign in participants
- Take blood pressure and heart rate measurements
- Review participant fatigue diary and step diary
- Identify any barriers to PA and come up with strategies to overcome barriers (behaviour change strategy)
- Revisit goals to ensure participant is staying on track (be prepared for any relapse)
- Revisit social support network worksheet



10 mins
- Dynamic warm up

14-16 mins
- Aerobic main phase
- Group walking (if raining indoor adaptable circuits)

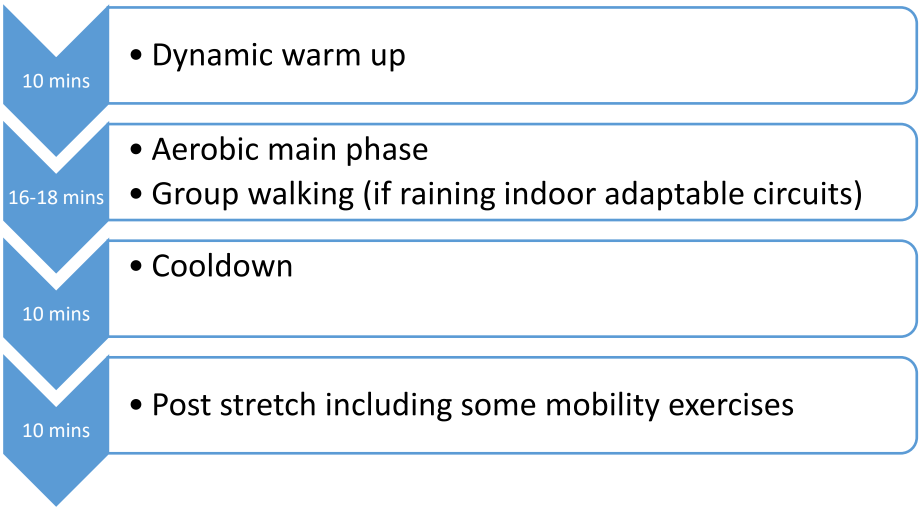
10 mins
- Cooldown

10 mins
- Post stretch including some mobility exercises

Week 7 – Exercise session (1 hour)

Content

- Sign in participants
- Take blood pressure and heart rate measurements
- Review participant fatigue diary and step diary
- Identify any barriers to PA and come up with strategies to overcome barriers (behaviour change strategy)
- Revisit goals to ensure participant is staying on track (be prepared for any relapse)



10 mins
- Dynamic warm up

16-18 mins
- Aerobic main phase
- Group walking (if raining indoor adaptable circuits)

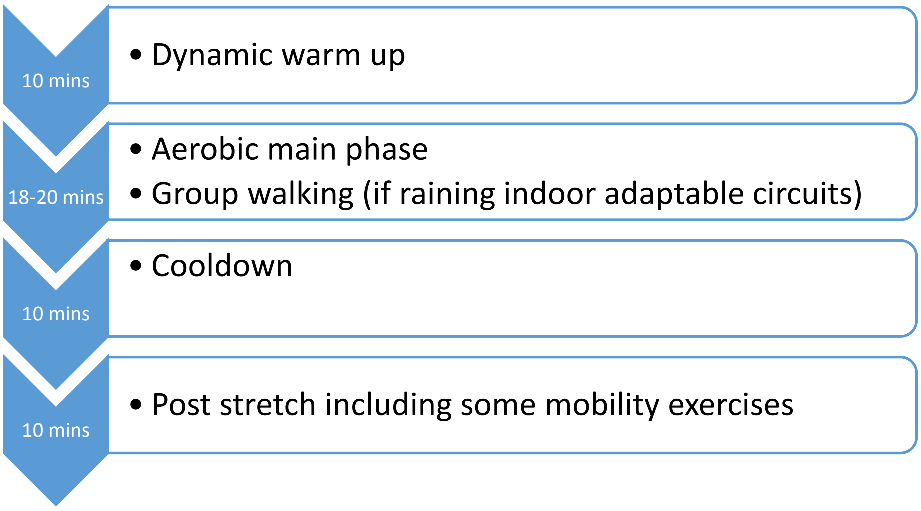
10 mins
- Cooldown

10 mins
- Post stretch including some mobility exercises

Week 8 – Exercise session (1 hour)

Content

- Sign in participants
- Assess fatigue (FACT-F)
- Take blood pressure and heart rate measurements
- Review participant fatigue diary and step diary
- Identify any barriers to PA and come up with strategies to overcome barriers (behaviour change strategy)
- Revisit goals to ensure participant is staying on track (be prepared for any relapse)



10 mins
- Dynamic warm up

18-20 mins
- Aerobic main phase
- Group walking (if raining indoor adaptable circuits)

10 mins
- Cooldown

10 mins
- Post stretch including some mobility exercises

Week 9 – Exercise session (1 hour)

Content

- Sign in participants
- Take blood pressure and heart rate measurements
- Review participant fatigue diary and step diary
- Identify any barriers to PA and come up with strategies to overcome barriers (behaviour change strategy)
- Revisit goals to ensure participant is staying on track (be prepared for any relapse)

10 mins	• Dynamic warm up
20 -22 mins	• Aerobic main phase • Group walking (if raining indoor adaptable circuits)
10 mins	• Cooldown
10 mins	• Post stretch including some mobility exercises

Week 10 – Exercise session (1 hour)

Content

- Sign in participants
- Book participants in for post testing
- Take blood pressure and heart rate measurements
- Review participant fatigue diary and step diary
- Identify any barriers to PA and come up with strategies to overcome barriers. Reinforce these strategies (behaviour change strategy)
- Identify if participant achieved 10 week goal reinforce positive feedback (behaviour change strategy)
- Revisit social network to ensure participants have identified key individuals to help with maintenance phase (behaviour change strategy)

10 mins	• Dynamic warm up
22-24 mins	• Aerobic main phase • Group walking (if raining indoor adaptable circuits)
10 mins	• Cooldown
10 mins	• Post stretch including some mobility exercises

Appendix 29

Chapter 4 additional participant supporting quotations.

Theme	**Subtheme**	**Additional supporting quotes**
Cancer survivor's experience of health care following treatment	Isolation and loneliness	*"There is a terrific sense of isolation" CRF030*
	Lack of after care	*"After we got better there was no one to look after us" CRF025*
Experiences of health care professionals in relation to CrF	Exercise not prescribed	*"No exercise was never brought into it either" CRF019*
Other issues experienced following treatment	Financial burden	*"*Even *if you have to go to hospital like it's the parking like and I had people bringing me down, and like you know, like you're conscious of that as well, they are hanging around for the few hours for the chemo, now we had a rota to bring me down and different things" CRF013*

What is needed/missing in cancer care	Need for cancer rehabilitation to be embedded in cancer care	*“You have the nurses telling you what the procedure is, but it would also be nice to have someone like yourself there saying, you know, ‘After this treatment now you are nearing the end of it’ and bring it in maybe a few weeks before you finish and say ‘Look we know now we know you are going to have fatigue but these are the things that are there for you if you opt to do them’” CRF020*
Benefits	Psychological benefits	*“Gave me a better outlook on life, would recommend to anyone” CRF043*
		” I really enjoyed it and it took me out of my lonely place” CRF025
	Educational benefits	*“… learning how to exercise at a moderate intensity and learning how to build myself up, like” CRF009*