Exploring Cancer-Related Fatigue and its Impact on Function and Work-Related Outcomes

by

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Abstract

The purpose of this dissertation is to explore, describe, and investigate cancer-related fatigue (CRF) in the context of functional work-related outcomes, with specific focus on physical exercise and work-related activities. The studies capture the perspective of individual cancer survivors and include stakeholder-driven data in the findings. The overall aim of this work is to inform current practice, and offer alternative approaches to the current systems in place.

PILLAR I. Exploration of CRF (from experiential and clinical perspectives). Chapters two and three present explorations of CRF. The first study (Chapter Two), known as the "JARS" study, presents an exploratory descriptive research study gathering information on CRF. The descriptors from 84 respondents, including cancer survivors, their support networks, and healthcare professionals were gathered across various clinical settings in Melbourne, Australia. The emergent themes of this study, namely "uncertainty" and "sense-of-self", offer novel targets for healthcare professionals to address in the management of CRF. The second study (Chapter Three), known as "TARGETing CRF", presents an exploratory descriptive research study gathering information on CRF from the perspective of 25 head and neck cancer survivors. The two emergent themes of this study, "CRF as a barrier to daily function", and "uncontrollable and unpredictable energy fluctuations", point to the day-to-day impacts of CRF on function, and call for a different approach to managing CRF. From the findings of this study, an 'energy cultivation' approach to CRF management is proposed.

PILLAR II. CRF in the Context of Work-Related Rehabilitative Opportunities (using the platform of a cancer-specific physical activity program). The final section of this dissertation consists of two sequential studies known as "ACE@Work"; results are presented across three chapters (Chapters Four, Five, and Six). The first study (presented in Chapter Four)

involved interviews, wherein 12 participants explored and described their experiences with CRF, work-related outcomes, and rehabilitative programming. The interview data were analyzed using a social theory framework, with the lens of a Person Environment Occupation model and a Social Ecological model, to consider the experiences of these individuals, who had already participated in cancer-specific physical exercise programming (which is beyond standard care for cancer). Three themes emerged specific to CRF and work-related outcomes, namely: valuing physical wellness, perceived cognitive impacts of CRF on function and workability, and the lack of transition from physical exercise to functional work-related activities. These themes guided the subsequent proof-of-concept feasibility study presented in Chapter Five. The ACE@Work pilot study presented in Chapter Five examined the feasibility of implementing tailored work-related functional activities to a cancer-specific exercise program, and the feasibility of exploring work self-efficacy as measured through components of performance and satisfaction. The results showed meaningful changes (2-point improvement) across all participants' Canadian Occupational Performance Measure scores of performance and satisfaction, improvement across all physical lift tests, and support further exploration of the value of work self-efficacy. Chapter Six is a knowledge translation article that shares the processes and challenges of carrying out the implementation study.

To summarize, the sequential studies presented in this dissertation first explore and describe current approaches to CRF management (Pillar I), and the final studies present a work-related intervention that proved feasible to implement (Pillar II). As this dissertation presents small-scale and pilot research, the findings of these studies call for further research, and larger-scale trials to continue to explore potential opportunities for managing CRF symptoms in the context of work-specific issues.

Preface

This dissertation is an original work by Naomi Dolgoy. The following three specific research projects, of which this dissertation is a part, required and received research ethics approval from the Health Research Ethics Board of Alberta: Cancer Committee (HREBA.CC):

1. "TARGETing CRF", HREBA.CC-15-0167_MODI, June 28 2016.
2. "ACE at Work", HREBA.CC-16-0905_MOD5, May 20, 2018.
3. "ACE at Work", HREBA.CC-16-0905_MOD6, October 18, 2018.

As an article-based dissertation, several chapters have been published, with myself as a primary author on all chapters. As a primary author, I took part in all aspects of research, analysis, and writing required for the publication. All listed co-authors contributed to aspects of the research and writing, as well as the data analysis. All published articles are approved by the respective journals for use in this dissertation, based on publication agreements. Chapter 2 was published in the European Journal of Cancer Care, with the co-authorship of Dr. M. Krishnasamy and Dr. M.L. McNeely. Chapter 4 was published in this British Journal of Occupational Therapy (Cancer Edition), with the co-authorship of J. Brose, T. Dao, K. Suderman, Dr. D.P. Gross, Dr. C. Ho, Dr. S.N. Culos-Reed and Dr. M.L. McNeely. Chapter 5 was accepted for publication in the Annals of Occupational Therapy and Physiotherapy, with the co-authorship of Dr. D.P. Gross, Dr. C. Ho, Dr. S.N. Culos-Reed, and Dr. M.L. McNeely. Chapter 6 was published in the SAGE Research Method Cases, with the co-authorship of Dr. S.N. Culos-Reed and Dr. M.L. McNeely.

Dedication

The work of this dissertation is dedicated to the cancer survivors and healthcare professionals whom I have had the privilege of working with during my career in cancer care. In particular, I extend the utmost of appreciation to all the patients/clients who encouraged me to pursue research, and without whom, I never would have come to know the effects of cancer-related fatigue and the imperative need to progress the current situation. I hope that in this work, I have captured your voices, your stories, and your experiences. Above all, I hope that I have done you proud.

Acknowledgements

It is as a result of the support and care of so many individuals that I was able to complete this dissertation. It is because of Dr. McNeely, my supervisor and mentor, that I started this dissertation in the first place. To Dr. Margie McNeely: thank you for seeing the research potential in me. It has been such a beneficial experience to work with you, learn from you, and contribute to the studies in the Cancer Rehab Clinic; my appreciation goes beyond words.

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To my Cancer Rehab Clinic lab-mates and co-authors: thank you for supporting me and being part of the research process. I truly appreciate the collaborative community we have built in the lab. I extend special thanks to Nicole Bell and Elaine Gobeil for their wizard-like administration and organization.

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To the Allied Health team at the Foothills Hospital, and specifically to Brian Ellis and Marg Lowe: thank you for making it possible for me to pursue research while maintaining my clinical role. I am so fortunate to be part of such an extremely supportive team.

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To my friends and family: thank you for sharing this research with me, and for sharing me with this research. For all the things that I have missed along the way, thank you for your kindness and understanding. I love and value all of you so much (and I am sorry I cannot mention each of you individually). In particular, to Mark Dolgoy, Francie Ratner, Noah Dolgoy, Taylin Wilson, Erin Dolgoy, Sujan Dan, and Michael Lee – this is as much your accomplishment as it is mine: thank you for being the ultimate of support networks. Shockingly, I am at a loss for words; just know that your actions, gestures, patience, and thoughtfulness over the course of this degree (and always) never go unnoticed.

Finally, to those of you reading this work: thank you for your interest in cancer rehabilitation. I continue to believe so strongly in the value of therapeutic interventions in cancer care. I know that with research we will continue to progress and improve our clinical practice.

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GLOSSARY OF TERMS

-**Alberta Cancer Exercise (ACE).** A five-year hybrid effectiveness implementation study investigating implementation of an Alberta-wide clinic-to-community-based cancer-specific physical exercise program. The principal investigator is Dr. Margaret McNeely, and co-leads are Dr. S. Nicole Culos-Reed and Ms. Melissa Shea-Budgell (McNeely et al., 2019).
- **Canadian Occupational Performance Measure (COPM).** A personalized outcome measure that uses a semi-structured interview format and structured individualized Likert -scale scoring method. The COPM measures client-perceived changes in satisfaction and performance over time (Law, Baptist, McColl, Opzoomer, Polatajko & Pollock, 1990).
- **Canadian Problem Checklist (CPC).** A 21-item screening tool for emotional, physical, family, practical issues. Recommended for use in cancer care (Bultz et al, 2011).
- **Cancer.** Diseases wherein abnormal cell division occurs without control (National Institute of Health [NIH], 2015).
- **Cancer-Related Fatigue (CRF)**. There are varying definitions for CRF; the most recent widely accepted definition from the National Comprehensive Cancer Network fatigue guidelines state that "cancer-related fatigue is a draining, ongoing exhaustion that limits one's ability to enjoy life and do activities" (NCCN, Cancer Fatigue Guidelines, Version 2, 2020). This dissertation recommends a definition change to explain CRF as a condition of limited and fluctuating energy required for everyday function, that negatively impacts activity engagement of cancer survivors following a cancer diagnosis.
- **Cancer Survivor(s) / Survivor(s).** A person with a cancer diagnoses is considered to be a survivor from the time of diagnosis until the end of life (NIH, 2015).
- **Cognition.** Referring to thinking or thought processing (Radomski & Latham, 2008).
- **Edmonton Symptom Assessment Scale (ESAS).** A short screening for distress and fatigue symptoms validated for use in cancer populations; the assessment uses terms of "tiredness" and "fatigue" to refer to CRF symptoms (Chang, Hwang, Feuerman, 2000).
- **Energy Allocation/Maximization.** The act of dividing or using a limited amount of a resource; in occupational therapy, energy allocation refers to the budgeting or prioritization of the resource generally for activity engagement (Radomski & Lathan, 2008). This strategy is currently used in CRF management.
- **Energy Conservation**. A strategy current used in managing CRF symptoms. The accepted National Comprehensive Cancer Network (NCCN)'s clinical definition is the "deliberately planned management of one's personal energy resources to prevent their depletion" (NCCN, 2020). This definition supports managing limited energy in order to most effectively manage tasks. The current NCCN cancer-related fatigue guideline recommends reducing fatigue through energy conserving techniques such as napping, and use of gait aids (NCCN, 2020).
- **Energy Cultivation.** A novel approach to CRF management developed through the work in this dissertation. Distinct from energy allocation and/or energy maximization, which focus on resource usage, energy cultivation focuses on managing the resource available AND growing energy like a natural resource. Energy cultivation facilitates engaging in activities that nourish and progress this resource.
- **Energy Depletion.** Part of the novel approach to CRF management developed through the work in this dissertation, energy depletion consists of activities and engagements that reduce a

cancer survivor's resource pool and, in doing so, may cause an individual to have an increase in CRF symptom manifestation and/or a decrease in life participation.
- **Exercise/ Physical Exercise.** Referring to physical movements and physical activities (Radomski & Latham, 2008).
- **Exploratory Descriptive research.** A branch of qualitative research which seeks to explore and describe less known phenomena (Brink, 1998).
- **Fatigue**. The National Comprehensive Cancer Network defines fatigue as "Severe tiredness despite getting enough sleep that limits ones ability to function" (NCCN, 2020).
- **Function/Functional**. Referring to purposeful or meaningful engagements (Radomski & Latham, 2008). In the context of this dissertation, functional interventions refer to interventions that have a real-world applicability.
- **Functional Assessment of Cancer Therapy (FACT) – Fatigue.** An assessment of fatigue symptoms validated for use with cancer survivors (Yellen et al., 1997).
- **Head and Neck Cancer (HNC).** Cancer that arises in the head and neck region including nasal cavity, sinuses, lips, mouth, salivary glands, throat or larynx (NCI, 2020).
- **Lift Tests**. Physical tests of exertion and strength that typically involve picking up, moving/carrying, and placing a weighted object, such as a crate (Matheson, Isernhagen, & Hart, 2002).
- **National Comprehensive Cancer Network (NCCN).** A not-for-profit alliance of cancer centers offering education, guidelines, programs and clinical tools for the management of cancer (NCCN, 2020).
- **Occupations.** Referring to activities and functional engagements (Radomski & Latham, 2008).
- **Occupational Therapy.** A discipline of rehabilitation in healthcare that focuses on facilitating engagement in activity (Radomski & Latham, 2008).
- **Person Environment Occupation (PEO) model**. The PEO model explores occupation through the relationship of the individual to his/her contextual surroundings and to the activities in which he/she engages (Baptiste, 2017).
- **Physical Therapy/Physiotherapy.** A discipline of rehabilitation in healthcare that focuses on movement and physical function (Radomski & Latham, 2008).
- **Return-to-Work / Return to Work (RTW).** Terminology around RTW reflects both the act or process of returning to work as well as the intervention itself; the programming for RTW may take various forms, including work-hardening or work-conditioning (Radomski & Latham, 2008). In the context of this dissertation, RTW is defined as the process implementing interventions into the rehabilitation programming of a survivor to support transition to a previous vocation after being away from work.
- **Social Ecological (SE) model**. A model that emphasizes behaviours and environments shaped by the influence of levels of social engagement, which include the following: individual, interpersonal, organizational, community, and public policy (Golden & Earp, 2012).
- **Social Theory**. An action-oriented meta-theoretical framework that allows for the examination of relationships and societal structures within their surrounding contextual environments and socially accepted norms; in healthcare-directed research, social theory offers a framework through which to explore practice norms, conventional assumptions, systems of care, and relationships between individuals, issues, and interventions (Meyer & Ward, 2014).

- **Therapeutic Resistance Group Exercise Training for Head *&* Neck Cancer Survivors (TARGET).** A randomized control clinical trial conducted in Edmonton, Canada, through the University of Alberta and the Edmonton Cross Cancer Institute, under principal investigator Dr. McNeely, which examines a combined approach to physical and therapeutic interventions for HNC survivors. Sixty participants took part in the TARGET study between 2016 and 2020 (McNeely, https://clinicaltrials.gov/ct2/show/NCT02647021).
- **Workability / Work ability / Work-ability**. This term is seen in healthcare and work-related literature in reference to two aspects of vocational engagement: first, possessing the specific training and/or skills required for a task; and second, having the health, basic standard competence and relevant necessary occupational virtues to manage a work role, within the context of reasonable work tasks and an appropriate work environment (Tengland, 2011). For the purposes of this dissertation, we specify the latter definition by using the term as one word: workability. Despite the interchangeable use of the term in much of the literature (Tengland, 2011), the work in this dissertation will use the singular word spelling of *workability*, which is intended to make clear that we are referring to the *health-related ability to do work and/or participate in a vocation in a given context* (and not referring to having the training or competency to do a particular job).
- **Work Self-Efficacy.** Work self-efficacy refers to one's belief and/or perception in one's ability to participate successfully in work-related activities and/or manage a work role successfully (Wolvers, Leensen, Groeneveld, Frings-Dresen & De Boer, 2018).

Chapter 1

Introduction

Chapter 1

Introduction

1.1 Overview of the Dissertation

Through medical advancements, cancer survivorship continues to improve (Foster, Calman, Richardson, Pimperton, & Nash, 2018). The direct result of this improvement is a growing population of cancer survivors with ongoing quality of life needs (Mayer, Nasso, & Earp, 2017). Since cancer survivors deal with a number of sequelae of cancer and anti-cancer treatments that can interfere with their routines and activities, these life issues have become an area of rehabilitative focus. Specifically, cancer-related fatigue (CRF), the most common consequence of cancer and anti-cancer treatments reported by cancer survivors, is a known barrier to daily living and, especially, successful work-related outcomes (Gehrke & Feuerstein, 2017). Currently, gaps in both rehabilitative research and clinical practice in workability and CRF-management point to an opportunity to further the functional rehabilitative approach to management of CRF and, in particular, to work-related outcomes for cancer survivors experiencing CRF (de Boer, Taskila, Ojajarvi, Van Dijk, & Verbeek, 2009; Nitkin, Parkinson, & Schultz 2011).

This dissertation comprises seven chapters in two pillars; in the first pillar, CRF is explored and described (Pillar I), and then in the second pillar CRF is investigated in the context of work-related rehabilitative opportunities (Pillar II).

Chapter One, the Introduction, focuses on the positionality, framework, and approach to the studies presented in this dissertation; this chapter describes and tracks the steps of the research, and outlines the series of studies that were performed as part of this doctoral work. The chapter also details the scope of the issue of CRF as a barrier to function and workability,

highlighting the current definitions and terminology, rehabilitative approaches, models of practice, and related body of published literature. Chapter Seven, the Discussion, provides a discussion on the dissertation, with particular focus on Pillar I with respect to clinically relevant information and the way in which the knowledge gained from Pillar I informed Pillar II, framing the way in which CRF could be approached clinically. This final chapter also explicitly tracks the following aspects of the dissertation: how the terminology used to describe CRF may effect the work-related outcomes seen in current practice; the importance of taking advantage of collaborative research opportunities, and the subsequent advantages and disadvantages of pursuing timely research; the relevance of emphasis on participant-reported outcomes including work self-efficacy and the individual perspective; and the implications and opportunities for more cohesive approaches to CRF-management, which address energy cultivation as a means to optimize work-related outcomes.

1.1.2. Pillar I. Exploration of CRF (from experiential and clinical perspectives)

Chapter Two (Study 1) focuses on the definition and descriptors used by healthcare professionals, cancer survivors, and the support networks of cancer survivors in describing CRF. Chapter Three (Study 2) focuses on head and neck cancer (HNC) survivors and how they frame their experiences with CRF in functional terms. This study was designed specifically for the HNC survivor population, which was targeted for two reasons: (1) HNC is known to have many sequelae including a high incidence of CRF; and (2) HNC survivors are an under-represented group in rehabilitation research, likely as a consequence of their limitations in communication second to their cancer and treatments (Simcock & Simo, 2016).

1.1.3. Pillar II. CRF in the Context of Work-Related Rehabilitative Opportunities (using the platform of a cancer-specific physical activity program)

Chapters Four, Five, and Six report the findings of the primary research study of this dissertation, which targeted participant-reported work-related issues and functional programming for cancer survivors who experienced CRF and had participated in a general cancer-specific physical exercise program. Chapter Four (Study 3) is an interview study that explores how former participants of a general cancer-specific exercise program—who met the criteria of (1) reporting CRF at a moderate or higher level, and (2) wanting to return to their previous work—addressed the program and their future work-related considerations. The themes that emerge from this study were used to inform and shape the subsequent study in Chapter Five. Chapter Five (Study 4) presents the results of a functional implementation approach to target participant-reported work-related issues within a cancer-specific physical exercise program. This study focuses on the feasibility of implementation, using measures of participant-reported performance and satisfaction ratings. Chapter Six centres on knowledge translation, articulating the strengths and challenges associated with the methodological approach used in Study 4 (Chapter Five).

1.1.4 Research Timeline and Specifics

The series of research studies presented in this dissertation took place between 2016 and 2019, the first in Melbourne, Victoria, Australia, and the second, third and fourth in Edmonton, Alberta, Canada. The studies/chapters are presented in chronological order, which also reflects the knowledge building from one study to the next, culminating in the final proof-of-concept implementation study. The approach to this dissertation moves from exploration of clinically relevant issues towards practical action in healthcare research. A common thread throughout the studies/chapters of this dissertation is the focus on cancer survivors experiencing CRF. The

studies were conducted with consideration of context-specific and time-sensitive opportunities, and within the limitations of a doctoral research timeline. As such, the development of the research moved from exploration of the condition of CRF (Pillar I) to exploration and action-orientated research for potential management of the work-related issues presented by the participants (Pillar II).

- Chapter Two: The study described in Chapter Two (known as the "JARS" study) was conducted by collecting written descriptors of the definitions and perceived experiences associated with CRF. The collection of data for this study was conducted by placing large jars in various healthcare centres, outpatient clinics, and healthcare professional settings (such as breakrooms and meeting rooms) in Melbourne, Australia, in order to capture a varied sample of written responses from cancer survivors, their support networks, and the healthcare professionals who work in cancer care. This study was conducted with the support and assistance of Dr. Mei Krishnasamy, the Peter MacCallum Cancer Centre and the University of Melbourne.
- Chapter Three: The study described in Chapter three (known as "TARGETing CRF") was conducted as an optional sub-study of the Therapeutic Resistance Group Exercise Training for Head & Neck Cancer Survivors (TARGET). TARGET is a randomized control clinical trial conducted in Edmonton, Canada, through the University of Alberta and the Edmonton Cross Cancer Institute, under the principal investigation of Dr. Margaret McNeely. The TARGET study examines a combined approach to physical and therapeutic interventions for HNC survivors. Sixty participants took part in the TARGET study between April 2016 and January 2020.
- Chapters Four, Five, and Six: The study described in Chapters Four, Five, and Six

(known as the "ACE@Work" study) was carried out in Edmonton, Canada, in conjunction with the Alberta Cancer Exercise (ACE) study. The ACE study is a five-year hybrid effectiveness implementation study that is investigating implementation of an Alberta-wide clinic-to-community-based cancer-specific physical exercise program. While the ACE study is conducted across sites in Alberta, the ACE@Work study was carried out exclusively in Edmonton, Canada, at the Cancer Rehab Clinic (University of Alberta) and the Wellspring Centre (a community-based cancer support centre). The principal investigator for the ACE study is Dr. Margaret McNeely, and co-leads are Dr. Nicole Culos-Reed and Ms. Melissa Shea-Budgell. The current structure of the ACE protocol is a generalized physical exercise program; however, until the ACE@Work study was conducted, the ACE study had not yet explored individualized functional work-related programming for cancer survivors.

1.2. Research Approach

1.2.1. Positionality

Researcher Background. As an occupational therapist, I have worked with children with cancer in school and clinical settings, and with adults with cancer in both in-patient and out-patient settings. Throughout my time working in oncology and cancer care, I have had concerns with the limited rehabilitation focus and sparse resources dedicated to supporting survivors in returning to their previous activities—in particular, productive ones, such as work—following cancer treatment. I have observed, questioned, and problem solved, to provide care to cancer survivors, given the limited systems in place to support cancer survivors after the acute phase of treatment has ended. While I did not have an overarching conceptualization of what rehabilitation for cancer survivors ought to look like, I knew from my clinical interactions and research review,

that: (1) cancer survivors were calling for a timeline that included earlier access to rehabilitation, and that (2) in other areas of occupational therapy, early interventions were often paramount in supporting functional outcomes. In my first few encounters with cancer survivors who were debilitated by the effects of cancer, including CRF—a condition, the existence of which I had never heard until I was working in cancer care—I came to see how profound the impacts of cancer sequelae were on survivors. More significantly, I saw how differently the symptoms of CRF manifested in individuals, and how without rehabilitative treatment, these symptoms were not simply resolving over time, and, in some cases, they were becoming more pronounced. Initially, I was unsure if these individuals debilitated by CRF symptoms were outliers or anomalies, but I believed that the standard rehabilitative practices to address CRF should be largely successful, and should offer sufficient care. However, as I continued to practice in cancer care, I noticed increasing numbers of cancer survivors reporting CRF as an ongoing concern; many of whom had major functional issues, occupational performance issues, as well as comorbid and newly diagnosed cognitive issues and mental-health conditions (such as depression and/or anxiety). Some of these individuals told me that while they were negatively impacted by their cancer diagnoses and treatments, from a life perspective, they were more significantly burdened by the chronic after-effects and suboptimal recovery. There were three major hurdles consistently impacting my patient care in this area: (1) incongruent timelines; (2) limited applicable research; (3) problematic practice models and guidelines.

Incongruent timelines. What I found most difficult clinically was the lag from symptom manifestation to rehabilitative intervention. I envisioned a more efficient system of practice that could include involvement of multiple healthcare disciplines at earlier stages of care; a system

where cancer survivors need not become deconditioned and decline so far from their normal function prior to having opportunity for any sort of rehabilitative-focused healthcare response.

Limited applicable research. When searching for answers as a clinician, I came across many systematic reviews outlining the issues with current cancer healthcare practice, and many qualitative studies highlighting individual cancer survivor experiences. Neither of these forms of research were scalable nor translatable, save for in their descriptions of the need for further research. Rather than continuing to simply explain the existence of these issues and/or share narratives of how a cancer survivor might be affected, I wanted to conduct clinically relevant research with a focus on implementable solutions.

Problematic practice models and guidelines. In seeking out practice models to use and guidelines to follow, I consistently found two clinical and research misconceptions applied to current practice in CRF management. These two misconceptions are as follows:

1. *CRF was considered a steady state of low energy.*

   This reported finding contradicted what I was seeing clinically, where patients reported a generous mix of what we clinically referred to as 'high energy' and 'low energy' days.
2. *Work-related interventions for cancer survivors need only focus on physical outcomes.*

   This reported finding was in discordance with the functional issues that clinical patients were reporting.

I found this second misconception was perpetuated by the models typically used in practice, and the musculoskeletal injury rehabilitation approach that was being applied in the cancer setting. At the time, fitting models of practice or protocols were relatively absent (as CRF was not yet a subject covered in detail in the occupational therapy clinical stream where I was working, nor

was it a subject of study when I was a student of occupational therapy, and finally, nor was it an area in which my provincial college felt able to support my queries). Without many options to improve my current practice situation, I turned to action-oriented research to seek answers to my clinical questions regarding CRF, work-related outcomes, and rehabilitation. Five years later, that objective has not changed. In fact, my desire to improve clinical practice outcomes through practical research has been strengthened, and I have a better understanding of how I now position myself as a researcher.

Researcher Situatedness. At the heart of this research lies an action-oriented, solutions-focused motive: my goal is to improve patient outcomes and make clinical practice more efficient, first through exploration, second through testable implementation strategies, and third (eventually) through quality improvement.

My situatedness with respect to rehabilitation of cancer is as follows: interventions need to consider the individual in context of his/her surroundings and the social systems in place. My situatedness with respect to cancer survivors and study participants is as follows: a cancer survivor is a whole person who exists in a societal structure and must be able to negotiate his/her needs at all phases of cancer treatment and care. My philosophical situatedness is as follows: I am pragmatic, in that I believe both inductive and deductive data analysis provide opportunities to progress research and inform practice.

I accept and appreciate that researcher positionality, including the lack of supports I encountered as a clinician, may have an effect on my decision to pursue research and the research conducted and, therefore, I have taken steps within each exploratory research project to ensure opportunities were present for the revisiting of positionality and situatedness, both for myself and together with my co-researchers/authors. In this regard, I have been able to grow and

develop research skills throughout each project/chapter of this doctoral dissertation.

1.2.2. Philosophical Framework

The research in this dissertation takes a pragmatic implementation approach, acknowledging the benefits and importance of both qualitative and quantitative approaches. Pragmatism seeks to translate aspects of data (Morgan, 2007). This dissertation presents findings from varied research approaches, with the goals of exploration and implementation. The qualitative-focused approach (through exploration) offers opportunity to provide subjective and inductive data analysis (Creswell & Creswell, 2017). In contrast, the quantitative-focused approach (through implementation) offers opportunity to provide objective and deductive data analysis (Creswell & Creswell, 2017). In exploring novel considerations in cancer rehabilitation, both approaches are warranted to optimise clear understanding of the issues, allowing for exploration of the findings to inform clinical practice.

1.2.3. Meta-Theoretical Framework

The framework guiding the research is presented explicitly in Chapters Two, Three, and Four. The research is consistently situated in social theory, which is an action-oriented meta-theoretical framework that allows for the examination of relationships and societal structures within their surrounding contextual environments and socially accepted healthcare norms (Meyer & Ward 2014). In healthcare-directed research, social theory offers a framework through which to explore the following aspects: practice norms; conventional assumptions; systems of care; relationships between individuals, issues, and interventions; as well as deviations from these accepted norms and practices (Meyer & Ward, 2014). Social action theory explores phenomena within context (meaning physical and social environments) and was considered an appropriate framework to build consistency across the series of studies pertaining to CRF and functional

work-related rehabilitation.

1.2.4. Guiding Practice Models

It was difficult to find an appropriate practice model to guide the research, given aforementioned clinical misconceptions I encountered and the limited rehabilitative-specific resources available. While the Cancer and Work model exists, the category of function is used as a heading encompassing physical exercise (Feuerstein et. al, 2010); whereas I required a model targeting functional outcomes exclusive of physical gains. Additionally, the Cancer and Work model is intended to be used in actual return-to-work (RTW) interventions, whereas the studies in this dissertation aimed to focus on delivery of early work-focused rehabilitation to prepare survivors for future RTW interventions. Further, while the amalgamated Cancer and Survivorship Work Model offers a broader examination of work interventions for cancer survivors, it also requires an actual developed RTW intervention and identified outcomes (Mehnert, de Boer, & Feuerstein, 2013). Thus, this model is beyond the scope of the work in this dissertation. To carry out the aims of the two pillars of this dissertation, two broader models for exploration and proof-of-concept were utilized. The Person Environment Occupation (PEO) model was used to guide the research process to situate the cancer survivor (individual focus) in context, and the Social Ecological (SE) model was used to guide the research process in terms of contextual surroundings (systems focus). These models are further described in Chapter Four.

The Person Environment Occupation (PEO) model.

This model was used to situate the research through a lens of individualized engagement. The PEO model explores occupation through the relationship of the individual to his/her contextual surroundings and to the activities in which he/she engages (Baptiste, 2017). A PEO-focused approach considers the individual as part of his/her surroundings. This model fits the

approach of the exploratory studies in this dissertation, as the PEO model explores human occupation with an implicit understanding of context (Strong, Rigby, Stewart, Law, Letts, & Cooper, 1999). Figure 1-1 reflects the PEO model in context.

The Social Ecological (SE) model.

This model was used to explore and facilitate understanding of interactions between social structures and the individual. The SE model emphasizes behaviours and environments shaped by the influence of levels of social engagement, which include the following: individual, interpersonal, organizational, community, and public policy. A major underlying concept in the SE model is that a supportive environment facilitates healthier occupational engagement (Golden & Earp, 2012). This model fits the approach of the studies in this dissertation, as the SE model explores influences of the individual in relation to surrounding social structures (Golden & Earp, 2012), such as opportunities for rehabilitation for overall wellness and/or workability. Figure 1-2 reflects the SE model in context.

The above two models interacted well within this dissertation research as they provided a focus on the individualized considerations of CRF and work-related outcomes, as well as on the overarching gap in services and research. Figure 1-3 reflects the relationship between the models and the research subject matter in context.

1.3. Terminology, Abbreviations, Acronyms, and Definitions

Cancer/oncology. While the general definition of cancer is widely known, the changing nature of approach to the diseases that make up cancer warrants clarification. Cancer is defined as diseases wherein abnormal cell division occurs without control (National Institute of Health [NIH], 2015). Cancer cells can also spread from the site of origin to other parts of the body through the blood and lymph systems. Oncology refers to the medical research and study on the

prevention, diagnosis and treatment of cancer (NIH, 2015). Over 200 types of diseases fall under the umbrella label of cancer (NIH, 2015). In the past, the oncological approach to cancer considered cancer as one term and as a disease of an acute and palliative nature (Phillips & Currow, 2010). With the progress in medical approaches and anti-cancer treatments, and with our furthered oncological understanding of the diseases that compose cancer, many cancers are now addressed as chronic diseases (Phillips & Currow, 2010). Consideration of cancer as many different diseases takes into account the heterogeneity in quality of life and ongoing symptom issues presenting among survivors. Further, the impact of CRF on an individual is also linked to other sequalae; for example, a soft tissue or osteosarcoma in a lower extremity treated with surgery may cause symptoms of physical weakness or fatigue in the affected leg, which may elicit similar activity-reducing outcomes to those resulting from generalized CRF, although they do not stem from the same source. An agreed definition of terms to better delineate these distinctions in disease and symptom will inform the way in which rehabilitation and work-related outcomes are approached; therefore, consistent usage of shared terminology is crucial in cancer care.

Cancer-Related Fatigue (CRF). The widely accepted definition of CRF is as a level of exhaustion disproportionate to activity output (Bower, 2014; American Psychiatric Association [APA], 2013). CRF is known to produce negative neurological and physical consequences, impacting emotional, physical, functional, social, and existential domains of life (Bower, 2014; American Psychiatric Association [APA], 2013). Common negative impacts of CRF include generalized physical weakness, depression, sudden mood changes, diminished concentration and memory, and decreased engagement in otherwise routine or typical activities (Bower, 2014). CRF differs from other presentations of chronic and acute fatigue and mental-health issues in

that it does not respond consistently to rest or pharmacological interventions (Bower et al., 2014; APA, 2013). CRF symptoms are not ameliorated by resting and/or reducing activities alone (Berger et al., 2015). In fact, sometimes, too little activity and too much rest can lead to enhanced CRF symptoms (Jones et al., 2016). Moreover, the effects of CRF can last for months or years post-treatment (Minton et al., 2013). Concerns with the current accepted definition of CRF include the fact that it neither considers the systemic changes that occur following a cancer diagnosis and treatment, nor provides a concrete timeframe for diagnosis (Dolgoy, Krishnasamy & McNeely, 2019). These considerations impact the types of research and interventions conducted, and the types of work-related interventions offered (particularly with current comparisons to CRF as generalized tiredness of fatigue) (Pearson, Morris, Di Stefano, & McKinstry, 2018; Jones et al., 2016). As well, these issues pose a challenge to the actual diagnosing and provision of funding for cancer survivors experiencing barriers to function, and specifically, to workability second to CRF symptoms (Berger et al., 2015).

Cancer Survivor/Survivor. Broadly defined, a survivor is an individual who continues to function during and after overcoming an adversity (Rodriguez & Lewis-Patterson, 2018). A cancer survivor (sometimes also referred to in the context of this dissertation as "survivor") refers to an individual from the time of a cancer diagnosis until end of life (Rodriguez & Lewis-Patterson, 2018). This term is considered controversial as it provides an ongoing, lifelong label (and in some cases, attaches stigma,) to a person who has had cancer (Berry, Davis, Godfrey Flynn, Landercasper & Deming, 2019); however, to date, no agreed upon alternative term has been endorsed.

Cognition. Mental action, understanding through thought, thinking processes, and acquisition of knowledge all fall under the term cognition (Radomski & Latham, 2008). Multiple

studies point to the negative effects of cancer and cancer treatments on cognition (Feng et al., 2019), sometimes referred to as "brain fog" second to chemotherapy treatments, or cancer-related cognitive impairment (CRCI) (Hardy, Krull, Wefel & Janelsins, 2018). Furthermore, cognition may be negatively impacted by co-existing stress and depression, and disease/ treatment-related inflammatory processes (Bower, 2014).

Energy Cultivation and Energy Depletion. These terms were developed through this dissertation research, and reflect a novel approach to CRF management. Energy cultivation focuses on managing the resource available while increasing energy available; essentially, likening growing or developing energy as a natural resource. Energy cultivation facilitates engagement in activities that nourish and progress this resource. Conversely, the concept of energy depletion consists of activities and engagements that reduce a cancer survivor's energy resources, such as stress and/or cancer treatments. For the cancer survivor, energy depleting activities may lead to increased CRF symptom manifestation and/or decreased activity engagement.

Function/functional. In this dissertation, function refers to the ability to perform the activities necessary to an individual's occupations, in alignment with the occupational therapy definition of this term (Randomski and Latham, 2008). Functional activities refer to the practical engagement in occupations and/or tasks. Functional interventions refer to rehabilitative strategies that focus on activity engagement and real-world or practical applicability.

Occupation/occupational. Outside of a rehabilitative and/or healthcare context, the word occupation is often used to refer to work or vocation. In this dissertation, in alignment with healthcare rehabilitation, occupation is primarily used in the context of engagement in activity. According to the occupational therapy-accepted definition, occupation is defined as "groups of

activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture" (Townsend and Polatajko, 2007).

Physical exercise / Exercise. Any planned, structured and repetitive activity that aims to maintain or enhance physicality, physical fitness, and/or overall wellness can be considered physical exercise (Caspersen, Powell & Christenson, 1985). Physical exercise is typically performed for physiological outcomes, although there are known positive correlations amongst physical exercise and emotional responsiveness, fatigue outcomes, and cognitive processing (Tomlinson, Diorio, Beyene & Sung, 2014; McNeely & Dolgoy, 2018). Physical exercise may include aerobic, muscle strengthening and endurance, balance and stretching components (McNeely & Dolgoy, 2018).

Return to Work/Return-to-Work (RTW). The programming for RTW may take various forms, including work-hardening or work-conditioning, which engage a potential worker in activities in a manner that increases endurance and tolerance for specific work tasks (Radomski & Latham, 2008). The overarching goal of work-conditioning is to ensure that an employee is able to return to his/her active vocation. In Canada, RTW stakeholders are often separate from rehabilitative health professionals, meaning that, in most cases, RTW and interventions for workability in cancer care are considered outside the realm of the medical system (Nitkin, Parkinson & Schultz, 2011). There is limited reflection in cancer research literature of the high rates of challenge with RTW for cancer survivors and the high levels of failed attempts at managing past vocations after a cancer diagnosis and treatment (Nitkin, Parkinson & Schultz, 2011). RTW terminology is complex and used in differing forms representing the rehabilitation (programming) and/or the process of progression to vocation. As such, in the context of this dissertation, the process of progression towards workability is referred

to as return-to-work (RTW).

Work self-efficacy. Self-efficacy refers to one's belief in one's ability to participate successfully in specific activities and/or accomplish specific tasks successfully (Bültmann & Brouwer, 2013). Work self-efficacy refers to one's belief in one's ability to participate successfully in work-related activities and/or manage a work role successfully (Wolvers, Leensen, Groeneveld, Frings-Dresen & De Boer, 2018). Research has shown that self-efficacy can be a major predictor of successful task engagement and that positive change in work-related self-efficacy can have parallel positive impacts on participation (Bültmann & Brouwer, 2013). In this dissertation, work self-efficacy was explored in connection with participant-reported task participation and satisfaction.

Workability/ Work ability / Work-ability. In this dissertation, workability and/or work-related outcomes, are used in connection with employment and/or paid occupations. The term workability is strengths-based and replaced disability language beginning in the 1970's (Jundt & King, 1999). In cancer survivor populations, however, workability is sometimes measured based on physical ability alone, or based on chronic fatigue symptoms rather than CRF symptoms, leading to unsuccessful work-related outcomes (Mehnert, 2011). The term is seen in healthcare and work-related literature in reference to two aspects of vocational engagement: first, possessing the specific training and/or skills required for a task; and second, having the health, basic standard competence and relevant occupational virtues to manage a work role, within the context of reasonable work tasks and an appropriate work environment (Tengland, 2011). For the purposes of this dissertation, the latter definition is specified by using the term as one word: workability. Thus, the term workability is used in this dissertation to refer to the ability of a cancer survivor to do work and/or participate in a vocation in a given context (rather than in

terms of having the training to carry out a particular job).

1.4. Statement of the Problem

CRF negatively impacts 50-90% of the cancer population (Campos, Hassan, Riechelmann, & Del Giglio, 2011). The symptoms of CRF, which include ongoing fluctuating fatigue disproportionate to energy output, have major negative impacts on workability (National Comprehensive Cancer Network [NCCN], 2018). A known fact is that working-aged (18-64 years) cancer survivors have more difficulty managing work-roles as compared to working-aged healthy cohorts (deBoer, Taskila, Ojajärvi, van Dijk, & Verbeek, 2009). While CRF is not the only issue impacting a cancer survivor's ability to work, it is recognized as a major barrier to activity engagement and considered an unmet rehabilitative need of cancer survivors (Gehrke & Feuerstein, 2017). Challenges in addressing CRF and its impact on workability include the following considerations: (1) a generic definition and a lack of cohesive terminology (Bower et al., 2014; Berger et al., 2015); (2) a focus on physical fatigue exclusively over other associated impacts such as on cognition (Berger et al., 2015); and (3) insular healthcare and work-specific site practices and/or a scarcity of CRF work-related rehabilitative programming opportunities (Nitkin, Parkinson & Schultz, 2011). Clinical practice examples and published rehabilitative research focusing on the functional, work-related impacts of CRF are currently limited.

Rehabilitation programming has the potential to improve CRF management for work-related outcomes. Healthcare professionals who work in cancer care, and occupational therapists in particular, are well positioned to introduce strategies and interventions to target CRF symptoms that impact work-related outcomes.

1.5. Scope of the Issue

The negative impacts of CRF symptoms on workability and the challenges of developing

relevant rehabilitative programming present two clear and time-sensitive research questions:

1. How should CRF be defined/approached?
2. How can CRF be best addressed with respect to function and work-related outcomes?

These issues are interrelated, since the way in which CRF and its relationship to workability are framed impact the way in which CRF is defined and addressed, and vice versa.

The accepted definition of CRF does not consider duration of fatigue, systemic issues of a cancer diagnosis, functional issues, or environmental contexts. The current definition addresses only the most tangible of symptoms and the most obvious causal physiological outcomes. Defining a systemic, chronic, flaring condition in this way—by using a medical model, meaning a cause-and-effect approach—is problematic, particularly when researching or treating through a rehabilitative lens. From an occupational therapy perspective, consideration of a person should be in context. A contextual understanding should, at the very least, consider the needs of the person and the meaningful activities in which he/she/they engage and/or wish to engage.

The research in this dissertation first focuses on the condition of CRF and the current rehabilitative approach to managing this condition. This dissertation then focuses on the individual in context, to frame the cancer survivor managing CRF within the workforce of Canadian society (the PEO model and the SE model). Framing CRF and its individual implications through the perspective of a cancer survivor seeking services, rather than through the lens of the medical system, requires a shift in focus from medical outcomes to functional outcomes. In changing the frame of reference for CRF, the individual factors that impact identity, quality of life, and engagement must also be considered as part of standard practice in addressing and treating the symptoms of the condition. A broader societal focus must consider the economic outcomes of unemployment and symptom management, as well as the impact of

limited acute rehabilitative services for CRF on long-term work-related outcomes. The data for these considerations have not yet been established, as only limited research has been conducted on CRF and work-related outcomes. Moreover, the models in place to guide these processes do not specifically consider functional interventions (nor occupational therapy) as an independent component of equal importance to physical interventions (Rijpkema, Van Hartingsveldt, & Stuiver, 2018).

Consideration of CRF and workability from the perspectives of both individual and societal impacts makes apparent the gravity of the issue: a more effective means of managing CRF symptoms must be established to avoid the growing rates of unemployment in working-age cancer survivors. In the United States, research reports that approximately 50% of survivor RTW attempts are unsuccessful (Mehnert, 2011). Working-aged survivors in North America are found to be 1.4 times more likely to be unemployed when compared to a working-aged non-cancer individuals (33.8% compared to 15.2%), with CRF cited as a major barrier to working (deBoer et al., 2009).

In the studies examining RTW in cancer, there has been a lack of both occupational therapy involvement and assessment of the specific functional needs of survivors (de Boer, Taskila, Tamminga, Feuerstein, Frings-Dresen & Verbeek, 2015). A 2018 systematic review of functional and work-related outcomes in breast cancer survivors supported the need for involvement of occupational therapists in RTW interventions in the cancer survivorship time period (Bijker et al., 2018). Current research studies on RTW programs for survivors appear to focus largely on a combination of education and exercise interventions (Bilodeau, Tremblay, & Durand, 2017). While effective for addressing some symptoms related to CRF, education and exercise-based interventions alone lack incorporation of functional or work-

hardening targets (Wells et al., 2013; Tamminga, De Boer, Verbeek & Frings-Dresen, 2010). With improved cancer outcomes there has been progressive interest in rehabilitation services to help survivors restore function and quality of life (Stubblefield, Hubbard, Cheville, Koch, Schmitz, & Dalton, 2013). Equally, there is a growing need for research to optimize work-specific outcomes of cancer survivors impacted by CRF.

1.6. Summary and Relevance

The research presented in this dissertation explores CRF in the context of work-related outcomes. The findings provide insight into potential strategies for more comprehensive rehabilitative programming to bridge the gap between physical exercise and functional workability interventions. More comprehensive interdisciplinary rehabilitative programming supports wellness promotion and productive activity engagement for survivors with CRF. There is a clear need for more research exploring work-related initiatives and outcomes. Occupational therapists, given their expertise in function, are well situated to effectively target the functional implications of CRF and advance the cancer-specific return-to-work research field.

1.7. Aim

Pillar I: The aim of the first aspect of the dissertation was to address the terminology used in discussing, assessing, and treating CRF, and to provide usable directives to healthcare professionals working with patients with CRF (including clinical materials and/or a more usable therapeutic conceptualization and lexicon of the condition of CRF).

Pillar II: The aims of the second aspect of the dissertation were to (1) enhance understanding of the survivor perspective and experience, at the level of the individual, with respect to both CRF and workability, and (2) to examine the feasibility of cancer-specific programming for work-related issues that combine physical exercise and functional work-related activities.

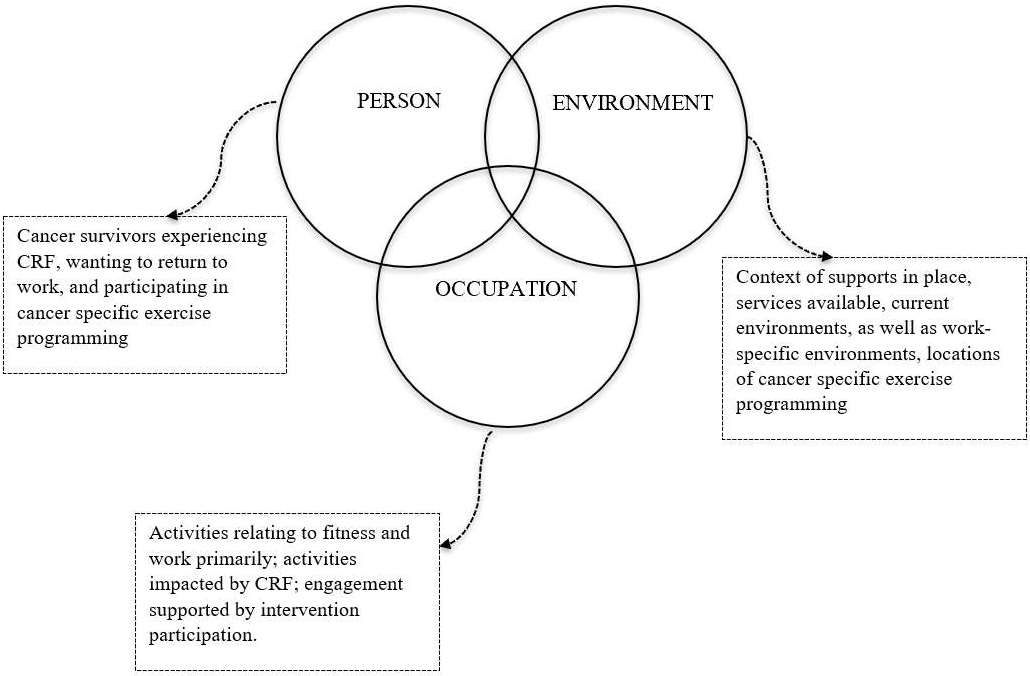
1.8. Study Goals

JARS study. The goals of the study were to (1) explore how people affected by cancer spontaneously describe the nature and impact of CRF, and (2) consider opportunity for novel targets for intervention.

TARGETing CRF. The goals of this study were to (1) explore the descriptors used by HNC survivors in expressing their experiences with CRF and in detailing the associated impacts of CRF, and (2) inform HNC-specific patient-centred therapeutic-communication about CRF.

ACE@Work1 - Interview study. The goals of this interview-based study were to (1) explore the physical exercise and work-related experiences of cancer survivors with CRF, and (2) inform potential novel work-related rehabilitative interventions.

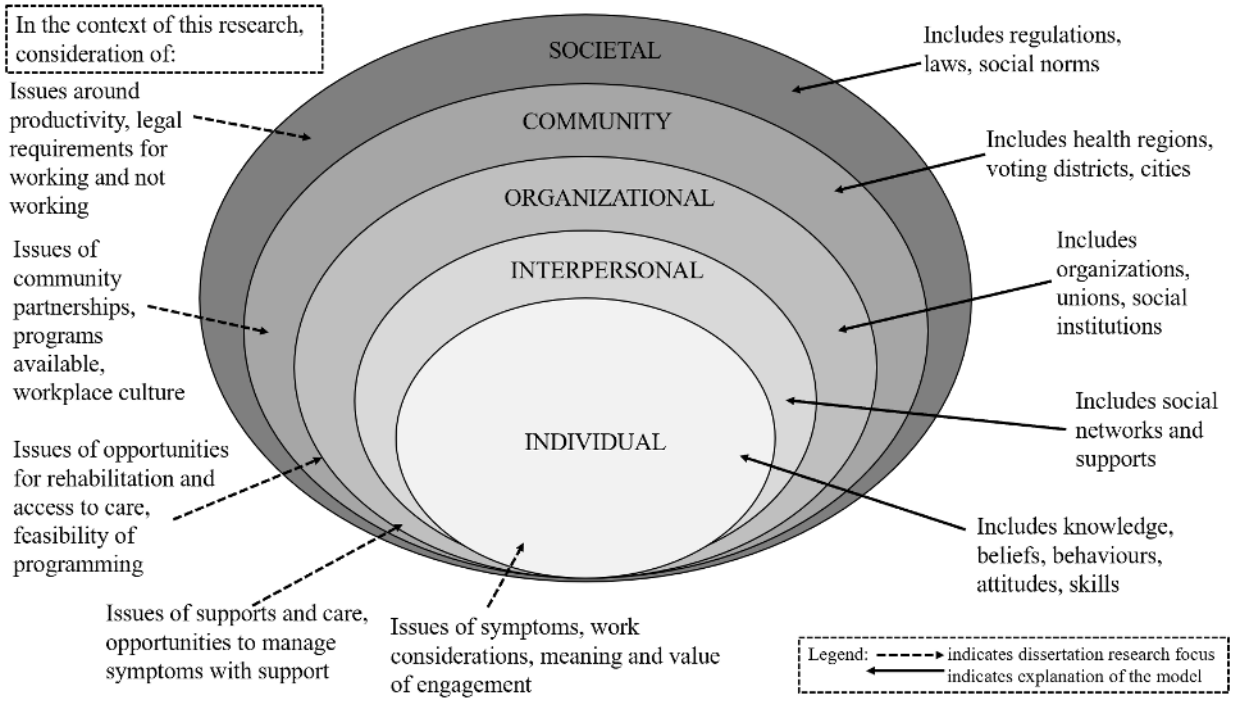
ACE@Work2 – Proof-of-concept study. The goals of this study were to explore the feasibility of improving participant-reported work self-efficacy (participation and satisfaction) outcomes through the implementation of tailored work-related functional activities in a physical exercise program for cancer survivors transitioning to their previous vocations after being off work due to cancer treatment. It was hypothesized that this additional rehabilitative component would be feasible in terms of participant demands, occupational therapy time commitments, and improvement of participant-reported outcomes, without adversely effecting participation in the general physical exercise program.



The original model is reflected in the three related circles, which depict an interplay of person, environment, and occupation. The specific relevance of the model to the projects in this dissertation is reflected through the dashed arrows and boxes, showing how the model was used in the ACE@Work interview study.

(Baptiste, 2017; Strong, Rigby, Stewart, Law, Letts, & Cooper, 1999)

Figure 1-1. The Person Environment Occupation Model



(Golden & Earp, 2012)

Figure 1-2. The Social Ecological Model

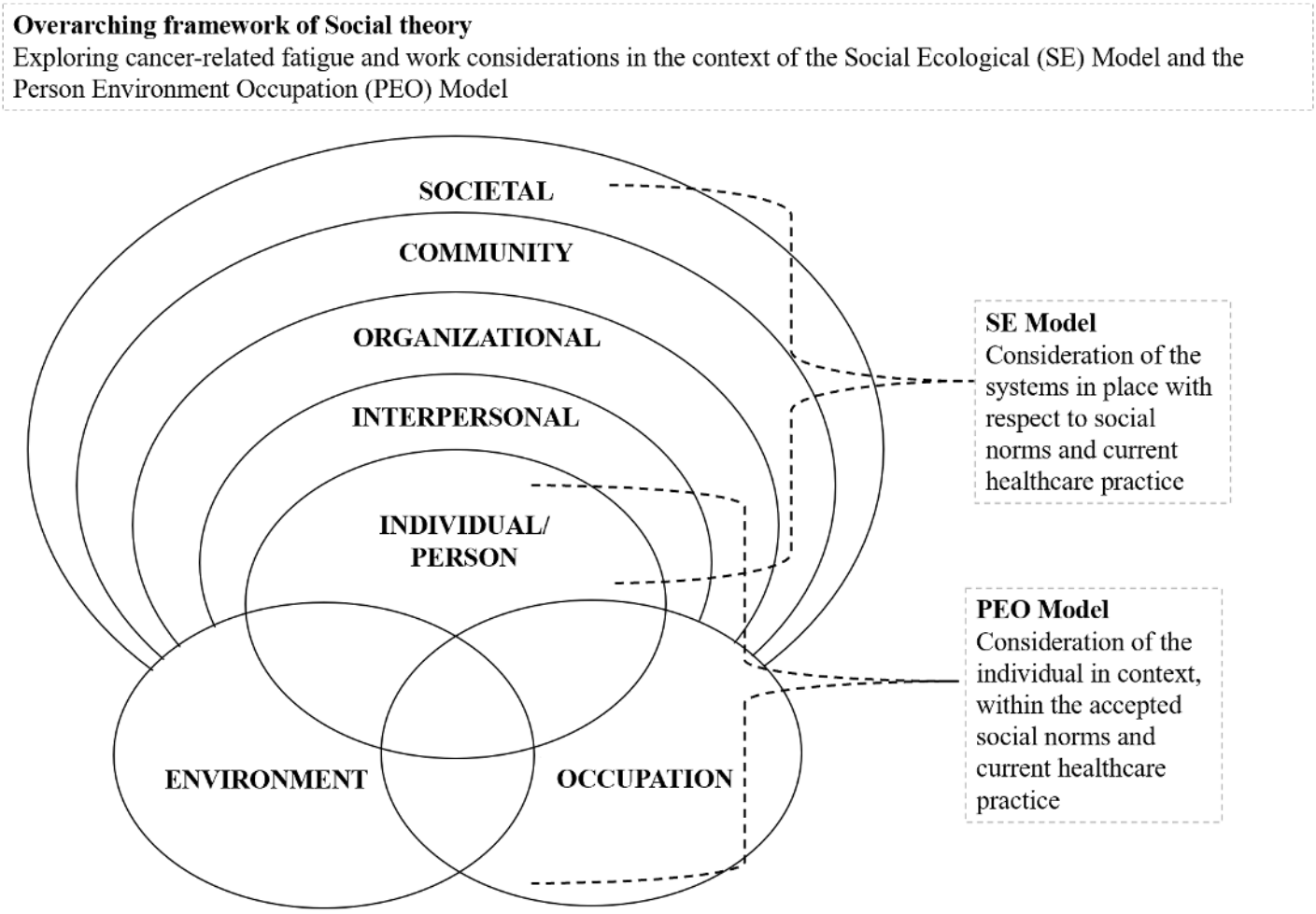


Figure 1-3. Study Conceptual Framework Based on the Person Environment Occupation Model Embedded in the Social Ecological Model, and Explored through Social Theory

Chapter 2

Targets of Uncertainty and Sense-of-Self in Cancer-Related Fatigue

"The JARS study"

Dolgoy, ND., Krishnasamy, M., & McNeely, M L. (2019). Uncertainty and sense-of-self as targets for intervention for cancer-related fatigue. European journal of cancer care, e13048.

2.1. Abstract

Background. Cancer related fatigue (CRF) can be a devastating consequence of cancer and cancer treatments, negatively impacting 50-90% of cancer patients regardless of age, sex, or diagnosis. Limited evidence and research exist to inform effective patient-centred interventions. To target symptom management, there must first be a broader understanding of the symptoms and the lived experience of the persons experiencing CRF and those caring for them, from a supportive as well as a healthcare perspective. **Objective**. This study set out to consider whether components of the language used or descriptors reported by patients, family members, or healthcare professionals, may provide new insights for potential targets for intervention development. **Methods.** Descriptors from 84 responses (n=84) from cancer survivors, family members, and healthcare professionals, were analysed for content. **Findings.** The descriptors reiterate the physical, emotional and functional consequences of CRF, but also reflect two new potential targets for intervention to mitigate the impacts of CRF: uncertainty and sense-of-self.

Keywords: cancer, fatigue, survivorship, quality of life, rehabilitation

Chapter 2

Targets of Uncertainty and Sense-of-Self in Cancer-Related Fatigue

2.2. Introduction

2.2.1. Background/Rationale

Cancer related fatigue (CRF) can be a devastating consequence of cancer and cancer treatments, negatively impacting 50-90% of cancer patients regardless of age, sex, or diagnosis (Campos, Hassan, Riechelmann, & Del Giglio, 2011). CRF is defined as a subjective sense of tiredness that interferes with emotional, physical, functional, social, and existential domains of life (National Comprehensive Cancer Network [NCCN], 2018). Despite almost two decades of investment in the development of standardized screening tools, assessment measures, and almost 500 published manuscripts on pharmacological and non-pharmacological interventions to minimize or ameliorate its impact on multidimensional domains of quality of life, robust evidence to inform effective patient-centred interventions for CRF remains limited (Pearson, Morris, di Stefano, & McKinstry, 2016; Bower et al., 2014; Howell et al., 2013). Where evidence does exist, such as exercise or psycho-educational approaches, its translation to usual care has been sparse (Weis & Horneber, 2015; Berger et al., 2011).

Qualitative literature explores lived experiences. For cancer survivors managing CRF, qualitative research offers a lens through which to better understand the functional barriers, and the impact of CRF on participation in daily living. Individuals experiencing CRF often describe activities that were once manageable as being too difficult to complete. A systematic review of 154 qualitative research articles on CRF described dynamic differences between symptoms of tiredness versus fatigue, wherein participants reported their CRF symptoms were not eased by

rest, and bore a heavy burden on their everyday lives (Scott, Lasch, Barsevick & Piault-Louis, 2011).

Many of the uni- and multi-dimensional screening tools and assessment measures recommended for use in research and clinical settings, have been informed by qualitative studies where peoples' descriptions of living with CRF have influenced the choice of items and domains included (NCCN, 2018; Howell et al., 2013). Ways in which people describe experiencing or witnessing the impact of CRF such as, lack of energy, inability to concentrate, excessive sleepiness, or exacerbation of pain, nausea or depression in the presence of CRF, have influenced development of interventions, such as exercise, psycho-educational approaches, mindfulness, sleep, yoga, diet and symptom management (Minton et al., 2013; Barsevick, Newhall, & Brown, 2008).

Given the recognized impact of CRF on the emotional health and wellbeing of people affected by cancer, this study set out to consider whether components of the language used or descriptors reported by patients, family members, or healthcare professionals, may provide new insights for potential targets for intervention development. To target symptom management, there must first be a broader understanding of the symptoms and the lived experience of the persons experiencing CRF and those caring for them, from a supportive as well as a healthcare perspective.

As such, this "real world" study was undertaken to collect spontaneous descriptors of CRF which may offer new insight or perspective with which to develop patient-centred, multidisciplinary CRF rehabilitative interventions.

2.2.2. Aim/Objective

This study set out to explore how people affected by cancer (patients, family friends and health care professionals) spontaneously describe the nature and impact of CRF, in order to consider opportunity for novel targets for intervention.

2.2.3. Context

This study was undertaken across two cancer centres, a cancer rehabilitation clinic, and a community support group environment in Melbourne, Australia during February-April 2017. People participated from ambulatory clinics, wellbeing centres, staff rooms, and at educational and information sessions across the cancer centres, the clinic, and the community support group setting.

2.3. Methods

This study used an exploratory, descriptive methodology drawing on social theory. Social theory is an action-oriented methodology, rooted in the examination of relationships and societal structures in context (Rozend, Santos Salas, & Cameron, 2017). Utilizing social theory in healthcare research provides a basis for exploring conventional assumptions about practice, systems of care and relationships between people, problems and interventions directed to them, offering opportunity for change or innovation (Wilson-Thomas, 1995). The purpose of this study was to collect spontaneous, unprompted descriptors of CRF by patients, family/friends, and healthcare professionals in order to consider and explore opportunity for novel targets for intervention. As such, a social theory approach with its focus on understanding phenomena in context, from a spontaneous, real-life perspective was considered an appropriate methodological framework for the project.

A content analysis approach was employed to guide data analysis. As a research method which systematically and objectively details and describes experiences, content analysis offers a means of exploring both qualitative and quantitative phenomena (Vaismoradi, Jones, Turunen, & Snelgrove, 2016). Exploring the descriptors in terms of commonalities, and drawing on recurring participant perspectives, allows for the development of themes derived directly from the words, phrases, and experiences described in the data. Content analysis offers opportunity to quantify and qualify the data generated into descriptors and themes, thereby making this information easily understandable and relevant to a broader audience, both from clinical and research scopes.

2.3.1. Sample and Recruitment

Three distinct groups of people were targeted for the study: 1) cancer patients/survivors currently undergoing or post-treatment; 2) family members or friends (including people in the patient/survivor's support network), and 3) oncology healthcare professionals, present in any of the project data collection environments.

As the study was set up to collect spontaneous descriptors of CRF, a decision was made not to establish a formal consent process whereby people would be asked to take part in a research study, as this would direct their thinking about CRF in a focused or "constructed" way. As such, no attempt was made to collect any disease or demographic data about any contributor. There was no attempt to request any information that might identify contributors; rather, individuals were simply invited to record, on a piece of paper provided, the first words that came to mind when asked to describe CRF ("The words used to describe any tiredness or fatigue you experience(d) or observe(d) because of cancer or its treatment").

With the permission of cancer centre and rehabilitation clinic managers and the support group lead, a glass jar, pens, papers, an invitation to take part and instructions for participation in

the CRF study were set out in a prominent place in each data collection environment. People interested in taking part were asked to write the first word or words that came to mind on the pieces of paper provided, when they thought of CRF. They were asked to return the piece of paper with their words/descriptors into the glass jar. Participants were asked to identify only whether they were a patient/survivor, family member/friend, or a healthcare professional, on the piece of paper with their words All data were gathered voluntarily. No member of the study team approached any contributor, and data collection relied solely on individuals' interest in contributing to, or motivation to provide, descriptors of CRF.

This "real world" study was deemed to be research of negligible risk, using non-identifiable data, and was exempt from a need for further ethical review.

2.3.2. Analysis

A content analysis approach was used, and a combination of quantitative (how many times the same word or words appeared), and qualitative approaches (how people described causes or consequences of CRF), were used to analyse the data provided.

The data were initially analysed independently (ND) and then in collaboration by two reviewers (ND, MK), both experienced cancer clinicians and familiar with CRF, and content analysis. Data were categorized into descriptors and emergent themes. Themes were generated through a process of analysis whereby similar words or phrases were allocated to broad groups of responses, such as physical or functional, until all data had been allocated.

Words used to describe CRF were counted more than once per respondent if the words of phrases were used to indicate different consequences. For example, if a patient wrote, "It's exhausting, it stops me from being able to work" and "It's exhausting, it makes me feel like a

different person" the term exhausting would be counted twice, linked to different consequences (described below).

2.4. Results

2.4.1. Respondents

Eighty-seven people provided descriptors from across each of the data collection environments (Table 1). A total of 84 responses were considered during data analysis. The three other responses were excluded because the content did not address CRF, rather these responses discussed either the overworking of nursing staff due to the time demands of nursing shifts (2), or pain and disease issues surrounding cancer progression from the perspective of a family member (1). The majority of respondents were patients/survivors (46/55%), followed by healthcare professionals (28/33%), and family/friends (10/12%).

2.4.2. Words and Descriptors

The words and descriptors provided by all respondents were analysed for common terms. The most frequently reported words are reported in Table 2. The words "tiredness" and "energy" were the most commonly reported across all respondent groups followed by "frustration" and 'lethargy". When considered in the context of descriptors (described more fully below), participants referred to a never-ending tiredness, "waking up tired" and being "bone tired", despite resting or sleeping. These words and the text within which they were reported by some individuals (that is, the descriptors), indicated that for some people, CRF had a profound impact on sense-of-self. This is considered more fully below. Descriptors that included reference to frustration, largely related to functional capacity, having to rely on others, and uncertainty about the ongoing and fluctuating nature of CRF.

2.4.3. Themes

Data analysis resulted in the generation of six key themes, common across patient/survivor, family/friends, and healthcare professional groups (Table 3). Four of the six themes referred to the consequences of CRF: 1) emotional consequence; 2) physical consequence; 3) cognitive consequence, and 4) functional consequence; and two themes related to the losses associated with those consequences: 1) impact on sense-of-self; 2) uncertainty. Table 3 depicts emergent themes and descriptors.

The theme "sense-of-self" was generated from descriptors that conveyed impact of CRF on identity and included references to a change or shift to a person's sense of who they are, and what they are capable of doing (Oyserman, 2015). Research on sense-of-self suggests that identity is a fluid construct, shifting based on situational requirements; essentially, individuals prefer consistency between their perception of identity, ability and meaningfulness within the environment around them. When functional or emotional difficulty or distress are experienced an individual may change their sense-of-self or reduce their perceptions of self-worth, and in doing so, may grieve their former sense-of-self and may withdraw from previously important activities, believing they cannot or should not participate anymore (Pilarska, 2015). In Table 4, the number of times descriptors were reported by respondents across each of the six themes is described.

Descriptors by respondent group.

When considered quantitatively, a greater proportion of health care professionals provided emotional (54%) and physical consequence descriptors (71%) than did patients/survivors (35% and 43% respectively) or family and friends (20% and 20% respectively). In both the healthcare professional and patient/survivor groups, physical consequence descriptors were the most commonly provided. In the patient/survivor group, functional and emotional consequence

descriptors and descriptors of CRF related uncertainty, were similar in proportion (30%, 35%, and 30% respectively). Family and friends most often provided descriptors relating to functional consequences and uncertainty (30% and 40% respectively). Interestingly, despite published evidence of its impact on cognitive capacity, there were few descriptors from any of the groups that referred to cognition and CRF (Hampson, Zick, Khabir, Wright & Harris, 2015). Reasons for these responses are considered below.

Themes of uncertainty and sense-of-self.

The two themes associated with loss (uncertainty, and sense-of-self) are important, new insights generated by this study. Patient/survivor (30%) and friends and family (40%) groups described more concerns with the uncertainty caused by CRF, compared to healthcare professionals (11%). The content of these responses from patients/survivors and family and friends described the challenge of managing the uncertainty of CRF, specifically its onset and duration, as well as its impact on planning and managing daily routines or productive (primarily work related) activities. The uncertainty descriptors relate to questions about the future, unknown challenges of dealing with symptoms, uncertainty experienced by friends and family with regard to planning for the future. In Table 5, examples of uncertainty descriptors are provided.

There was a similarity of language across the three respondent groups with regard to the impact of CRF on sense-of-self. Although there were only a few descriptors about sense-of-self, individual responses from the patient group reflected powerful experiences regarding the burden of living with CRF. The following descriptors from six different participant responses relate to sense-of-self: “Relying on other people”; “Independence loss”; “All pervading; takes over”; “Draining life out of me”; “Takes everything out of you”; “Lifeless.”

The descriptors and themes generated in this study, are closely aligned with the language and domains included in best-practice uni- and multidimensional CRF measures– that is, emotional, physical, cognitive, and daily functioning domains (Howell et al., 2013; Bower et al., 2014). There was considerable similarity between words and phrases used by patients, family/friends, and healthcare professionals to describe their experience of CRF. When the words and phrases generated by respondents were de-identified for group allocation, it was not possible to distinguish between them, suggesting a commonality of experience whether lived or observed.

2.5. Discussion

Consistent with previous research regarding CRF all three groups of respondents in this "real world" study reported descriptors of emotional, physical, and functional components to their fatigue experiences. Importantly, the study also provided insight into aspects of CRF- not routinely captured in CRF screening or assessment: uncertainty and sense-of-self.

Emotional considerations. Across all three groups the descriptors used by participants to describe CRF reflected its potential for profound emotional impact. These findings support data presented in other studies where the negative impact of fatigue on emotional wellbeing has repeatedly been demonstrated (Minton et al., 2013). In discussing emotional considerations regarding CRF with patients, research suggests that early education and awareness is more beneficial to patients/survivors and their support networks (Corbett, Groarke, Walsh, & McGuire, 2016). Our data suggest that attending to the emotional impact of fatigue may offer a key target for therapeutic intervention, and that aspects of these interventions should address the uncertainty and lack of sense of self engendered by CRF.

Physical considerations. Symptoms of CRF are known to impact physical performance, activity tolerance, and endurance (McNeely, Dolgoy, Onazi, & Suderman, 2016). Limitations in physical function featured prominently across descriptors of all groups in this study, reflective of the considerable body of evidence that described the impact of CRF on peoples' lives (Bower et al., 2014). Findings from our study indicate that interventions to minimise or obviate CRF, notably the growing body of evidence for exercise as medicine in cancer, continue to be an important target for therapeutic benefit (McNeely et al., 2016).

Functional considerations. Many patients/survivors in this study described their experiences of CRF in terms of loss of function; this is a commonly reported finding from studies of CRF, suggesting that interventions specifically targeting functional capability require ongoing attention (Scott et al., 2011). However in the context of our data, the link between function, uncertainty and loss-of-self may offer a new lens on an established problem. In addressing the functional impacts of CRF, attention to the "downstream" effects on certainty and sense-of-self may offer novel approaches to enhancing patient perception or experience of functional impairment.

Cognitive considerations. Despite considerable evidence linking cognitive impairment and CRF, few responses or descriptors from any of the groups in this study referred to cognitive concerns (Hampson et al., 2015). It may be that people did not necessarily associate cognitive issues with CRF or that our convenience sample had few issues with cognitive impairment.

Uncertainty. Uncertainty relating to onset, duration, impact, and management of CRF was evident in the words and descriptors of patients/survivors and family/friends. Frustration regarding and its impact on being able to plan from one day to the next characterised the responses. The impact of the unpredictability of CRF is not currently captured in CRF screening

or assessment tools. Focusing on uncertainty as a novel target for CRF to minimize its emotional impact requires further exploration.

Sense-of-self. Respondents from each of the study groups described how CRF impacted sense-of-self. Descriptors provided presented a construct that has potential to overwhelm an individual's sense of self, to take the person who is fatigued and make them a fatigued person (Krishnasamy, 2000). In healthcare, the current focus of CRF management relies heavily on its physical and tangible symptom manifestations (Minton et al., 2013). However sense-of-self, a salient aspect of psychosocial wellbeing, is challenging to describe, understand and manage (NCCN, 2018). Attention to altered sense-of-self may offer a new target for CRF screening assessments and interventions.

2.5.1. Recommendations For Future Research and Practice

Integrating a focus on uncertainty and sense-of-self into the care and support of people affected by CRF will require healthcare professionals to develop skills to elicit and respond to uncertainty and altered sense-of-self (Howell, Hack, Green, & Fitch, 2014). Our findings offer novel, patient and family informed insight to address CRF, that has largely remained intractable to most interventions.

2.5.2. Limitations

This project is limited by small number of respondents ($n<100$), and the descriptive, convenience sample. This project did not collect identifying information from respondents, and therefore cannot analyse impacts of CRF based on cancer-diagnosis, treatments, or disease-related outcomes.

2.6. Conclusion

Data from this study have reiterated the physical, emotional and functional consequences of CRF. Importantly it has proposed two new potential targets for intervention to mitigate the impacts of CRF: uncertainty and sense-of-self. Further research is required to explore and better understand the potential of targeting uncertainty and sense-of-self as opportunities to reduce the multifaceted impacts of CRF.

Table 2-1. Respondents

Group (total respondents, n=84)	Number of descriptors provided by responder group	Location of data collection environment
Patients/survivors (n=46)	78	outpatient clinic (11); rehabilitation clinic (6); community-based support group (28); wellness centre (25)
Family/friends (n=10)	14	outpatient clinic (1); community-based wellness centre (13)
Health professionals (n=28)	52	outpatient clinic (5); healthcare meeting or break room (46); wellness centre (1)
Total number of descriptors across all responders (n=84)	144	

Table 2-2. Frequently Occurring Words by Respondent Group

Words/phrases	Respondent Groups			
	Patient/survivor (n=46)	Family member/friend (n=10)	Healthcare professional (n=28)	Total Respondents (n=84/100%)†
Frustrat[ion/ed]	4 (9%)		4 (14%)	8
Tired[ness]	18 (40%)	3 (30%)	9 (32%)	30
Weak[ness]	1 (2%)	1 (10%)	4 (14%)	5
Letharg[y/ic]	3 (7%)		4 (14%)	7
Motivation	1 (2%)		3 (11%)	4
Energy	7 (15%)	1 (10%)	7 (25%)	15

†The total number of terms exceed the numbers of participants as individual respondents provided multiple terms in their responses.

Table 2-3. Themes and Descriptors

Theme	Respondent group	Example of descriptors
Emotional	Patient/Survivor	“Frustrated by lack of energy.”
	Family/Friend	“We encouraged him to exercise even though it feels impossible to move the body, but as hard [as] it is for patients, it is also hard [on] family members to encourage they don’t feel like doing it.”
	Healthcare professional	“Frustration; desire to engage more than able to.”
Physical	Patient/Survivor	"Hit by a mac truck". So intense, […] greater than any other type of 'tiredness’.”
	Family/Friend	“Drained. Listless.”
	Healthcare professional	“Extreme tiredness where it's difficult to stay awake for any length of time.”
Cognitive	Patient/Survivor	“Sinking sands. Mind boggy.”
	Family/Friend	“Confusion through tiredness.”
	Healthcare professional	“Poor concentration.”
Functional	Patient	“Non-stop tiredness (doesn't go away); tired after sleep; can't do dinner - by afternoon too exhausted; too tired to walk after tea; must do shopping and exercise early in the day.”; “Waking up tired; unable to do jobs.”
	Family/Friend	“Sudden loss of energy”; Dad doesn't like to get dressed in the morning because he thinks he will just sleep before noontime.”
	Healthcare professional	“Inability to complete tasks you want to do; requirement of rest throughout the day”
Sense-of-Self‡	Patient/Survivor	“Takes everything out of you. Completely worn; lifeless.”
	Family/Friend	“Surprize at inability to do things that were in the past "just normal."
	Healthcare professional	“Reduced sense of purpose.”
Uncertainty	Patient/Survivor	“How long does fatigue last? How bad does it get? I feel tired these days, but is it worth asking my nurse about?”
	Family/Friend	“It is very hard to plan out the day, because sometimes the fatigue is bad and sometimes it is better, but there is no routine about this fatigue.”
	Healthcare professional	“I don't know how to explain fatigue save for extreme tiredness”

Table 2-4. Themes, Descriptors and Respondents

Themes	Number of times the descriptors were reported per group, and numbers of respondents per group			
	Patient/survivor (n=46)	Family member/friend (n=10)	Healthcare professional (n=28)	Total n=84 (100%) Descriptors n=144§(100%)
Emotional consequence	16 (35%)	2 (20%)	15 (54%)	33
Physical consequence	20 (43%)	2 (20%)	20 (71%)	42
Cognitive consequence	5 (4%)	1 (10%)	2 (7%)	8
Functional consequence	14 (30%)	3 (30%)	7 (25%)	24
Sense-of-self	9 (20%)	2 (20%)	5 (18%)	16
Uncertainty	14 (30%)	4 (40%)	3 (11%)	21

§Total number of descriptors exceed the numbers of participants as individual respondents provided descriptors across several themes.

Table 2-5. Uncertainty Descriptor Examples

Group	Current Uncertainty Issues	Future Uncertainty Issues	Intervention Uncertainty
Family/friend	"Unsure how to help my husband with his fatigue. It comes and go and it is hard to guess how he will feel."		
Patient/survivor		"Where does it end?"	
Patient/survivor		"What will happen to me?"	
Patient/survivor	"Sometimes it is there, and sometimes it is there more, and sometimes it is there less - so I can't be sure what will happen in a day."		
Family/Friend			"How do I help him? I wish there were more answers."
Healthcare professional			"[It's] not always taken seriously – so how do we help people?"

Chapter 3

Cancer-Related Fatigue in Head and Neck Cancer Survivors: Energy and Functional Impacts

"TARGETing CRF "

Dolgoy N., O'Krafka P., McNeely ML.

3.1. Abstract

Background. Survivors with head and neck cancer (HNC) report cancer-related fatigue (CRF) as a devastating, prevalent health issue that limits activity engagement and adversely influences quality of life. **Objective.** To explore HNC survivors' written responses and descriptors regarding CRF, and offer potential healthcare strategies based on findings. **Methodology.** In written format, similar to responses on intake forms in outpatient-clinics, 25 HNC survivors provided descriptions of their CRF experiences and their perspectives on its impact. An exploratory descriptive research design was utilized, drawing on social theory for content analysis and thematic development. **Results.** Two main themes regarding CRF arose from the data: (1) CRF as a barrier to daily function; and (2) uncontrollable and unpredictable energy fluctuations. **Conclusions.** To enhance outcomes of CRF symptom management in HNC survivors, a healthcare approach that targets the functional implications of CRF, and utilizes energy cultivation strategies when communicating about the negative impacts of CRF (including limited function and fluctuating energy levels) may be beneficial for HNC survivors. Further research into the effects of CRF on function for HNC survivors is warranted.

Key words: *rehabilitation, head and neck cancer, cancer-related fatigue, energy*

Chapter 3

Cancer-Related Fatigue in Head and Neck Cancer Survivors: Energy and Functional Impacts

3.2. Introduction

Head and neck cancer (HNC) accounts for approximately 4% of all cancers in the United States (American Cancer Society, 2020). In 2020, approximately 53,000 people in the United States will be diagnosed with HNC (Siegel, Miller, & Jemal, 2020). Medical advances in cancer treatments have improved survival rates. The term "survivor" refers to all individuals from the point of cancer diagnosis onwards (American Cancer Society, 2020). For HNC survivors, ongoing issues include limitations in speech and communication, impaired oral-maxillary function, and high incidence of cancer-related fatigue (CRF) (Siegel et al., 2020; American Cancer Society, 2020). These impairments make it difficult for HNC survivors to participate in research studies requiring oral communication and verbal response.

Cancer-related fatigue (CRF) is the most common chronic effect of all cancers and their treatments, affecting 45-90% of survivors, regardless of cancer diagnosis or demographics (Dorland et al., 2011; Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). Defined as an ongoing level of exhaustion disproportionate to activity output, CRF is distinct from other forms of chronic and acute fatigue and mental-health issues in that it does not respond consistently to rest or pharmacological interventions (Bower et al., 2014; American Psychiatric Association [APA], 2013). Further, CRF is a highly distressing consequence of cancer and its various treatments that negatively impacts emotional, physical, functional, social, and existential domains of life (APA, 2013). Symptoms associated with CRF often include generalized physical weakness, depression, sudden mood changes, diminished concentration, and

a lack of motivation to engage in otherwise typical activities (Bower, 2014). Despite rest and reduced activities, survivors may experience overwhelming CRF for months to years post-treatment (Minton et al., 2013). While the pathophysiology of CRF is complex, research confirms that the condition manifests both neurologically and physically (Bower, 2014). Additionally, increased risks of depression and anxiety correlate with untreated CRF (Dorland et al., 2011; APA, 2013).

Few interventions are in place that target CRF specifically for HNC survivors (Shiraz, Rahtz, Bhui, Hutchison, & Korszun, 2014; Molassiotis & Rogers, 2012). General interventions that support CRF management have been largely based on evidence related to physical outcomes in the breast cancer population (Mewes, Steuten, Ijzerman & van Harten, 2012; Berger et al., 2015). Thus, these interventions may not target the specific needs of the HNC survivor population. A greater understanding of HNC survivors' perspectives on CRF is needed to help healthcare professionals identify and develop CRF-specific strategies and interventions for HNC survivors.

3.2.1. Aim

The primary aim of this study was to explore the responses and descriptors HNC survivors used in expressing their experiences with CRF. The secondary aim of this study was to inform healthcare-communication about CRF, specific to the HNC survivor.

3.2.2. Context

This study was embedded within a large-scale trial (referred to herein as "the parent study") examining a physical exercise intervention for neck and shoulder dysfunction, fatigue, and quality of life in HNC survivors (McNeely, Debenham, Jha, Chan, & Seikaly, 2016).

Participants enrolled in the parent study were invited to participate, and complete the open-ended questionnaire, in this CRF sub-study.

3.3. Methods

3.3.1. Theoretical Framework

Social theory in healthcare-directed research offers opportunities for exploration of the following conventions: routine practice assumptions; systems of care; and the relationships between people, issues, and treatments (Wilson-Thomas, 1995). In this study, social theory was utilized to examine the perspectives of HNC survivors in relation to their experiences with CRF within the contexts of the socially accepted healthcare practices and assumptions associated with CRF—namely the ongoing level of exhaustion, generalized physical weakness, negative mental health impacts, diminished concentration, and lack of motivation for task engagement (Rozend, Santos Salas, & Cameron, 2017; Morrow & Brown, 1994). Given the study aims, use of social theory was seen as a means to frame the findings of this study within the social context of current healthcare practice.

3.3.2. Research Design

Within a social theory framework, this study utilized an exploratory descriptive research design. In a healthcare context, use of social theory allows for exploratory descriptive research to seek and acquire new insights into less understood health-related phenomena, thereby isolating gaps in current and accepted healthcare practices (Brink, 1998; Meyer & Ward, 2014). Exploration assumes information and knowledge are fluid constructs, such that exploration of healthcare approaches is an ongoing process (Brink, 1998; Meyer & Ward, 2014). Descriptive research offers opportunity to explain and express these findings in context (Meyer & Ward, 2014). As healthcare norms and practice standards progress and change, continued exploration of

HNC survivor needs is warranted. Exploration and description help inform how rehabilitation can best address HNC survivors' CRF-specific impairments. Figure 1 presents a flow diagram of the study schema from conceptualization to completion.

Given that HNC have speech limitations making oral communication stressful and challenging, a questionnaire was designed to collect demographic and background information on each participant and on his/her experiences with CRF. Verbal interviews were not conducted, as doing so would have limited the scope of eligible participants. The questionnaire was available in both paper and electronic formats. The written questions were designed with two goals in mind: first, to gather information from HNC survivors in a manner comfortable and efficient for them; and second, to mirror current outpatient-clinic approaches which routinely employ written screening tools in initial assessments for CRF, thus making the data collection process practical. The questionnaire was pre-tested by four research assistants who had varying knowledge of CRF and then reviewed by three HNC survivors for transparency and readability.

3.3.3. Sample and Recruitment

Adults with a HNC diagnosis were recruited via the parent study. Inclusion criteria consisted of the following: minimum age of 18; stable disease status (no local recurrence or distant metastases); completion of cancer treatment (chemotherapy, radiation, and/or surgery) at the time of participation; approval by and participation in the parent study; ability to read and write English; and ability to provide handwritten or typed responses to questions.

3.3.4. Ethics

Ethics approval was received through the Health Research Ethics Board of Alberta Cancer Committee, in conjunction with the parent study. Written informed consent for the parent

study and amended consent for the CRF study were obtained from the participants prior to distribution of the questionnaire.

3.3.5. Data Collection

While many exploratory studies employ a battery of questions, the approach in this study was to ask a few basic questions and to allow the participants to guide their own responses. The questionnaire in this study consisted of three types of questions: categorical, closed-ended responses (yes/no), and open-ended responses. The categorical questions pertained to background medical information (including baseline fatigue responses) and demographic baselines. The closed-ended responses pertained to experiences with CRF. Finally, the open-ended responses asked participants to explain in their own words: (1) What does cancer-related fatigue mean to you?; and (2) Describe your experience (if any) with cancer-related fatigue. A research assistant not involved in the study administered and collected the questionnaires and compiled the data into a tabled format.

3.3.6. Researchers

The research team included three individuals with backgrounds in oncology and in both occupational therapy (ND, POK) and physiotherapy (MM). None of the researchers had any personal connection to the participants, and all of the researchers were blinded to the participants' identifying information.

3.3.7. Data Analysis

Exploratory data analysis was guided by two approaches, with a focus on social theory in context of current healthcare practice: a content analysis approach, and a thematic analysis approach.

Content analysis.

For content analysis, the scores of closed-ended responses and demographic information, such as the prevalence of CRF symptoms amongst the participants, were recorded with numeric values and percentages. Responses were first quantified by counting repeated words and similar phrases. Descriptors were manually counted by two researchers (ND, POK) and quantified based on the number of times the descriptors appeared in the raw data. Any descriptor appearing more than once was counted, regardless of the number of participants who used that descriptor; consequently, one participant could provide multiple counts for a specific descriptor.

Thematic analysis.

For thematic analysis, the data from the open-ended responses were coded, categorized, and then collated into themes. Data were first coded and then categorized by systematically grouping the commonalities and similar patterns in written perspectives. Analysis continued until all data had been allocated to conceptual categories. All concepts were collated into sub-themes, which were then reduced into two final themes agreed upon by the researchers. The final step involved defining and naming the selected themes.

3.3.8. Positionality

To reduce bias in data analysis, positionality and situatedness of the researchers were explored prior to commencing data analysis. Throughout the data analysis process, these concepts were visited through open communication.

Since all researchers have a background in oncology, which could have led to bias, the medical and demographic data was separated from the rest of the questionnaire data, so that any identifying medical details of a participant would not impact thematic interpretation. To counter for any transference of responses from a specific participant, responses were analyzed through

comparison of all responses to a particular question, rather than through separate review of each participant's entire questionnaire.

3.4. Findings

All participants chose to respond via paper format, rather than via electronic format. All responses were legible. Of the 37 participants in the parent study, 25 participants agreed to participate in the study. Participants (n=25) included males (n=15) and females (n=10), with a mean age of 62 years. All participants were post-cancer treatment by a minimum of one month. Table 1 describes the medical and demographic details of the participants.

3.4.1. Responses

While 100% (25/25) of the participants described experiencing CRF since diagnosis, only 88% (22/25) reported that they believed they had CRF symptoms at the time of the study. Additionally, only 48% (12/25) of participants reported that their medical teams had addressed the issue of CRF and, of that group, 75% (9/12) reported having received education on CRF solely through provision of a printed resource. Table 2 details the responses to closed-ended questions.

3.4.2. Descriptors

The descriptors of "low/lack/loss of energy", "lack of participation", and "unpredictability of symptoms" were most common in the data. These descriptors were often used in relation to avoidance of, or inability to accomplish functional or routine tasks. For example, participants described a lack of enjoyment from previously enjoyable activities, second to low energy for task engagement, and the unpredictable nature of CRF symptoms. See Table 3 for commonly occurring phrases.

3.4.3. Key Themes

Results from thematic analysis provide a more intimate understanding of the particular words and concepts used by participants to describe their experiences with CRF. Two themes that reveal participants' deepest concerns emerge from the data: (1) CRF as a barrier to daily function, and (2) uncontrollable and unpredictable energy fluctuations. The essence of both themes reflect the significant impact of CRF on function and participation as reported by the participants. The unpredictable and erratic nature of symptoms and fluctuating energy levels (within and between days) points to the negative impact of CRF on the daily lives of HNC survivors. Table 4 describes the themes with participant occurrence rates across the responses.

CRF as a barrier to daily function.

Participants consistently described their CRF in the context of functional activities and "routine" or "normal" function. When asked "What does CRF mean to you?" most participants, rather than describe CRF in terms of physiological symptoms, discussed the functional implications of CRF in relation to how their activities were impacted. Participants repeatedly described their fatigue in concrete terms relating to its effect on "daily activities", "daily functions", or "day-to-day tasks". The definition of CRF provided by these participants consistently centered on their ability or inability to participate in or complete tasks related to their perceptions of normalcy. Some participants described CRF in the context of motivation to participate in tasks: "Fatigue means…the loss of desire to get things done." Many participants discussed a loss of interest in activity, or a loss of enjoyment in routine tasks. One participant stated, "Household chores have turned from enjoyable to drudgery." Even when participants discussed comorbid mental health or cognitive impacts of CRF, they often did so in the context

of function. One participant reported, “At times I feel so tired that it is difficult to make even simple decisions regarding everyday life events.”

Uncontrollable and unpredictable energy fluctuations.

In this study, the understanding of CRF as an unpredictable, uncontrollable, energy-altering consequence of cancer and its treatments emerged as the contextual basis for describing how CRF impacts the function of HNC survivors. Participants reported that CRF is unpredictable, manifesting in a way that is disruptive to routine activity. For example, one participant described CRF as the “Coming and going of fatigue that is uncontrollable”. The unpredictable nature of fatigue also reportedly provoked concern, affected cognition, and created distress and frustration for some participants. One participant described the impact of CRF on energy levels as “Random. Unpredictable. Annoying. Can be somewhat depressing. Life altering”.

3.5. Discussion

The themes of this study align with the social theory approach of addressing socially accepted norms in healthcare. While much of the published literature on CRF in the HNC population reports on the physiological underpinnings, the data in this study reveals that participants describe their CRF symptoms in terms of functional impacts and fluctuating energy levels, thus deviating from accepted norms about how CRF manifests for an individual. Current CRF rehabilitation for HNC survivors is challenging, as it utilizes four problematic approaches: (1) a generic definition of CRF, equating CRF with tiredness, and therefore omitting considerations of the individualized perspective of CRF; (2) a medical, symptoms-based rating of CRF, rather than a functional or activity-based rating related to energy levels; (3) exploration of mainly physical symptoms, rather than physical and cognitive symptoms as they relate to

personal, everyday activities; (4) limited exploration of psychosocial and psycho-emotional symptoms that are distinct from mental-health issues. Moreover, the National Comprehensive Cancer Network (NCCN) CRF guidelines state that the management of CRF is best addressed by an interdisciplinary team, which should include "experts in medicine, nursing, social work, physical therapy, and nutrition" (Berger et al., 2015). These current CRF management guidelines do not include occupational therapy or functional interventions as part of standard interdisciplinary teams. Based on our findings, we the authors suggest that the above accepted guidelines and medical practice norms may miss significant personalized symptoms, fluctuations in energy levels, and functional issues affecting HNC survivors.

The findings of our study present a novel perspective from a research lens in comparison to the above listed, widely accepted, medically-derived, rehabilitative approaches to CRF management. Future research needs to focus on developing commonly defined terms shared by cancer survivors and healthcare professionals and a systematic approach to diagnosis. Having cohesive language with respect to CRF management for HNC survivors would be beneficial in identifying fluctuating energy levels and the physical, psychological, emotional, and cognitive impacts of CRF on function (Lacchetti, 2014). While these recommendations have previously been made with respect to CRF management in a general cancer population, we would recommend ensuring that shared terminology and approaches appropriately target HNC survivors with CRF, and their unique functional needs. For example, CRF symptoms related to feeding and swallowing do not appear in general management guidelines for CRF, but we suggest these issues are relevant to address CRF with HNC survivors (Berger et al., 2015; Bower et al., 2014). Further, symptom information obtained through a HNC survivor's lens would

ensure that the rehabilitative approach to CRF management targeted the specific, individualized functional needs of the person.

Currently, CRF is measured primarily through physical symptoms and reported tiredness (Bower, 2014). Previous fatigue research has suggested a progressive scale of tiredness, fatigue, and exhaustion be used to measure the severity of symptoms (Olson, 2007). However, the findings of our study suggest that CRF in HNC survivors is less of a steady state of tiredness or consistently low energy, and more of an unpredictable, uncontrollable, fluctuating energy-related barrier to function. Therefore, a functional-directed approach to symptom management in terms of daily activities and quality of life could effectively target individual issues with consideration of the variability of CRF. Park and Hashmi (2018) recommend providing cancer survivors early education on CRF; however, from the findings of our study, we suggest that this education be expanded to include strategies to mitigate fluctuating and inconsistent presentations of CRF, including both energy allocation (use of current energy) and energy cultivation (progressed increase of energy) approaches. Strategies can be explored with each HNC survivor to both cultivate and optimize energy as a means to better management of daily activities.

Utilizing members of an interdisciplinary healthcare team, such as occupational therapy and physical therapy, would be beneficial in targeting CRF issues and energy usage in daily function. Specifically, occupational therapy practitioners—with their expertise in function and energy allocation—have a clear role on the interdisciplinary team, however, this role has yet to be explicitly defined in the research literature and has yet to be included in the documented guidelines and agreed upon in clinical practice (Pergolotti, Williams, Campbell, Munoz, & Muss, 2016; Stein Duker & Sleight, 2019; NCCN, 2018). While research supporting occupational therapy interventions specific to CRF in HNC survivors' care is currently limited, involvement

of occupational therapists in HNC survivors' CRF care would ensure that functional needs are addressed. The findings of this study support previously published literature advocating for expanding occupational therapy services as a means to optimize management of CRF in HNC survivors (Sleight & Stein Duker, 2016).

Substantial published literature on CRF management supports the benefits of physical exercise on reduction of CRF symptoms; physical exercise has become a common method of intervention for specific CRF symptoms (Capozzi, Dolgoy & McNeely, 2018). Physical activity is an example of a CRF management strategy used to cultivate energy through activity engagement. Moreover, engagement of HNC survivors in daily activities that are meaningful to them potentially increases activity tolerance, similar to the incremental activity increases made possible through physical exercise interventions. Despite the research attention given to physical exercise strategies for CRF management, the findings of this study point to functional engagement and energy cultivation as essential means of managing CRF symptoms in the HNC survivor population. Occupational therapy practitioners should be paramount in providing this type of CRF management through functional activity as it relates to energy cultivation. Approaches to CRF management should consider the pursuit and development of energy cultivating activities, the avoidance of energy depleting activities (e.g. high stress situations, unhealthy eating habits, lack of sleep, imbalance of activities), and the promotion of increased endurance and/or enhanced activity tolerance through a balance of energy and engagement.

3.5.1. Clinical Relevance

In this study, the majority of participants described their CRF experiences in functional terms, suggesting that survivors may benefit from a clinical-communication focusing on occupational engagement. Instead of a discussion on 'tiredness', CRF can be broached in terms

of its impact on a HNC survivor's function, energy level, and activity participation. Figure 2 offers a simple visual example of energy balance; HNC survivors should be supported in determining how their activities impact their CRF symptoms. Additionally, this type of approach rooted in meaningful activity engagement may provide a means to discuss the personal impact of CRF on a HNC survivor, which may be a more effective strategy than the current generalized symptoms-focused approach (Cheville, Beck, Petersen, Marks, & Gamble, 2009). Moreover, HNC survivor-reported issues regarding function loss and challenges with energy allocation should alert the healthcare team to the need for occupational therapy and physical therapy involvement in the HNC survivor's care.

3.5.2. Future Directions

Very limited research exists from a functional perspective that focuses on both the energy fluctuations of CRF in HNC survivor populations and the impact of the inconsistent (fluctuating) nature of CRF on activity engagement (Bower et al., 2014; Howell et al., 2015). The findings of this study reflect a need to progress research and advocate for care plans in the management of CRF that consider that variable nature of symptoms and their impacts on function.

3.5.3. Limitations

The scope and findings of this study were limited by several factors. While the study was conducted through written questionnaires, face-to-face interviews may have gleaned additional information and more robustly captured the HNC survivors' perspectives. The written format was chosen to be inclusive of survivors with HNC, many of whom had limitations in verbal communication. Selection bias may have occurred as all participants in this study were approached based on their enrolment in the parent study.

3.6. Conclusion

Participants reported CRF in the context of experiencing unpredictable and uncontrollable fluctuations in energy levels and through the negative impact on function and daily routines. In light of this study's findings, more research is needed examining strategies to facilitate energy cultivation and management of limited and inconsistent levels of energy. The reported impact of CRF on function and participation highlights the need for occupational therapy practitioners to be included in the management of CRF for HNC survivors. Further rehabilitation-directed research that focuses on the experience of CRF in a broader HNC population is warranted.

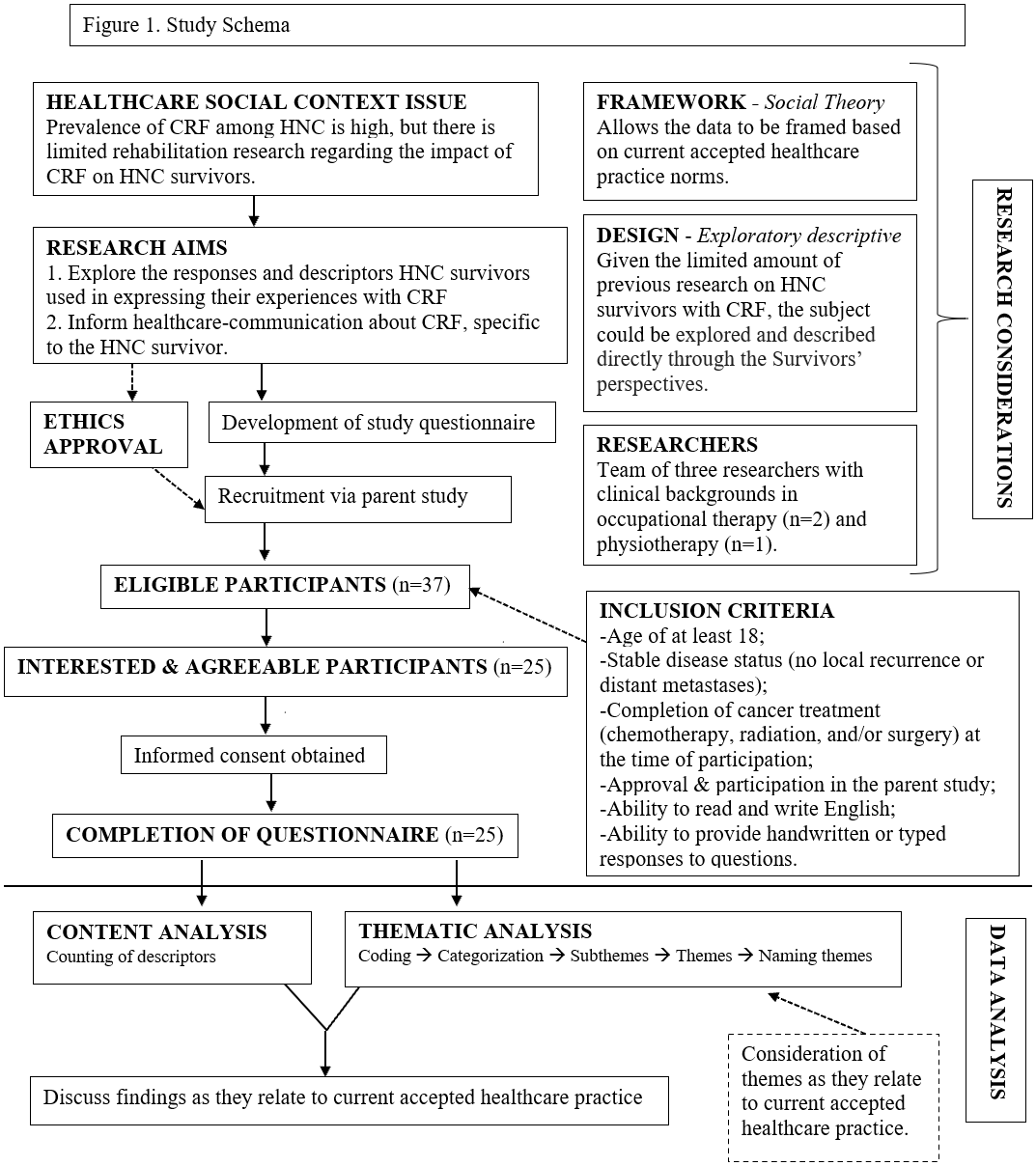
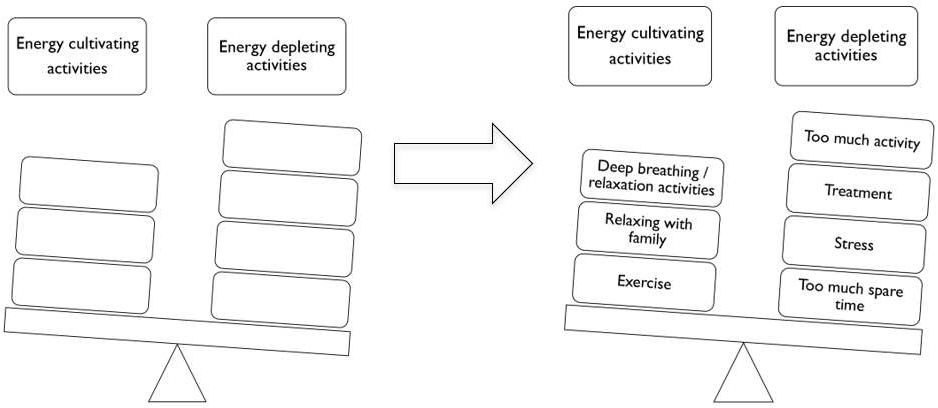


Figure 3-1. Study Schema

The idea is that the scale will either balance or favour the energy cultivation activities, through an individual's pursuit of engagement in meaningful pursuits. The scale facilitates awareness of the energy required in any task, and the need to self-manage one's own energy resource. Different individuals are expected to respond to activities uniquely, so a blanket approach to care would not be ideal.



2a. Balance Scale that can be discussed with patients

2b. Example of filled scale

1. As explained in Koornstra et al., 2014—"As management of CRF is currently sub-optimal, ideally a change of approach is required, where fatigue is treated as central to patient management both during and after systemic anti-cancer treatment."
2. As explored in Berger et al., 2015—Distress and management systems for CRF need to take into account the personal factors affecting an individual.
3. As described in McCorkle et al., 2011—In order to support individuals with ongoing health issues, a clinical approach should enable activity engagement.

Figure 3-2. Energy Cultivation and Energy Depletion Balance Scales

Table 3-1. Demographics

Table 3-1. *Demographics (n=25)*	
Variable	Value
Age: *Mean (± SD)* *Range*	 61.8 (6.8) 47-73 years
Sex: *Female* *Male*	 10 15
Tumour Type: *Oropharynx* *Larynx* *Thyroid Cancer*	 20 3 2
Stage: *Stage I-II* *Stage III* *Stage IV*	 4 3 18
Employment Status: *Working* *Disability* *Retired/ Not working*	 6 6 13
Marital Status: *Married* *Divorced* *Single*	 21 1 3
Time Since Diagnosis: *5 months to 1 year* *> 1 year*	 20 5
Treatment Received: *Surgery alone* *Surgery &radiation therapy* *Surgery, chemotherapy & radiation therapy*	 1 13 11

Table 3-2. Baseline Yes/No Responses

Table 3-2. *Baseline Yes/No Responses*	
Question	Agreement response
Perceived experience of fatigue symptoms since HNC diagnosis	25/25 (100%)
Perceived experience of CRF since HNC diagnosis	22/25 (88%)
Has your healthcare team ever discussed CRF or fatigue with you?	12/25 (48%)

Table 3-3. Common Descriptors

Table 3.

Common descriptors

Descriptors	Occurrence
[Low/lack/loss of] Energy	12 (50%)
Lack of participat[ion/ing] in event[s]/routine[s]/activit[y/ies]	14 (56%)
Unpredictab[le/ility] of symptoms	8 (32%)

*The total number of terms exceed the number of participants as individual respondents provided multiple terms in their responses.

Table 3-4. Themes with Participant Occurrence Rates Across Responses

Table 4. *Themes with participant occurrence rates across responses*		
Theme	Example of descriptors	Occurrence across participants (n=25)
CRF as a barrier to function	"Lack of interest in physical activity."	18/ 25 (72%)
	"I need to lay down now! I don't want to move, too lazy to cook or eat."	
	"Impact was felt more when I returned to work."	
	"What I now accomplish in a day is a fraction of what I accomplished before I was treated. I always seem to need to push myself."	
	"Missing some activities I probably would have participated in pre-cancer"	
	"I must adjust my activities to meet the decreased energy levels."	
	"Unable to perform tasks after cancer; I get tired."	
	"I used to be able to complete household chores much quicker and now I have to take breaks in between."	
Uncontrollable and unpredictable energy fluctuations	"No energy or mind to do much of anything anymore."	21/25 (84%)
	"Low energy affecting your general health condition that reflect on your daily routines."	
	"Fatigue is frequently changeable - sometimes worse, sometimes not there."	
	"Coming and going of fatigue that is uncontrollable."	
	"It is uncontrollable, it comes when it wants and leaves when it wants. Best to just relax until it leaves."	
	"A loss of energy to perform daily function."	
	"Changeable. One day minimal activity can cause fatigue, on another day I am able to accomplish many activities."	
	"Random. Unpredictable. Annoying. Can be somewhat depressing. Life altering."	

Chapter 4

Functional, Work-Related Rehabilitative Programming for Cancer Survivors Experiencing Cancer-Related Fatigue

Alberta Cancer Exercise at Work ("ACE@Work") – Interview Study

Dolgoy, N., Brose, J. M., Dao, T., Suderman, K., Gross, D. P., Ho, C., Culos-Reed, S.N., & McNeely, M. L. (2020). Functional, work-related rehabilitative programming for cancer survivors experiencing cancer-related fatigue. British Journal of Occupational Therapy. https://doi.org/10.1177/0308022620927351

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4.1. Abstract

Introduction. Cancer-related fatigue (CRF) negatively impacts 50-90% of cancer survivors (survivors). In North America, approximately 50% of return-to-work interventions initially fail for survivors, with CRF often cited as a barrier to workability. Occupational therapy-driven CRF work-related programming for survivors is sparse, despite many published reviews calling for interdisciplinary interventions; to address work-related performance, specific functional interventions are likely needed. Further exploration and a broader understanding of survivors' CRF management, participation in rehabilitative programs, and plans for return-to-work are necessary to better target survivor needs. **Methods.** Drawing on social theory, this exploratory descriptive study utilized content and thematic analysis of interviews from 12 survivors to explore and describe the perspectives of survivors experiencing CRF yet desiring to work. **Results.** Content analysis reflected distinct differences in fatigue-related terminology. Thematic analysis identified three themes specific to CRF and workability: valuing physical wellness, perceived cognitive impacts of CRF on function and workability, and the lack of transition from physical exercise to functional work-related activities. **Conclusion.** Survivors identified gaps in care related to managing cognitive symptoms and the need for functional, work-related interventions to manage CRF. With their expertise in function, occupational therapists are well positioned to facilitate work-specific interventions, within cancer-specific exercise programming.

Keywords: cancer, fatigue, survivorship, workability, rehabilitation

Chapter 4

Functional, Work-Related Rehabilitative Programming for Cancer Survivors Experiencing Cancer-Related Fatigue

4.2. Introduction

Cancer-related fatigue (CRF) is a known negative consequence of cancer and anticancer treatments, impacting 50-90% of cancer survivors (survivors) regardless of age, sex, or initial diagnosis (Minton et al., 2013). The National Comprehensive Cancer Network (NCCN) defines CRF as a subjective sense of tiredness that interferes with emotional, physical, functional, social, and existential domains of life (Mehnert, 2011). Significantly, working-aged (18-64 years) survivors are 1.4 times more likely to be unemployed compared to a healthy cohort (deBoer, Taskila, Ojajärvi, van Dijk, & Verbeek, 2009; Mehnert, 2011). Ongoing unemployment for these survivors threatens their quality of life, and imposes significant costs on both the individual and society (Kale, & Carroll, 2016).

CRF is a known barrier to workability (the ability to work) (deBoer et al., 2009; Mehnert et al., 2013). Whereas occupational therapy-driven functional interventions have been integrated in other return-to-work contexts, such as post-traumatic injury and cardiovascular care, CRF-specific work-related programming has not yet been extensively explored (Parkinson & Maheau, 2019; Nitkin, Parkinson & Schultz, 2011; Minton et al., 2013). Interventions for CRF currently focus on physical exercise-based programming; however, there are limitations in the functionality that general physical exercise alone can offer (McNeely et al., 2016). Addressing rehabilitative aspects of CRF, and work-related effects in particular, should include occupational therapy, in order to most effectively target functional outcomes (Alfano, 2017; Sleight & Duker, 2016).

Multiple research studies, even those looking at exercise and CRF, have suggested that a more individualized and functional approach to CRF and cancer-care is necessary (Gracey et al., 2016; McNeely et al., 2016; Cheville et al., 2017; Silver & Gilchrist, 2011). A 2015 Cochrane Review on the effectiveness of interventions to enhance return-to-work for survivors found no occupational therapy-focused studies evaluating CRF and workability (deBoer et al., 2015). A recently published article by Sleight and Duker (2016) reported a need for increased engagement of occupational therapy in functional interventions for survivors. Given that occupational therapy focuses on the individual's functional needs, a survivor-perspective approach to research provides a lens through which to pinpoint the specific functional work-related effects of CRF and the experience of engagement in a cancer-specific physical exercise program (Radomski & Latham, 2008; O'Brien et al., 2014). As such, this study explored the physical exercise and work-related considerations of 12 survivors—all of whom experienced CRF, had completed a cancer-specific exercise program, and were planning, in process, or had returned to gainful employment—with the aim of identifying novel targets for work-related survivor interventions.

4.3. Methods

4.3.1. Research Aim

This study had two aims:

(1) to explore and describe the physical exercise and work-related experiences of survivors with CRF; and (2) to inform future potential implementation of novel work-related rehabilitative interventions through consideration of the current cancer-specific exercise program in which participants had engaged.

4.3.2. Research Design

An exploratory descriptive research design was utilized. Exploratory descriptive research seeks to acquire new insights into less understood phenomena, isolating gaps in current and accepted practices and understanding phenomena in context (Brink, 1998). Essentially, exploratory descriptive designs allow researchers to question and investigate social experiences without the premise of a hypothesis or expectation. Exploration relies on the principle that information and knowledge are fluid constructs, tentative in nature; therefore, exploration is an ongoing process (Brink, 1998). Descriptive research offers opportunity to explain and express findings. As norms and standards in healthcare practice progress and change, continued exploration into how rehabilitation can best be conducted to satisfy the needs of patients, and description of how to explain and express these findings, are warranted. This study utilized an exploratory descriptive design, which enabled the researchers to explore and describe CRF, work-related barriers, and effective rehabilitation programming directly through the survivors' perspectives.

4.3.3. Theoretical Framework

Social theory is an action-oriented meta-theoretical framework rooted in the examination of relationships and societal structures within their surrounding contextual environments and norms (Meyer & Ward 2014). Drawing on social theory in healthcare-directed research offers the opportunity to explore practice norms, conventional assumptions, systems of care, and relationships between individuals, issues, and interventions (Meyer & Ward, 2014). Since social theory explores phenomena within context, and this study explored and described the perspective of survivors regarding their vocational pursuits, its use was considered an appropriate framework to guide the study design, data collection, and analysis.

4.3.4. Practice Models

In order to consider the individual in context of both their environment and the social parameters of current western medicine healthcare practice, two models were used: the Person Environment Occupation (PEO) model, and the Social Ecological (SE) model.

The PEO model considers the individual in context of their surroundings and the activities in which they engage (Strong, Rigby, Stewart, Law & Cooper, 1999). The PEO model was used to consider the data with respect to how each participant engaged in activity within the context of their surroundings.

The SE model positions interactions between the individual and the various levels of social structures in their surrounding contextual environments (Golden & Earp, 2012). The SE model emphasizes behaviours and environments shaped by the influences of the individual, interpersonal interactions, organizational systems, communities, and public policies (Golden & Earp, 2012). The SE model conceives that supportive environments facilitate healthier occupational engagement, which made this an appropriate model to use in framing the levels of social influence with respect to access to rehabilitative services.

4.3.5. Study Context

This study was conducted through recruitment of participants who had completed the Alberta Cancer Exercise (ACE) hybrid effectiveness implementation study. The ACE study was a 12-week community-based exercise program that focuses on full body physical exercise to optimize quality of life outcomes in survivors (McNeely et al., 2019). Over the course of the 12-week program, participants attend exercise sessions two times per week, for approximately 60-90 minutes per session. Throughout the 12-week intervention, the complexity of the exercises were increased and/or adjusted by the research team, which included kinesiologists, certified exercise

physiologists, and physiotherapists. In its current form, the ACE study did not routinely include occupational therapists as part of the interdisciplinary research team. Additionally, the ACE study did not address participant-driven work-related concerns or goals as part of routine interventions, nor did it carry out functional interventions. The interviews of past-participants of the ACE study took place during the summer of 2018 in Edmonton, Alberta, Canada.

Research Team. The research team for this study consisted of an interdisciplinary group of clinician researchers who come from different healthcare disciplines (occupational therapy, return-to-work, kinesiology, and physiotherapy) and who are all familiar with CRF, rehabilitation, and qualitative analysis. Specifically, the research team included the following members: an occupational therapist with expertise in workability (TD); an occupational therapist clinician and researcher with expertise in cancer care (JB); an occupational therapist clinician and researcher with expertise in cancer care and workability (ND); a graduate student with expertise in exercise programming and cancer care (KS); and a physiotherapist clinician and researcher with expertise in impairment-based cancer rehabilitation and exercise (MM). The research team's interdisciplinary backgrounds provided multiple perspectives throughout the data analysis.

4.3.6. Sample and Recruitment

Participants were recruited via purposive sampling as identified through criteria already gathered from past participants of the ACE REDCap database. Inclusion criteria consisted of the following requirements:

- Survivors of 18-64 years of age;
- Successful completion of ACE within three months of study recruitment;

- No current active involvement with the ACE program;
- Baseline demographic data from the ACE study indicating previous vocation with intent to return to work at least part-time;
- ACE study final assessment score of four or higher for the item of "tiredness" on the Edmonton Symptom Assessment Scale (ESAS), *or* a level of fatigue described as "somewhat" or higher on the Functional Assessment of Cancer Therapy-Fatigue (FACT-F) subscale question "I feel fatigued" (Richardson & Jones, 2009; Yellen et al., 1997);
- ACE study final assessment score indicating concerns or problems with vocation on the Canadian Problem Checklist (CPC) (Bultz et al., 2011).

Exclusionary criteria consisted of the following constraints:

- Recurrence and/or progression of cancer;
- Inability to participate in an oral interview conducted in English.

A sample of approximately 10 participants was expected to sufficiently explore the research aims. Eligible participants were purposively selected via the aforementioned inclusion criteria as extracted from the ACE REDCap database by the ACE coordinators. A list of potentially eligible participants was generated from the database and placed in a random order by an independent research assistant. The ACE coordinators then contacted participants in order on the list, confirmed eligibility, explained the parameters of the study, and invited eligible participants to take part. Any participant interested in taking part in the study was required to initiate contact directly with the research team. Interested participants were then scheduled for the interview with the researcher (ND).

4.3.7. Data Collection

Each interview was scheduled for a two-hour session. At the start of the session, the researcher reviewed the study purpose and procedures, risks and relevance of the research, and obtained written informed consent from the participant. The original consent form was retained by the research team and a copy was provided to the participant.

The interviews were semi-structured, and relied on the baseline data which had identified issues of CRF and work-related concerns. The interviews were based on the following guiding prompts:

1. Please provide a short description of yourself;
2. Please explain your fatigue symptoms and describe your experience with fatigue;
3. Please discuss your experience with work and symptoms of fatigue;
4. Please describe how participation in the <study name blinded> study had an effect, if any, on the fatigue symptoms and any work-related concerns you experienced;
5. Please explain any support you received or ways that you dealt with returning to work and fatigue management;
6. Please describe how you best address fatigue issues and work-related barriers, through exercise or otherwise.

The prompts were designed by two experienced interdisciplinary researchers (ND, MM) and then piloted by two occupational therapists (JB, TD) and three survivor volunteers to ensure that language was appropriate and prompts were clear. The prompts and responses were open-ended and provided a directed guideline for the interview to ensure that fatigue concerns were well explained and that the language used by the interviewer mentioned fatigue specifically and not tiredness or other confounding terms. The interviews were audio recorded and then transcribed

verbatim by a research assistant. The transcriptions and audio recordings were then reviewed to ensure that the transcriptions accurately reflected the audio files. All personal details including names were then removed from the transcribed data. All researchers had access to de-identified transcripts.

4.3.8. Quality Assurance

Exploration of the data using social theory required that researchers first be transparent about their own guiding principles and foundational beliefs (Meyer & Ward, 2014). Researchers must have an awareness of the impact their beliefs and experiences may have on the analysis process. A priori self-explanation and critical reflection of researcher positionality and situatedness were paramount for study rigour and successful exploration of new data. Appropriate reflexive and self-explanatory processes were built into the research and consistently revisited during the research process to ensure rigour. For example, as this study was focused on the functional, work-related issues described by the participants of a physical exercise program, the occupational therapist researchers might have been more inclined to approach the data from a functional perspective, whereas the physiotherapist researchers might have been more inclined to view the data through a physical lens. A reflexive space for the researchers to acknowledge and account for these considerations as part of the data analysis process created opportunity for engagement in active self-explanation and checking of biases throughout the data analysis.

4.3.9. Data Analysis

Content analysis.

Content analysis is a method that focuses on the systematic and objective details, descriptions, and shared perspectives of participant experiences (Vaismoradi et al., 2016). Use of

a content analysis approach provided researchers the opportunity to explore commonly occurring phenomena in the data (Vaismoradi et al., 2016). Each transcript was explored for commonly occurring words, and preliminary counts of descriptors were compiled. To be considered a common word for content analysis, the research team agreed on the parameters that a word had to present across at least four participants, and appear at least 30 times (Bengtsson, 2016). One research assistant and two researchers (ND, MM) completed the final counts. Common descriptors were counted more than once per participant if the same words or phrases were used in reference to different issues. For example, if a participant stated, "Issues with work are tiring", and "I am tired of being fatigued", the word "tiredness" was counted twice.

Thematic analysis.

Thematic analysis is a method that focuses on the clustering of similar patterns or commonalities across data, with the goals of identifying shared meaning and finding implicit relationships from the explicit data (Vaismoradi et al., 2016). Thematic analysis was guided by the exploratory design and social theory approach. The following considerations from the participant data were paramount in thematic analysis: (1) experiences and struggles; (2) emotional considerations; and (3) misinformation or lack of information about CRF.

Data were first read and organized by each researcher to identify codes. Coding anchors key points in data gathering. These codes were then grouped into concepts. Concepts serve as a collection of similar codes. The concepts were then clustered into categories. Categories are broader groups used to generate themes. The categories were then developed into sub-themes, and the researchers reviewed and discussed these sub-themes as a group. Sub-themes were then modified and consolidated to generate the working themes. Working themes were reviewed

again by each researcher for consistency before collation of the final themes and the final step of naming the themes.

All researchers (ND, JB, TD, MM, KS) were involved in the data analysis process of exploration and description. Thematic analysis developed directly from the participant data, ensuring that analysis did not involve any researcher's preconceptions of what rehabilitation programs ought to entail. At each step of the data analysis process, each researcher independently reviewed the data. Then, the independently reviewed data were synthesized and reviewed collaboratively by all researchers. This sequential analysis approach ensured that the research process reflected the data of the participants and enabled the researchers to construct the themes directly from the participants' experiences.

4.3.10. Ethics

Informed consent was obtained from each participant prior to the interview. The ACE study and this sub-study of ACE received scientific and ethical approval from the Health Research Ethics Board of Alberta: Cancer Committee [HREBA.CC-16-0905].

4.4. Results

4.4.1. Participants

Twenty individuals who had taken part in the ACE study and met the current study criteria were identified from the REDCap database. Given the goal of 10 participants, the first 15 of 20 individuals on the random ordered list were contacted by the research assistant. Of the 15 potential participants, 12 survivors consented to the study and completed the interview. Three candidates did not consent to participate in the study for the following reasons: timing (n=1), concerns with stress and personal factors involving the survivor's work (n=1), and family or other personal issues (n=1). The participants were at different stages of work; some had returned

to full or part-time employment, whereas others were not yet working or remained on long-term disability. Table 1 outlines the baseline demographic data of the participants.

4.4.2. Common Words and Descriptors

The following frequently occurring words and descriptors were used across all participant data and throughout all responses (Table 2). “Fatigue” was the most commonly occurring term. “Fatigue”, “tiredness” and “exhaustion” were often used with respect to functional activity engagement, work-related or otherwise. Some participants also reported that they did not understand the difference between “fatigue” and “tiredness”, which may also account for variation in the number of times each word presented. The terms regarding “cognition” were reported by participants in connection with the impacts of CRF on thinking processes for work-related issues and with respect to difficulties following commands and instructions in the exercise program. Participants used the terms “frustration” and “emotional” to describe the negative impacts of CRF on daily living, including in regard to workability and activity engagement. “Frustration” and “emotional” were frequently used words with respect to the manifestation of CRF symptoms as inconsistent and lengthy. “Frustration” was also used in describing limited healthcare and work-related rehabilitative services.

Many of the participants reported specifics about their work-related experiences. Terms of “un/safe”, “un/supportive”, and “positive” or “negative” were reviewed in relation to work environments. Terms were divided based on whether or not they appeared within statements of a favourable nature. Depending on how the above terms were discussed by the participants, the type of work environment was determined: safe versus unsafe, supportive versus unsupportive, and positive versus negative. Four participants (33%) reported having supportive work environments while eight (67%) reported having unsupportive work environments.

4.4.3. Themes

Three key themes emerged from the thematic analysis. The themes were named as follows: (1) valuing physical wellness; (2) perceived cognitive impacts of CRF on function and workability; (3) the lack of transition from physical exercise to functional work-related activities. Table 3 presents examples of participant phrases that were salient in thematic development.

The theme of valuing physical wellness reflects resultant priority and activity changes in the participants following participation in an exercise program. The prioritization placed on physical wellness is equated by one participant to a full-time job—a vocation requiring effort and attention. Challenges in maintaining a balance between work and wellness was noted in several participant responses. The following quotes describe physical wellness valued and prioritized over work:

- "I've become, after cancer, just such a stressed person, I just thought "Forget it! I'm not doing this job anymore, I cannot be healthy and have a career."
- "Before cancer, I used to care about work, but then after all this fatigue and stress, I don't think about it the same way anymore. It matters less. I'm at the point where maybe I am physically well. But mentally, emotionally…I'm nowhere near "normal". My work needs to be on those parts of my life."
- "I think those of us who are attempting to return to work, we stumble and fall, we stumble and fall. It eats into our confidence, our sense of self. I've learned to balance and have healthy things in my life in other ways, volunteering, exercise, the studies, those types of things. But I was very much an identifier with my career. It was a very strong identifier."

The theme of CRF-related perceived cognitive impacts on function and workability reflects the struggle of participants and their call for services. This theme developed from participants sharing their experiences of the 'unseen' impacts of CRF, namely in thinking processes and in managing typical activities. The experience of being told that they 'look good', and therefore should 'feel good', reflects a social construct around appearance and wellness. This theme aligns with the content analysis findings of frequent use of terms relating to "frustration", "cognition" and the "brain". This participant quote reflects the complex nature of cognitive symptoms and strategies used to address these issues:

- "Mine is a stressful and demanding job, and it always has been, and I always knew that. I can kind of feel it in myself, and I really do have to practice more self-care, like yoga and meditation. And I leave on time. And I find the boundaries and balance help with the mental fatigue. My brain just gives up sometimes. Even though my body is stronger, my brain still needs healing."

The theme of the lack of transition from physical exercise to functional work-related activities developed from the participants' descriptions of their struggles to decide the amount of activity to undertake outside of the exercise setting, the degree of energy to expend, and how best to translate the physical exercise conditioning to real-world applicability. The following list reflects some of the more powerful statements and suggestions driving this theme:

- "I would have liked something like that to help me progress in all the things I was doing outside of exercising at the gym—like when do I increase the time for grocery shopping? Or, how do I know if I can work for six hours instead of four?"

- "My wish list, my dream list, is that all survivors who were working, and expect to work again, get to have that baseline functional capacity assessment done before treatment and then be able to follow up on these measures down the road."
- "Before a survivor goes back to work, especially with a physical job, shouldn't there be help to relearn how your body moves for your work? So you don't hurt yourself and end up back out of work again. Shouldn't we do something like that? I wish someone could help me with work, like I got the help getting this far with exercise."

4.5. Discussion

4.5.1. CRF Terminology

The content analysis revealed that "tiredness", "fatigue", and "exhaustion" presented as related, but not necessarily interchangeable terms. The use of these terms as related descriptors of CRF symptoms aligns with the Fatigue Adaptation Model, which suggests that tiredness, fatigue and exhaustion are states on a continuum of adaptation to symptoms of limited energy second to CRF (Olson, 2007). While the Fatigue Adaptation Model suggests that behavioural patterns are associated with fatigue, the findings of this study indicate that function and activity engagement serve as markers of the severity of symptoms. This study's findings also point to the potential role of occupational therapists in facilitating early education regarding terminology relating to CRF and in delivering interventions for management of CRF symptoms as they relate to functional engagement and work-related outcomes.

4.5.2. Valuing Physical Wellness

A positive relationship between physical exercise and activity engagement has been reported and is socially accepted as a treatment method for CRF symptoms (McNeely et al., 2016). However, unique from the literature on CRF and the benefits of physical exercise,

through use of the PEO model, this study found that participants who reported benefits to physical wellness reflected on the ways in which their wellness impacted their individual function and activity engagement. Our results support the importance of the 'window of opportunity' or 'teachable moment' following a cancer diagnosis to promote positive health and wellness as a means to increase likelihood of return to work (Demark-Wahnefried et al., 2015).

4.5.3. Perceived Cognitive Implications

The perceived cognitive impacts of CRF were evident in content tallies and thematic development. From both the individual experience in context (PEO model) and the social parameters of wellness and working (SE Model), addressing the alteration of thought processes secondary to CRF is warranted, particularly given the negative impact of cognition on successful return-to-work (Dorland et al., 2016). Currently, more focus is given to the physical symptoms and the benefits of exercise, rather than on the cognitive (and typically unseen) symptoms (Bower, 2014). Moreover, much of the research has examined CRF-related cognition either in terms of treatments, such as part of cognitive behavioural therapy of psychological symptom-management, or in isolation, not in relation to other factors of daily living (Mitchell et al., 2014; Minton et al., 2013).

Through use of the PEO model in context of societal norms, this study found that distinct from the literature, participants experienced cognitive issues across many aspects of their lives including following simple directions or managing cues in the exercise program. These findings point to the need for occupational therapists, as experts in cognitive rehabilitation, to ensure that terminology and directive language are accessible for all survivors. Further, cognitive training could be strategically implemented into exercise programming, such as through incremental increases to directions or to the complexity of movement and commands. To our

knowledge, no published studies have been performed that utilize combined cognitive and physical training programs for survivors with work-related barriers second to CRF symptoms.

4.5.4. Transition from Physical Exercise to Functional Work-Related Activities

Across the word counts of both "emotion" and "frustration", and in the theme of a lack of transition from physical exercise to functional work-related activities, participants shared concerns regarding translation of the physical exercises and activity endurance from the gym sessions to their daily activities and work-related tasks. While the literature points to physical exercise programming as the key to building stamina and routine, the framework of social action theory with the combined approach of considering an individual in context facilitated this study's unique findings that gains from physical exercise do not naturally transition to, or obviously result in improvements in function or work-related activities. In support of this finding, where evidence of the relationship between CRF and function does exist, such as in exercise or psycho-educational approaches, its translation to daily activities has been sparse (Weis & Horneber, 2015). Moreover, the original NCCN guidelines did not include strategies for the practice of occupational therapy in CRF management, and did not provide suggestions for workability and CRF (Bower et al., 2014; Howell et al., 2013). Occupational therapy-focused interventions that target energy allocation and maximization would therefore be warranted to support survivors with interventions for balancing the amount of activity required for task engagement with their available levels of energy (McNeely et al., 2016). Thus, occupational therapists are equipped with skills to engage survivors with CRF in work-related contexts through: (1) facilitating the building of activity tolerance to progress task engagement, and (2) isolating and identifying the component parts of activities to develop and/or modify vocational tasks. These unique aspects of

occupational therapy allow occupational therapists to support survivors in transitioning physical and cognitive gains from a rehabilitative setting to specific vocational tasks.

4.6. Limitations

As purposive sampling was used, participants who did not self-report issues with returning to work following the ACE exercise program may have been missed for participation in this study. In terms of the participants, given their previous involvement in the ACE program, it is conceivable that they hold a high opinion of the importance of physical wellness than would a differently sourced sample. In addition, there were substantially more female than male participants (n=9 versus n=3), which may skew the results based on gender norms for vocations and physical wellness.

A potential limitation of the work was the exclusive use of the term "fatigue" in the interview questions, which may have led to higher reporting of this descriptor by survivors. From a SE model perspective, the aim was to use consistent wording across questions as there is not yet an established language specific to CRF (Moore et al., 2015). Further, from a PEO model perspective, the aim was to use appropriate terminology in session to allow survivors to describe their experiences as accurately as possible. A further limitation of the work was that questions were focussed on the reported deficits, and were not open ended in nature. However, given that baseline data were already accounted for, the questions were guided to be directive of existing issues with fatigue and work-related concerns. Finally, while the longer interview time did support development of rapport and comfort with the participants, in the clinical setting a lengthy interview of this nature is unlikely; it is conceivable, however, that therapists would be seeing patients in clinical settings more than once, and would thus have opportunity to develop rapport over time.

4.7. Future Research and Practice

At present, the research and clinical availability of occupational therapy in functional, work-related CRF management is limited (Sleight & Duker, 2016). Opportunities for occupational therapy in the management of CRF and work-related interventions are evident: occupational therapists are experts in function, and the issue of workability is rooted in function. Having occupational therapists involved in CRF and work-related rehabilitation ensures a transition from rehabilitation activities to functional applicability, with a focus on individual needs in the context of meaningful activity engagement. Further exploration and implementation-based research in CRF and workability would be beneficial in developing interventions and programming that look at practical, work-related outcomes of physical exercise interventions, and on the specific opportunities for occupational therapists to use their expertise in components of activities to be involved in the translation of physical outcomes to functional outcomes. Building on the findings of this study, future research is needed to explore both the immediate effects and long-term implications of implementing work-related occupational therapy interventions.

4.8. Conclusion

Through a social theory lens, with consideration of the individual in their own context and of the social parameters (PEO and SE models respectively), this exploratory descriptive study offers a participant-driven perspective on the needs and desires of survivors with CRF regarding participation in physical exercise programming and interventions in workability. Further occupational therapy-driven research and practice is warranted to explore and develop interventions that effectively and efficiently utilize resources while targeting CRF and work-related issues.

4.9. Key Findings

Interventions for CRF and work-related issues could target the following considerations: valuing physical wellness; perceived cognitive impacts; and the lack of transition from physical exercise to functional work-related activities.

4.10. What The Study Has Added to The Field of Occupational Therapy

The themes of this study point to the need for inclusion of occupational therapy in survivor rehabilitation. Importantly, interventions are needed to address the individualized physical and cognitive impacts of CRF in the context of transitioning to return to work.

Table 4-1. Participants

Table 1. *Participants (n=12)*	
Variable	Value
Age in years	
Mean (± Standard Deviation)	48.7 (4.8)
Range	35-65 years
Sex	
Female	9
Male	3
Employment Status	
Working (as per prior to diagnosis)	5
On disability (not working, receiving a percentage of income from insurance provider)	2
Not working (no work-related income)	2
Part-time or partial work status	3
Vocations (current or previous)	
Education	4
Management / Human Resources	3
Finance	1
Trades	3
Government	1
Physical Exercise Program Adherence (completed all sessions)	
Adherence rate: 24/24 sessions	88.4%
Total completing > 90% of all sessions	7
Marital Status	
Married /partnered	10
Single	2
Cancer Diagnosis	
Breast	5
Head and neck	3
Gynecological	2
Sarcoma	1
Hodgkin Lymphoma	1
Baseline CRF scores	
Mean (± Standard Deviation)	5.5/10 (1.8)
Time Since Primary Cancer Treatment Completion	
Median	6 months
Range	3-30 months

Table 4-2. Common Words and Descriptors

Table 2. *Common Words and Descriptors*		
Words/descriptors	Number of participants who reported (n=12/100%)	Total number of participant responses (n=12/100%)†
Fatigue[ing/d]	11 (92%)	130
Tir[ed/edness/ing]	11 (92%)	77
Exhaust[ing/ion]	4 (33%)	36
Cogniti[on/ive]/Brain	5 (42%)	61
Frustrat[ion/ed]	4 (33%)	32
Emotion[al/s]	6 (50%)	31

†The total number of terms exceed the number of participants, as participants provided multiple terms in their responses.

Table 4-3. Emergent Themes

Table 3. *Emergent Themes*	
Theme	Example of descriptors/phrases
Valuing physical wellness	"Maintaining health can actually be a full-time job. Workplaces talk about work-life balance, but it's hypocritical, because you are also expected to work like it is the most important thing in your life. Now I approach health as my most important job."
	"So there's a lot that benefitted me being a part of an exercise program. I would say physically there were improvements; in my energy there was improvements. And my routine now always includes exercise."
	"Exercise is so much more than the physical aspect of it. It's about getting stronger. Exercise has improved my emotional and mental strength. I think the exercise program saved me."
Perceived cognitive impacts of CRF on function and workability	"I'll be going along, I won't really feel fatigued. And then poof! All of a sudden out of the blue, it's like, wow! And you don't, and what will happen is, I'll just forget things, my concentration and focus get really bad…I need help with these issues"
	"Everyone was saying, 'You look good, you move well…what's wrong with you?' but the fatigue and the fogginess were bad. When I started work, I was forgetting to go to meetings. The cognitive thing was really worrying me. I was really afraid. I didn't think that brain exhaustion could ever happen, but I now know it can, because it happened to me."
	"I'm not back to work yet, but if I was back, they would probably fire me because I just don't function like I used to before cancer. I am scared to go back to work, I don't know if I can handle the stress. I want a purpose. I want my job. But, my brain is so ruined. I don't know where to start."
The lack of transition from physical exercise to functional work-related activities.	"There was stuff I wanted to do outside of [the exercise program]. I would try cutting the grass, and I'd end up having to go to the hospital because I just wore myself out too much. How was I supposed to know how much I could [physically] do in a day?"
	" When the exercise program was done, it's kind of like "Okay you're done, there's the door." How do I get from 1 hour at the gym to 7 hours at my job?"
	-"I gave all my energy for the exercise classes, but that meant as soon as I left and was driving home, I was exhausted. I could see the progress when I could walk up and down the stairs with a basket of laundry in my house without taking breaks. There were a lot of benefits, but I am not sure if I did a good job balancing how much I was doing. There ought to be a place to help people going back to their jobs. Who helps them? Who helps them that know about cancer and work?"

Chapter 5

Tailored Functional Activities for Self-Reported Barriers to Return-to-Work in Cancer Survivors

Alberta Cancer Exercise at Work ("ACE@Work") – Proof-of-Concept Study

Dolgoy N., Gross D., Ho C., Culos-Reed S.N., & McNeely M.L (2020). Tailored Functional Activities for Self-Reported Barriers to Return-to-Work in Cancer Survivors. Annals of Occupational Therapy and Physiotherapy.

5.1. Abstract

Purpose. Working-aged cancer survivors (18-64 years) are on average 1.4 times more likely to be unemployed after completing cancer treatments than are similar aged healthy cohorts. Given the personal and financial burdens on working-aged cancer survivors, improving return-to-work outcomes is necessary. There is sparse cancer-specific research in work-related functional interventions with self-reported measurable outcomes. Research of cancer-specific exercise programs targeting stamina and endurance show promise in improving return-to-work, though these programs do not specifically address work-related activities. A foundation of successful work outcomes is self-efficacy, which has not yet been researched as a primary endpoint in cancer-specific studies examining work-related interventions. This pilot study explored 1. the feasibility of adding tailored work-related functional activities to a cancer-specific exercise program, and 2. the value of using the Canadian Occupational Performance Measure (COPM)'s productivity section as an outcome to measure performance and satisfaction as aspects of work self-efficacy. **Methods.** This study utilized a single group pre-test/post-test design with working-aged cancer survivors (n=7). Outcome measures included work-related physical performance (lift tests), participation (adherence to the program - attendance and participation logs), and work self-efficacy satisfaction and performance (the COPM). **Results.** All participants completed their functional interventions. 6/7 participants completed pre- and post-lift tests, showing improvements at the post-lifting assessment. Participant perception of goal attainment (performance and satisfaction) showed clinically meaningful improvement (2-point change) in all participants. **Conclusion.** This pilot study demonstrates the feasibility of embedding work-related functional activities into a physical exercise program and the effectiveness and potential scalability of using the COPM as a tool for measuring performance and satisfaction.

Keywords: cancer survivorship, return-to-work, occupational therapy, rehabilitation, exercise programs

Chapter 5

Tailored Functional Activities for Self-Reported Barriers to Return-to-Work in Cancer Survivors

5.2. Introduction

5.2.1. Background/Rationale

Working-aged cancer survivors (18-64 years) are 1.4 times more likely to be unemployed than comparatively healthy working-aged individuals (deBoer et al., 2015). As cancer treatments advance and patient outcomes improve, concern grows for cancer survivors who are reintegrating into work roles after completion of cancer-related medical treatment. Approximately 50% of all cancer-related return-to-work interventions in the United States of America result in failed work attempts, reflecting the complexity of work-related issues in cancer survivor populations, from both individual—referring to quality of life and productivity—and systemic—referring to economic—perspectives (Van Egmond et al., 2017). Unsuccessful work attempts and ongoing unemployment for working-aged cancer survivors are serious issues, as ongoing unemployment negatively impacts health, and imposes significant costs on the individual and society (Mehnert, 2011).

In response to the clinically identified yet unmet need for work-related support, a call has been issued for functional, work-related interventions to address the unique and individualized needs of cancer survivors (deBoer et al., 2015). Multiple research studies have suggested that cancer-specific vocational rehabilitation is warranted, with the caveat that more tailored approaches are needed (Nitkin, Parkinson, & Schultz, 2018). A recent Cochrane Review found that no studies were led by occupational therapists and no studies focused on functional approaches to enhancing the return-to-work experience for cancer survivors (deBoer et al.,

2015). To date, many work-related interventions for cancer survivors involve physical reconditioning, which may help address certain cancer-related sequelae such as fatigue, but typically do not include support for specific work-related concerns reported by cancer survivors (McNeely et al., 2016). A recent multidisciplinary trial that explored productivity and vocational outcomes following a combined intervention involving occupational counselling and physical exercise showed promise for return-to-work outcomes (Leensen et al., 2017). While functional restoration and work-specific programming in many other return-to-work contexts, such as musculoskeletal rehabilitation following physical injury or trauma, have been successful in facilitating positive return-to-work outcomes, cancer-specific return-to-work programming has not yet been extensively explored (Adam, Gibson, Strong, & Lyle, 2011; Nitkin, Parkinson & Schultz, 2018; deBoer et al., 2015). Canadian and American guidelines for managing side effects of cancer have been developed, including protocols for activity engagement, but work-related protocols (referring to the ability to work) remain largely absent in these publications (Nitkin, Parkinson & Schultz, 2018; Bower et al., 2014). Further, limited interdisciplinary healthcare research on the association between functional outcomes and work self-efficacy has been conducted. Work self-efficacy, defined as a belief in one's ability to work, is known to be foundational both in goal development and in outcome achievement (Bültmann & Brouwer, 2013); therefore, use of work self-efficacy as an outcome may be a beneficial means of engaging an individual in work-related rehabilitation, and a useful marker of success in return-to-work related programming. As a first step, this proof-of-concept pilot study made use of the opportunity of an existing cancer-specific physical exercise program as a platform in which to embed a functional intervention, and included the Canadian Occupational Performance Measure (COPM)'s productivity section as a means of developing and measuring the tailored approach.

5.2.2. Aims/Objectives

This study explored the feasibility of implementing tailored functional activities into a physical exercise program for cancer survivors who were transitioning to their previous vocations after being off work due to cancer treatment. Feasibility-related issues of interest included the following:

(1) At the participant level: The extra time commitment necessary for completion of the additional work-related functional activities;

(2) At the level of the occupational therapist: The additional time needed to create and administer the program;

(3) At the level of the institution: The environmental (location and equipment) and additional time requirements necessary to accommodate both the pilot study and the exercise program;

(4) At the level of the assessments: The feasibility of using of performance-based lift tests for the examination of functional (i.e. physical activity) outcomes, and the use of the COPM—a tailored individualized assessment tool—for the examination of participant-reported work self-efficacy in performance and satisfaction ratings.

5.2.3. Context

This study was conducted within the context of a multi-site, community-based exercise study for adult cancer survivors, the Alberta Cancer Exercise (ACE) hybrid effectiveness implementation study (McNeely et al., 2019). The ACE study involves a 12-week community-based exercise program, with focus on full body exercise to optimize quality of life outcomes in cancer survivors. During the 12-week program, participants attend exercise sessions twice per week, for approximately 1-1.5 hours per session. The physical exercises are progressed as

appropriate over the 12-week intervention by the research team—which includes kinesiologists, certified exercise physiologists and physiotherapists (referred to hereafter as ACE exercise specialists). In its current form, the ACE study neither addresses work-related concerns nor goals as part of the program.

The pilot study took place during the fall of 2018 in Edmonton, Alberta across two community sites—a cancer rehabilitation clinic and a cancer-specific community-wellness centre—with the intervention occurring during the final 7-weeks of the ACE exercise program (with pre and post-intervention testing on week 6 and after week 12, respectively).

5.3. Methods

5.3.1. Study Design

This study used a proof-of-concept (PoC) pre-test/post-test design. PoC designs are used to demonstrate feasibility and verify the practical potential of a concept as a means for decision making and problem solving across interdisciplinary research (Kendig, 2016). The pre-test/post-test design was chosen, as it allowed for exploration of the effects of embedding work-related activities into an existing exercise program. As each participant's intervention was tailored to his/her vocation and work-related goals, the results before and after the intervention could be compared at the level of the individual prior to examination of the group's overall performance.

5.3.2. Ethics and Consent

Informed written consent was obtained. The ACE study and the present sub-study received scientific and ethical approval from the Health Research Ethics Board of Alberta: Cancer Committee.

5.3.3. Sample and Recruitment

Participants were selected based on their baseline assessments in the ACE study. This pilot study focused on functional work-related activities to potentially improve work self-efficacy of cancer survivors in general, and thus, eligibility included all cancer types. Based on normative data for pilot studies of a similar nature, we aimed for a minimum sample of 5-10 participants.

Inclusion criteria included:

1. Current ACE participant aged 18-64 years whose demographic data indicated previous vocation, with intent to return to their previous work.
2. Score of 4 or higher on the item "Tiredness" on the Edmonton Symptom Assessment Scale (ESAS) (Richardson & Jones, 2009); *or,* indicating a level of fatigue described as "somewhat" or higher on the FACT-Fatigue subscale question "I feel fatigued" (Yellen et al., 1997).
3. Identifying issues related to "work" on the Canadian Problem Checklist (CPC) (Bultz et al., 2011).
4. Attending an ACE site offering a group personal training exercise format.

Participants were excluded if there were any changes related to disease or health status that required active treatment, or if they were currently working at their previous level of vocational engagement.

Eligible ACE participants were randomly selected to participate in this optional pilot sub-study. ACE research coordinators contacted potentially eligible participants. Participants were informed that this pilot would be a supplement to their prescribed ACE exercise program, and that work-related activities would be carried out concurrently with their exercise sessions. Those

who expressed interest in taking part were then telephoned by a research assistant to answer any further questions about the optional study, and to set up the baseline assessment session.

5.3.4. Outcome Measures

Information about each participant was collected from the following sources: (1) ACE assessments; (2) Participant attendance and participation logs; (3) Lift tests, for determination of physical work-related outcomes over time; (4) COPM, as a measure of work self-efficacy through scores of task importance, satisfaction, and performance over time. Thus, endpoints of measure included work-related physical performance (lift tests), participation (adherence to the program - attendance and participation logs), and satisfaction and performance as components of work self-efficacy (COPM). Figure 1 (Study Flow Diagram) illustrates the measures in context of recruitment and study timeline.

Information about the feasibility of the intervention was collected through feedback from ACE exercise specialists, time records of the occupational therapist, and timetabling and scheduling information from the sessions at the venue.

ACE assessments for baseline data.

Participant demographic and medical information provided to the parent ACE study was accessible for this pilot. Vocational history was gathered as part of the COPM. Employer and company details were not used as part of the collected data in the study. In order to protect the identities of all participants, each participant was given a code number, and all identifiable data were excluded/removed from study-related documentation.

Feasibility.

Feasibility at the level of the participant was measured through adherence and engagement. Participant attendance for both the exercise programming and the tailored,

functional work-related activities were recorded for each session and collected weekly to review. Since ease of implementation was an important consideration for embedding functional activities within a physical exercise program, the time commitment and attendance records were significant measures in ensuring that participants were not burdened by too many activities and that the added activities did not result in negative impact or excessive physical overload on the participants.

Feasibility at the level of the occupational therapist was measured by recording the time required for developing and implementing the additional activities, and the timing and requirements for implementing the intervention for each of the seven participants. Again, with ease of implementation being an important consideration for embedding functional activities within a physical exercise program, it was important to quantify the impact of the additional workload.

Feasibility at the level of the institution was measured through our ability to utilize existing gym space and equipment, and to schedule and carry out the intervention. The feasibility of timing and scheduling of the activities was measured through feedback from the participants and ACE exercise specialists, time-tabling for the shared used of space, and participation logs indicating successful completion of session activities.

Feasibility at the level of the assessments was measured by evaluating the findings of study outcomes used for individualized interventions, which included lift tests and the COPM, described below.

Lift tests.

To compare physical work-related outcomes, lift tests were utilized, as they have been found reliable and are moderately associated with return-to-work outcomes in other

health-compromised populations (Gross & Battié, 2002; Kuijer et. al, 2012; De Baets et. al, 2018). Lift tests involved three separate tests of lifting and carrying a weighted crate: (1) lifting a weighted crate from waist height to floor; (2) lifting a weighted crate from waist height to shoulder height; (3) carrying a weighted crate at waist level while walking a short distance (10m). The starting weight category was determined based on job requirements and on whether the participants were able to statically lift the expected amount for the weighted crate. Performance on the lift tests was categorized into limited, light, medium, or heavy, based on the National Occupational Classification (NOC) database job descriptions and participant-reported work tasks (Government of Canada, 2018). Weight categories were divided into limited 0-5 kg (0-11 lbs.), light 5-10 kg (11-22 lbs.), medium 10-20 kg (22-44 lbs.), and heavy >20kg (>40 lbs.). Less physical vocations (sedentary roles) were considered in a limited to light weight category. Moderate physical vocations were considered in the medium category. High physical vocations were considered in a heavy category. Details of vocation-specific physical demands can be found in the NOC database. Lift tests were progressed incrementally to either the maximum as reported or demonstrated by the participant (i.e. psychophysical endpoint) or the maximum ability required for the vocation (Banks & Caldwell, 2019; Snooke, 1999). The test was stopped if the participant had observable signs of maximal physical effort which included groaning, wincing, and/or poor posture/ lift form (Snooke, 1999). An improvement of 5kg per week in lifting, and/or progress to a higher NOC lift category can be considered meaningful improvements in lift testing (Gross, Haws, & Niemeläinen, 2012); for this study, the NOC category change was used to measure a meaningful improvement

Canadian Occupational Performance Measure (COPM).

The COPM scores were used to measure work self-efficacy through the combined respective pre- and post-intervention individual performance and satisfaction ratings (Dedding, Cardol, Eyssen, & Beelen, 2004). The COPM is a standardized individualized assessment, which has a section devoted to productivity (work-related activities). Each participant ranked his/her most important productivity (work-related) concerns on a scale of one (least important) to ten (most important); the highest ranked three-to-five activities were used in the subsequent aspects of the COPM assessment, and in the development of the tailored, functional work-related activities. Then, on a ten-point scale, each participant rated his/her current level of performance and satisfaction for each of the selected items. Participants could rate importance, performance, and satisfaction as low as zero an as high as ten respectively. To be used in the intervention, activities could not have initial performance ratings of 10/10, as there would have been no goal to achieve. The maximum score a participant could begin with is performance at 9/10 and satisfaction at 9/10. The performance and satisfaction ratings reported by each participant at the end of the program were compared to his/her initial scores to better understand changes in individual perceived work self-efficacy in performance and satisfaction (i.e. perceived task performance and level of satisfaction) over time. A positive change of 2 points on each COPM category of performance and satisfaction is considered a meaningful improvement (Dedding, Cardol, Eyssen, & Beelen, 2004).

5.3.5. Procedures

The COPM scores were used to measure work self-efficacy through the combined respective pre- and post-intervention individual performance and satisfaction ratings (Dedding, Cardol, Eyssen, & Beelen, 2004). The COPM is a standardized individualized assessment, which

has a section devoted to productivity (work-related activities). Each participant ranked his/her most important productivity (work-related) concerns on a scale of one (least important) to ten (most important); the highest ranked three-to-five activities were used in the subsequent aspects of the COPM assessment, and in the development of the tailored, functional work-related activities. Then, on a ten-point scale, each participant rated his/her current level of performance and satisfaction for each of the selected items. Participants could rate importance, performance, and satisfaction as low as zero an as high as ten respectively. To be used in the intervention, activities could not have initial performance ratings of 10/10, as there would have been no goal to achieve. The maximum score a participant could begin with is performance at 9/10 and satisfaction at 9/10. The performance and satisfaction ratings reported by each participant at the end of the program were compared to his/her initial scores to better understand changes in individual perceived work self-efficacy in performance and satisfaction (i.e. perceived task performance and level of satisfaction) over time. A positive change of 2 points on each COPM category of performance and satisfaction is considered a meaningful improvement (Dedding, Cardol, Eyssen, & Beelen, 2004).

The baseline session took place during week six of the ACE program. In this initial session, participants met with an occupational therapist and were given an explanation of the study interventions and outcomes. The COPM-productivity section was completed and a custom protocol lift test was performed (Dedding, Cardol, Eyssen, & Beelen, 2004; Matheson, Isernhagen, & Hart, 2002).

Following this initial session, the occupational therapist developed between three and five supplemental, tailored, functional, work-related activities based on the COPM and lift test results. Consideration of the equipment and resources available, such as the range in dumbbell or

sandbag weights available at each site, was required in developing the activities (see Limitations for further details). These new activities were then added to the participant's ACE exercises, to be performed during weeks seven through twelve of the ACE program. Each of the supplemental functional activities was designed to be integrated into the participant's ACE programming and to require 5-15 minutes to complete (about 25 minutes in total for all activities).

The occupational therapist progressed the functional activities weekly based on both observations of performance and participant self-report. Grading, modification, and adaptation of the activities followed the "just right" principle of occupational therapy practice (Trombly & Radomski, 2002). As a participant demonstrated ease in task completion and/or reported manageable task completion, the activity was progressed to provide a greater challenge with the aim of eventually reaching the determined end goal (Trombly & Randomski, 2002). The functional activities made use of the gym equipment available in the ACE study—such as weighted wheels, sandbags, treadmills, balance equipment, stairs—to simulate the functional, physical, work-related task demands. Some examples of the gym-equipment used in real-work functional contexts include the following:

- Use of a weighted wheel in a seated position to practice driving a vehicle, wherein the weighted wheel simulates the steering wheel of a vehicle.
- Use of weighted sandbags to practice carrying babies and children in a nursing context.
- Use of incline and front bars on a treadmill to simulate pushing objects, such as a hospital bed.

The final post-intervention session involved completing the COPM and repeating the lift testing. Figure 1 is a diagram depicting the study flow.

5.3.6. Analysis

Feasibility.

Participant intervention adherence measures were analysed descriptively through participation and attendance logs, and as well as the number of weekly progressions of activities. The occupational therapist-time commitment was analysed descriptively, as were the environment, equipment and resources needs at each exercise location. Finally, the feasibility of assessments were analysed descriptively through the work-related outcomes.

Work-related outcomes.

Similar to the analyses of a single-subject design, which looks at the changes in each participant individually, change scores in this study were evaluated first at the level of the individual, and then overall as a group (Johnston & Smith, 2010). As each intervention was tailored to the participant and his/her reported goals, individual evaluation ensured that data could be measured based on the unique performance of each participant (as compared to him/herself before and after the intervention), prior to examination of the group's overall performance.

Physical, work-related outcomes.

The lift test outcomes (NOC lift categories) were analysed pre- and post-intervention for changes in the NOC categories, to compare individual improvements over time.

Work self-efficacy performance and satisfaction.

Work self-efficacy performance and satisfaction were measured through the COPM performance and satisfaction scores over time. These scores were hand calculated as per the assessment guidelines, to compare improvements specific to important vocational issues reported by participants.

5.4. Results

Of a total of 68 ACE participants in the cohort, 22 ACE participants were deemed eligible for the study, 10 participants were randomly selected to participate and seven agreed to take part. Two potential participants declined due to the increased time commitments of the pilot study and one potential participant declined due to lack of interest. Of the seven participants who took part in this pilot study, two were males and five were females, with five involved in healthcare vocations (see Table 1).

5.4.1. Feasibility

At the participant level, feasibility was demonstrated by adherence and completion rates. All participants (n=7) completing the initial and final COPM sessions, and 6/7 completed the initial and final lift tests. One participant sustained an injury unrelated to the study, and was unable to complete the final lift test. There were no drop-outs during the study. At baseline, each participant was able to identify his/her most important issues regarding workability through the COPM, and rate these issues in terms of his/her performance and satisfaction. All participants attended 100% of the sessions throughout the 6-week intervention. The overall time for functional work-related activities per session was approximately 25 minutes. The time commitment for participants was deemed acceptable based on participant attendance and participation. ACE exercise specialist feedback included no reported issues with the additional time commitments for this study, and the neutral impact of the additional activities on symptoms and performance of the prescribed ACE program.

At the level of the occupational therapist, feasibility was demonstrated through the ability to use the participant-driven COPM data to generate functional, work-related activities for the intervention. The time commitments were deemed feasible given that one occupational therapist

was able to develop the interventions and prescribe the activities within 21 hours (approximately 3 hours per participant) prior to the interventions, observe and adapt interventions at a commitment of 5 hours per week, all within the timeframe of the study (7 weeks).

At the level of the institution, managing equipment and space-usage was deemed feasible, and made possible through time-tabling and clear communication.

Table 2 depicts the vocational concerns and functional interventions, as well as the time commitments for activities, equipment and space used, and total number of times that activities were progressed. As seen in Table 2, the occupational therapist progressed each participant's activities at least three times during the 6-week intervention.

5.4.2. Work-Related Outcomes

Table 3 describes the outcomes of the lift tests. Three of 7 participants initially lifted the required amount of weight for their personal job description, whereas 4/7 participants initially could lift 1-2 weight categories below their appropriate work-related weight category (i.e. a participant requiring middle weight category of lifting for their work, but could only lift light weight on their initial measure; see Measures section for NOC descriptions). At the end of the 6 weeks, 5/6 participants were able to lift within their appropriate job category; 1/6 participants showed improvement in lifting, though remained one category below the vocational requirement for weight lifted in job tasks. Based on the final lift tests, all participants showed either stability or improvement in their lifting abilities.

Work self-efficacy in performance and satisfaction.

Table 3 describes the outcomes of the COPM pre- and post-intervention scores including work self-efficacy performance and satisfaction outcomes. The combined performance and satisfaction scores indicate the changes in work-self efficacy ratings across each of the two domains.

These COPM averaged scores per participant are reflected in Figures 2 and 3, showing both the individual and group scores. Both satisfaction and performance ratings improved from initial to final measures by a minimum of 2 points across all individuals. The group mean performance score improved by 3.0 points (median 3.0 points), and the group mean satisfaction change score improved by 4.4 points (median 4.0 points). As all mean change scores are greater than 2 points, the findings suggest a meaningful improvement in self-efficacy.

5.5. Discussion

5.5.1. Evaluating Feasibility

This pilot study demonstrates the feasibility of implementing tailored, functional work-related activities into an existing physical exercise program to inform the development of formal return-to-work programs and functional simulations.

At the participant level, results suggest participants were interested and able to complete both their routine ACE program and additional work-related functional activities. Adherence, as reflected in 100% participation and completion, has been difficult to obtain in other previously published cancer-specific return-to-work interventions (van Egmond et al., 2016; deBoer et al., 2015). In our study, by facilitating an embedded and functional work-focused program into the already existing and scheduled ACE program, participants could maximize their time in each session, with minimal additional time burden. The participants' individual logs reflect an overall

modest increased time commitment (approximately 25 minutes per session) for the additional functional activities.

At the level of the occupational therapist, there were no issues with managing the development of the tailored interventions from the issues reported by each of the participants. Previously published literature has reported challenges in implementing and completing cancer-specific return-to-work interventions given the lack of rehabilitative personnel with expertise in cancer management and function (Tamminga et al., 2019; van Egmond et al., 2016). In our study, the involvement of occupational therapy may have contributed to the 100% intervention completion rate, as having the occupational therapy involvement weekly ensured that functional goals were being addressed and progressed.

At the level of the institution, there were challenges and successes that arose from using a fitness centre and clinic space to conduct a functional, work-related intervention. While the challenges of limited equipment have been explained, the success of having a cohesive functional and physical program carried out in one location has benefits of efficiency and familiarity (Gagliardi, Dobrow, & Wright, 2011).

At the level of the assessments, use of lift tests and the COPM offer potential for outcome measures used in cancer survivor return-to-work research.

5.5.2. Testing Effectiveness: Lift Tests

While this study was proposed to test feasibility, results of the lift tests showed promising improvements across all participants who completed the pre- and post-intervention lift tests. The results reflect the conditioning and strengthening gains from the general physical exercise program, pointing to the potential benefits for combined interventions for work-related rehabilitation. While the results of the lift tests are promising, there is not a direct comparison

that can be made to other studies of this nature. What is known is that cancer survivors with physically demanding vocations involving heavy lifting are at greater risk of failing attempts to return to work after their cancer treatment (Feuerstein, et al., 2010). Moreover, those with heavy-lifting vocations are less likely to reintegrate into the workforce, despite the attention given on strength and conditioning in work-hardening programs (Feuerstein, et al., 2010;Mehnert, 2011). Our findings warrant further investigation of such interventions and outcomes in well-designed clinical trials.

5.5.3. Work Self-Efficacy Performance and Satisfaction: the COPM

The COPM is not typically used in return-to-work research in cancer care (Enemark Larsen, Rasmussen, & Christensen, 2018). However, at present, no cancer-specific functional outcome measure related to self-efficacy in return-to-work is mentioned in the literature (Silver & Gilchrist, 2011; Niktin, Parkinson & Schultz, 2011); this current lack of measure could be the result of limited occupational therapy-driven research in this area. While the graphed depiction of COPM outcomes (see Figures 2 and 3) is not commonplace, it serves well for visually reflecting the results of this PoC study. Meaningful improvements were seen across the measured domains of performance and satisfaction in the category of productivity, from each individual participant and across the overall group. Interestingly, in most studies exploring the COPM, all categories of self-care, leisure, and productivity are examined, wherein self-care then often becomes the category of focus (Roberts et al., 2008). Emphasis on self-care leads to the possibility of a reduced focus on productive, or work-related, outcomes (Roberts et al., 2008). Further, in studies looking at the COPM as a work-related measure in breast cancer survivors, it was found that the COPM, completed in its entirety, did not effectively capture work-related goals (Désiron, Donceel, de Rijk, & Van Hoof, 2013). In this pilot study, only the productivity

category was used, allowing for work-related issues to be the sole focus of the importance, performance, and satisfactions ratings of the COPM.

Since the COPM is an individualized evaluation, we could explore the COPM results of each participant, from baseline to post intervention on work self-efficacy performance and satisfaction ratings. Additionally, since the COPM is a standardized assessment, we could then compare the change scores amongst the group. Each of the participants showed meaningful improvements in their own perceived performance and satisfaction ratings. In addition, the overall group findings reflected meaningful gains on both performance and satisfaction scales. The results of the self-reported participant measures reflect a positive association between the participation in the functional work-related activities and improved participant work self-efficacy outcomes in terms of performance and satisfaction. These findings are consistent with work-related self-efficacy literature, which suggests that self-perception and self-belief are key components of positive task outcomes (Wolvers, Leensen, Groeneveld, Frings-Dresen & de Boer, 2018). Our findings suggest that the COPM shows promise as a measure of work self-efficacy performance and satisfaction for participants in a functional work-related intervention; further investigation of this outcome measure in a well-designed clinical trial would be beneficial.

5.5.4. Limitations and Strengths

PoC and pilot studies typically use a small number of respondents (n<20) to determine whether the study's findings warrant further research. Given that each participant was compared to him/herself over time, a small sample size is not considered a limitation (Lilli et al., 2011). While this study included randomly selected participants from several professions, it happened that 3/7 participants were frontline nursing professionals (NOC code 3152). Moreover, given the

inclusion criteria related to reporting RTW issues and having cancer-related fatigue or tiredness reported at moderate or higher level, the overall sample to draw from was quite small (n=22 who met eligibility criteria for inclusion from the n=65 ACE participants). Further, this study explored workability from a particular perspective, namely changes in work self-efficacy participation and satisfaction. As such, the details of specific vocations and roles were obtained primarily from participants' self-report, and therefore may not be generalizable to those reporting similar concerns even within the same vocation.

Because the study coexisted in the same space as the parent study, equipment and baseline assessments were predetermined. Specifically, the gym equipment, including weights and machines, available in the exercise areas used were limited to fitness equipment and lighter weights. The lack of functional, work-specific equipment required creativity and problem solving to create certain functional activities. While a vocational rehabilitation space would have provided more opportunity to carry out work-related functional activities, the focus of this study was on the feasibility of embedding work-related functional activities into an exercise program, not work simulation. For example, in the case of the paramedic, heavier weights (sandbag weights were at a maximum of 40lbs), stair-climber equipment, and practice with an actual ambulance, would have allowed for a more tailored simulation. Given the fatigue issues reported by the participants, embedding work-related functional activities into an exercise program was used as a means to progress activities in preparation for future work rehabilitation.

5.5.5. Future Directions

The ongoing integration of tailored work-related functional activities into a cancer-specific exercise program will require further collaboration amongst occupational therapists, physiotherapists, exercise physiologists, and kinesiologists. The findings of this pilot study

present a first step in delivering functional work-related activities and appropriate outcomes, which are currently lacking in the cancer rehabilitation setting. This pilot study can be used to inform future research in the field of CRF and work-specific outcomes. Clinically, integrating tailored work-related activities into existing exercise programming may provide a means of offering rehabilitation to enhance work-related outcomes.

5.6. Conclusion

This study offers two novel considerations for future research and practice: (1) feasibility of implementing tailored, functional work-related activities into existing cancer-specific exercise programming; and (2) the potential benefits of considering individualized assessments, such as the COPM in measuring work self-efficacy performance and satisfaction in functional, work-related interventions. Exploration of the individualized work-related needs and outcomes at the level of the cancer survivor allowed us to focus intensively on each survivor, and tailor the intervention to his/her specific work-related issues. This approach has potential to improve awareness and understanding of the subjective experience of cancer survivors in rehabilitative return-to-work contexts. Future research in functional work-related activities and measures of work self-efficacy is necessary, including well-designed clinical trials testing effectiveness.

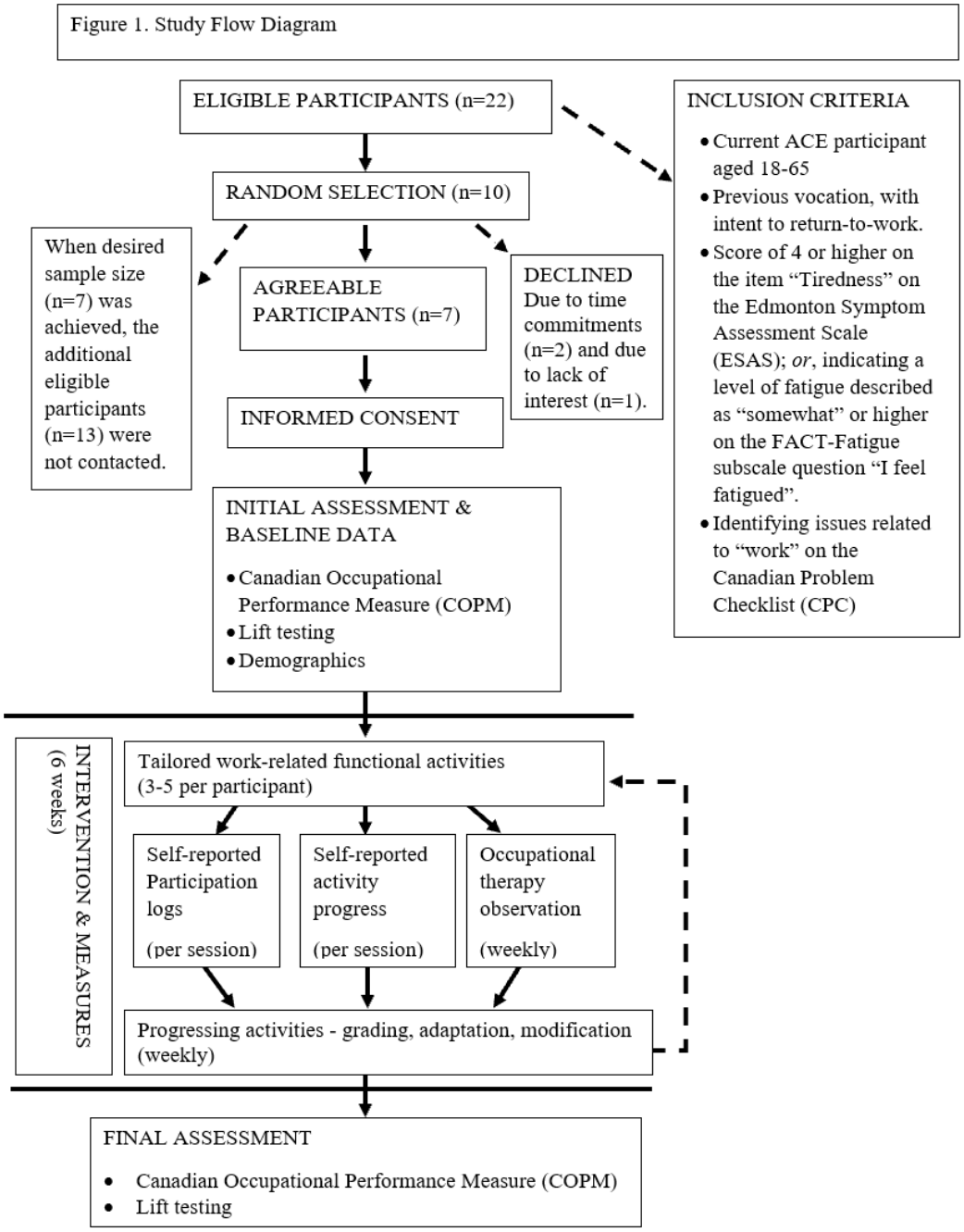

Figure 5-1. Study Flow Diagram

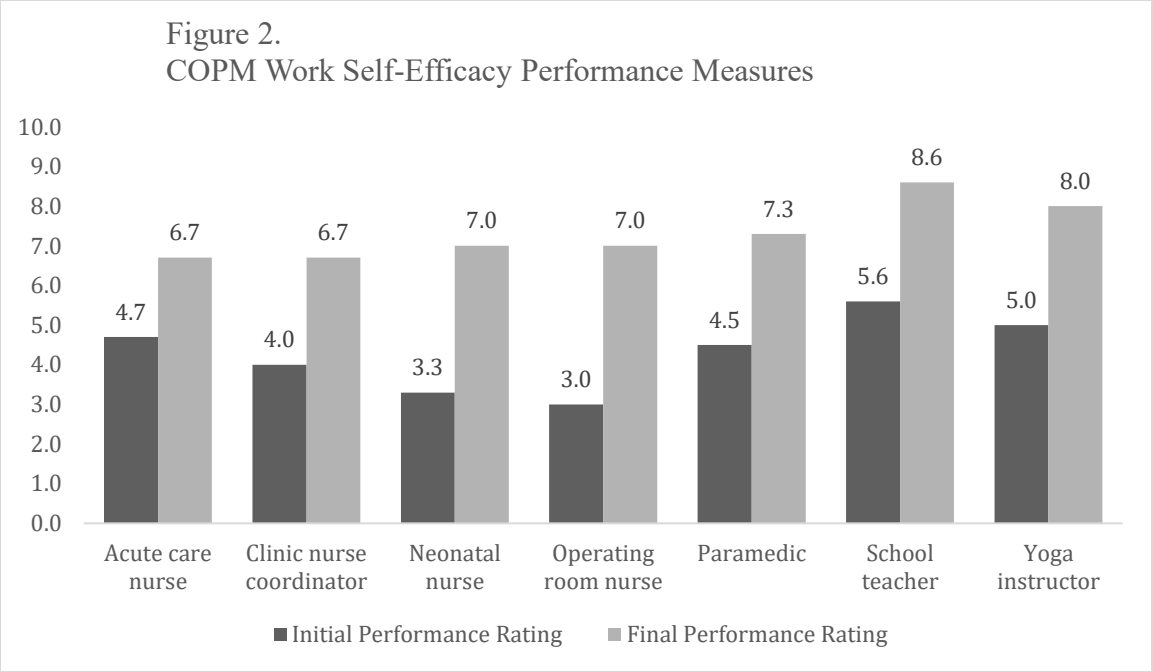

Figure 5-2. COPM Work Self-Efficacy Performance Measures

Figure 5-3. COPM Work Self-Efficacy Satisfaction Measures

Table 5-1. Participant Characteristics

Table 1. *Participant Characteristics (n=7)*	
Variable	Value
Age in years: Mean (Min-Max)	44.3 (26-62)
Sex:	
Number of Females	5
Number of Males	2
Employment Status:	
Number returning to partial work within 3 months prior to pilot-study commencing	2
Number returning to work/partial work during pilot-study	2
Number intending to return to work/partial work 1 month post-pilot study	1
Number not intending to return to work during study or 1 month post-study	2
Time Since Diagnosis:	
Within the first year	4
> 1 year	3
Vocations (National Occupational Classification job description code):	
Acute care nurse (3152)	1
Clinic nurse coordinator (3151)	1
Neonatal nurse (3152)	1
Operating room nurse (3152)	1
Paramedic (3234)	1
School teacher (4142)	1
Yoga instructor (5254)	1

Table 5-2. Vocational Concerns and Functional Interventions

Table 2.
Vocational concerns and functional interventions

Vocation	Work-related/COPM concerns*	Intervention goals	Activities	Equipment used	Total number of times activities were progressed during 6 week intervention (weekly basis)
Acute care nurse	Difficulty completing shift at work due to fatigue and limited stamina	Tolerate 2.5 hours of sustained activities with only micro (less than 3 minute) breaks.	-On ACE session days, progressively reduce breaks and duration of breaks in session; grade activity to eventually include the hour prior to ACE and ½ hour following ACE to simulate a shift and break timeframe. -Education and practice of mini and microbreaks (of less than 3 minutes)	- N/A	5x
	Difficulty managing post-operative care for patients second to deconditioning (dynamic standing, 20 minutes)	-To successfully complete ACE free weight exercises in standing without a break (20 minutes) -To successfully simulate 20 minutes of patient-care in standing at side of plinth	-Using resistance bands and light free weights for shoulder/upper extremity movements; focus on body mechanics for dynamic standing including posture and weight shift.	-Free weights (light) -Resistance band -Plinth/ adjustable height rolling table -Timer	
	Difficulty moving patient beds in 20m hallway (push/pull)	To successfully push weighted cart/plinth in hallway 10m	-Progress from treadmill inclined to treadmill with incline and forward push motion for 2 minutes to use of plinth in -Progress to plinth in hallway and add weights to plinth to incrementally simulate patient in hospital bed, to reach 20m.	-Treadmill -Plinth -Hallway -Weights	
Clinic nurse coordinator	Limited stamina walking to and from work (20 min, 2x daily)	Successfully walk for 20 minutes 2x daily at a moderate pace	-Progressive walking performed twice in a session, either on a treadmill or outside, for 20 minutes each time.	-Treadmill -Hallway -Outdoor space	4x

	Difficulty with picking objects off of floor	Successfully manage lunges to lift light object from floor 3x in session	-Progressive review of lunges and transfers to safely pick up object on floor	-Paper and light objects placed on floor -Mat	
	Difficulties lifting and moving supplies (10lbs or less) from waist height to higher or lower and shifting files from one counter to another	Successfully move weighted crate (less than 10lbs) from floor to waist and waist to shoulder height 3x in session. Successful drag then push of crate for 1 metre each, along counter.	-Progress with weights in crate and duration of activity to reach goals, Review of body mechanics and lift techniques in sessions.	-Crate -Light weights (1-10lbs) -Countertop space -Shelf space	
Neonatal nurse	Unable to manage fast movements at work, i.e.. Fast paced walking (approx. 30 seconds, 3x shift)	To complete treadmill sprint walks 3x for 30 seconds each while walking on treadmill	-Progress speed and duration of fast-paced walking up to goal of 30seconds	-Treadmill -Timer	3x
	Unable to hold a baby for 20 minutes	To carry a weighted sandbag of 8lbs during walking activity for 20 minutes	-Progress with use and duration of weight to simulate baby carry	-Treadmill -3-10lb sandbag weights	
	Difficulty transferring babies from incubator to beds (lift and carry)	Successfully complete 3 simulated transfers from incubator to bed in standing position	-Sandbag weight (8lbs) transfer using weight shift of 8lbs from chest height crate to waist height plinth; progress the weight of the sandbag and number of repetitions	-Sandbag weights (5-10lbs) -Plinth -Table with crate	
	Difficulty multitasking walking while completing other work tasks, such as carrying a baby while walking, or moving IV poles.	Complete 10 minutes of moderate paced walking while moving weighted objects across midline on inclined treadmill	-Progress activity to include light weights transferred across the midline of the body. Alternate this task with the fast-paced walking task.	-Treadmill -Light weights -Timer	
Operating room nurse	Difficulty tolerating scrubbing in	To successfully simulate scrubbing in, which includes	-Progress activity with static and dynamic standing at the sink to reach 10 minutes of	-Sink -Hospital gown, mask, and gloves	4x

	prior to surgeries second to fatigue	wearing operating room garments and cleaning equipment for 15 minutes	simulated scrubbing in. Task includes washing objects in the sink and turning to place on table behind. -Simulated operating bed set up for 5 minutes with crossbody movements to place equipment properly for simulated surgery.	-Objects in sink, including cups and sponges -Table at waist height -Plinth -Simulated operating equipment, including small pens and rulers	
	Difficulty standing/walking during surgery of more than 1 hour	Throughout 1 hour of ACE session, will successfully manage exercise and activities without a seated break (1 hour standing/dynamic mobility)	-Use of treadmill and ACE exercise activities to progress to 1 hour of continuous activity. Grade by reducing break times and frequency of breaks.	-N/A	
	Unable to manage cart sort (high/low movements, including squatting) to set up station.	Successfully complete 10 minute cart sort and set up simulation	-Progress with lunges, squats, high-low movements in ACE exercise program for use in cart sort and set up. Simulated cart to include items stacked in progressively challenging ways (i.e.. All objects on lowest shelf to start)	-Rolling cart -Plinth -Simulated operating equipment, including small pens, rulers, water bottles, light sandbag weights for fluid bags etc.	
	Unable to push/pull cart or plinth due to deconditioning.	Successfully complete 20 minutes of walking with completion of simulated plinth/cart push using treadmill at incline 3x for 2 minutes.	-Progress walking slowly on treadmill, to moderate-paced walking. Increase repetitions and duration of incline, and progressively increase level of incline.	-Treadmill -Timer	
Paramedic	Difficulty entering and exiting back of ambulance	To self-manage approx. 2 foot jump at rear of ambulance 3x in 1 hour without fatiguing	-Lunging on stairs over 3 stair spread -Jumping on mat, progressing to jumping from higher step to base of stairs (3 stair spread)	-Access to stairs - Access to hallway - Exercise mat - Object for target (i.e.	3x

			-Leaping over target object.	Tape marking “x”)	
	Difficulty lifting patients (with a partner) from floor to waist level	To self-manage lifting a 40lb sandbag weight from floor to waist level with 30 second hold (simulating a child, based on weights available)	- Progressive lifting of sandbag weight in carrier bag (starting with 10lbs and progressing to maximum weight available) -Progressive timing of lift and lower to include up to 30 second hold at maximum	-Cylindrical sandbag weights with carrier bag -Clock or timer	
	Difficulty transferring patients from bed to stretcher	To self-manage 2x simulated sliding transfers of 40lb weighted sandbag in a session with proper body mechanics.	-Simulation of sliding transfer using sandbag weight, with use resistance bands at legs and arms to cue for body mechanics, with progressive reduction in physical cues.	-Light to medium stretch resistance bands, tied to hold body in position -Plinth/table at waist height -Sandbag weights in carrier bag	
	Unable to manage 2 flights of stairs in an emergency call	To complete accelerated paced climb and descend of 26 stairs; to consistently run stairs for 2 minutes in a session without fatiguing.	-Progressive increase in stair climb and speed over sessions	- Stairs -Timer	
School teacher	Unable to lift/carry boxes with supplies (approx. 20lbs) for any length of time	To complete 5 minutes moderate-paced walking on a treadmill with carry of weighted objects (up to 20lbs).	-While walking on treadmill, using either weighted sandbag, 1 free weight, or small crate to simulate sustained carrying task in ambulation	-Treadmill -Free weight (5-10lbs) -Sandbag weight (20lbs) -Small crate	3x
	Difficulty with balance/cross body movements to reach and place objects in the room	To self-manage balance tasks with object placement for 2 minutes	-While standing in balance postures for ACE program, adjust activity to include grasp and place of school objects for simulated balance and crossbody movements;	-School objects, including: water bottles, pens, binders, books, pages in a folder	

			objects provided and placed at varied heights		
	Difficulty mobilizing while multitasking, such as walking and delivering student papers, second to proprioceptive changes post-cancer diagnosis and treatment	To complete 10 minutes of moderate-paced walking on a treadmill with cross body object transfer	-While walking on treadmill, objects placed on left and right sides of treadmill, for grasp and place tasks.	-Objects, including: light free weight (5lbs max), school-type objects (folders, binders, books), weight sandbag (max 10lbs)	
	Unable to stand up from floor level, either after picking up small objects from the floor or from seated on the floor	To complete 5 repeated floor-to-stand transfers, and 1 sustained (more than 10 minutes) floor-to-stand transfer	-Low squats with object pick up; lunges and floor-to-stand lunge transfers with object pick up -After floor/mat work for ACE, practice lunge to stand	- Mat -Objects for pick up (i.e. Books, small ball, water bottle)	
	Unable to complete filing for paper items at or above shoulder level.	To complete 5 minutes of sustained filing simulation tasks, including object placement waist to shoulder to level.	-At filing cabinet, using papers, 1lb weights and files, placing objects into cabinets of varying levels of height (floor to shoulder)	-Filing cabinet or tall shelf -1lb weight -Papers/files	
Yoga instructor	Difficulty with seated tolerance in driving and floor sitting, more than 5 minutes	To tolerate 15 minutes of dynamic sitting either in chair or floor	-ACE upper extremity free weight and shoulder exercises completed in seated, with directions to calf pump and shoulder check to simulate a car (approx. 15 minutes) -Seated cool down at end of session on the floor in modified cross legged positions (approx. 5 minutes)	-Free weights - Chair -Timer -Mat -Towel rolls for modified floor sit positions as need be	4x
	Difficulty and instability with transfers from the floor to standing	To successfully complete 3 floor-to-stand lunge transfers in 1 hour	-Low lunge transfer progression -Stair lunges	-Hallway -Staircase (3 steps) -Mat	
	Prolonged squatting more than 2 minutes	To successfully tolerate static squatted hold for > 2 minutes	-Squat-to-stand transfers, review of weight shift -Progressive squat hold x2 minutes, beginning with 20 second, 6x.	-Mat	

	Weighted carry and drag to position cushions for classes (approx. 10lbs each, approx. 20x per session)	To successfully drag/carry weighted objects of 10lbs 20x in session	-Simulation of yoga cushions using 10lb weight sandbag in pillow and pillowcase; drag 5m, carry 5m in session, 2 sets (beginning and end of ACE program), 10 repetitions	-Pillow -Pillowcase -10lb sandbag weight	

*As derived from the Canadian Occupational Performance Measure (COPM) results; see Table 3 for details.

Table 5-3. Outcome Measures per Participant Lift Test and Canadian Occupational Performance Measure ratings

Table 3. *Outcome Measures per Participant: Lift Test and Canadian Occupational Performance Measure (COPM) ratings*

Participant vocation (n=7)	Required physical lifting ability (NOC)	Lift test initial	Lift test completion	COPM areas of productive importance*	COPM initial perfor-mance rating	COPM final perfo-rmance rating	COPM initial satisfa-ction rating	COPM final satisfac-tion rating
Acute care nurse	Heavy	Middle	Heavy	Difficulty completing shift at work due to fatigue and limited stamina	5/10	7/10	2/10	4/10
				Difficulty managing post-operative care for patients second to deconditioning (dynamic standing, 20 minutes)	4/10	6/10	3/10	5/10
				Difficulty moving patient beds in 20m hallway (push/pull)	5/10	7/10	2/10	4/10
				Pre- and Post-intervention scores (sum of ratings / number of issues)	**14/3 = 4.7**	**20/3 = 6.7**	**7/3 = 2.3**	**13/3 = 4.3**
				OVERALL COPM CHANGE SCORES (final-initial)	**Performance: +2.0**		**Satisfaction: +2.0**	

Clinic nurse coordinator	Light	Light (with difficulty	Light	Limited stamina walking to and from work (20 min, 2x daily)	5/10	9/10	1/10	9/10
				Difficulty with picking objects off of floor	4/10	6/10	2/10	4/10
				Difficulties lifting and moving supplies (10lbs or less) from waist height to higher or lower and shifting files from one counter to another	3/10	5/10	2/10	4/10
				Pre- and Post-intervention scores **(sum of ratings / number of issues)**	**12/3 = 4.0**	**20/3 = 6.7**	**5/3 = 1.7**	**17/3 = 5.7**
				OVERALL COPM CHANGE SCORES **(final-initial)**	**Performance: +2.7**		**Satisfaction: +4.0**	
Neonatal nurse	Middle	Middle	Middle	Unable to manage fast movements at work; i.e. Fast paced walking (approx. 30 seconds, 3x shift)	5/10	7/10	2/10	9/10
				Unable to hold a baby for 20 minutes	3/10	7/10	1/10	9/10

				Difficulty transferring babies from incubator to beds (lift and carry)	3/10	6/10	3/10	8/10
				Difficulty multitasking walking while completing other work tasks, such as carrying a baby while walking, or moving IV poles.	2/10	8/10	2/10	10/10
				Pre- and Post-intervention scores **(sum of ratings / number of issues)**	**13/4 = 3.3**	**28/4 = 7.0**	**8/4 = 2**	**36/4 = 9**
				OVERALL COPM CHANGE SCORES **(final-initial)**	**Performance: +3.7**		**Satisfaction: +7.0**	
Operating room nurse	Middle	Light	Middle	Difficulty tolerating scrubbing in prior to surgeries second to fatigue	4/10	6/10	1/10	3/10
				Difficulty standing/walking during surgery of more than 1 hour	3/10	7/10	2/10	4/10
				Unable to manage cart sort (high/low movements, including	4/10	8/10	5/10	5/10

				squatting) to set up station.				
				Unable to push/pull cart or plinth due to deconditioning.	2/10	7/10	1/10	5/10
				Pre- and Post-intervention scores **(sum of ratings / number of issues)**	**13/4 = 3.0**	**28/4 = 7.0**	**9/4 = 2.3**	**17/4 = 4.3**
				OVERALL COPM CHANGE SCORES **(final-initial)**	**Performance: +4.0**		**Satisfaction: +2.0**	
Paramedic	Heavy	Light	Middle	Difficulty entering and exiting back of ambulance	5/10	8/10	3/10	8/10
				Difficulty lifting patients (with a partner) from floor to waist level	6/10	8/10	4/10	8/10
				Difficulty transferring patients from bed to stretcher	4/10	6/10	2/10	6/10
				Unable to manage 2 flights of stairs in an emergency call	3/10	7/10	4/10	7/10
				Pre- and Post-intervention scores	**18/4 = 4.5**	**29/4 = 7.3**	**13/4 = 3.3**	**29/4 = 7.3**

				(sum of ratings / number of issues)				
				OVERALL COPM CHANGE SCORES **(final-initial)**	**Performance: +2.8**		**Satisfaction: +4.0**	
School teacher	Middle	Light	Middle	Unable to lift/carry boxes with supplies (approx. 20lbs) for any length of time	7/10	10/10	7/10	10/10
				Difficulty with balance/cross body movements to reach and place objects in the room	6/10	8/10	3/10	6/10
				Difficulty mobilizing while multitasking, such as walking and delivering student papers, second to proprioceptive changes post-cancer diagnosis and treatment	5/10	8/10	2/10	7/10
				Unable to stand up from floor level, either after picking up small objects from the floor or from seated on the floor	5/10	9/10	7/10	9/10
				Unable to complete filing for paper items	5/10	9/10	2/10	9/10

				at or above shoulder level.				
				Pre- and Post-intervention scores (sum of ratings / number of issues)	**28/5 = 5.6**	**43/5 = 8.6**	**21/5 = 4.2**	**41/5 = 8.2**
				OVERALL COPM CHANGE SCORES (final-initial)	**Performance: +3.0**		**Satisfaction: +4.0**	
Yoga instructor	Middle	Middle	N/A	Difficulty with seated tolerance in driving and floor sitting, more than 5 minutes	5/10	8/10	3/10	10/10
				Difficulty and instability with transfers from the floor to standing	5/10	7/10	3/10	8/10
				Prolonged squatting more than 2 minutes	3/10	8/10	2/10	8/10
				Weighted carry and drag to position cushions for	7/10	9/10	4/10	8/10
				Pre- and Post-intervention scores (sum of ratings / number of issues)	**20/4 = 5.0**	**32/4 = 8.0**	**12/4 = 3.0**	**34/4 = 8.5**

				OVERALL COPM CHANGE SCORES **(final-initial)**	**Performance: +3.0**	**Satisfaction: +5.5**

*Used to develop the interventions/activities described in Table 2.

Chapter 6

Working Together: The Opportunities and Challenges of Integrating an Interdisciplinary, Single Subject Pilot Study Within a Large-Scale Implementation Study.

Alberta Cancer Exercise at work ("ACE@Work"): Knowledge Translation

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Chapter 6

Working Together: The Opportunities and Challenges of Integrating an Interdisciplinary, Single Subject Pilot Study Within a Large-Scale Implementation Study.

6.1. Abstract

This article presents the challenges, opportunities, and successes associated with the development and implementation of an interdisciplinary pilot study embedded within a large-scale implementation study. The pilot study focuses on cancer-related fatigue (CRF) and work self-efficacy, through the integration of an occupational therapy tailored functional intervention into a physical exercise intervention parent study. CRF is the most common cancer survivor reported sequelae of cancer and anti-cancer treatments. Functionally, CRF is reported as a major barrier to workability amongst working-aged (18-65 years) cancer survivors. Recent studies that target physical ability as an endpoint show positive results of exercise interventions on reduction of CRF symptoms. Very limited research on functional outcomes for work self-efficacy exist, particularly outcomes that combine tailored physical and functional activity programming. As research in rehabilitation for CRF grows, interdisciplinary interventions show promise, offering potentially more effective and efficient delivery of rehabilitation services to cancer survivors, targeting both physical and functional CRF-related concerns.

The large-scale parent study provided an opportunity to explore an interdisciplinary approach to enhance work-related self-efficacy in survivors with CRF. The challenges in embedding the pilot study included determining how to set up the pilot study interventions without disrupting the exercise intervention of the parent study, establishing distinct measurements and an appropriate analytical design to inform outcomes, and ensuring fidelity in delivery of the interdisciplinary intervention.

6.2. Learning Outcomes

By the end of this case, students should be able to

- Recognize the valuable contributions that interdisciplinary research can make in the rehabilitation sciences.
- Appreciate and anticipate potential barriers associated with the development and implementation of interdisciplinary projects that involve collaboration with researchers from different backgrounds and scopes of practice.
- Describe the specificity of single subject designs and their contribution to the body of healthcare research.
- Understand and appreciate that a greater participant time commitment is required when participating in concurrent studies.
- Utilize and draw from the *learnable* and *teachable* moments presented in this case study to support their future interdisciplinary learning opportunities.

6.3. Case Study

6.3.1. Context and Project Overview

Context.

Approximately 50% of all new cancer diagnoses in North America affect working-aged (18-65 years) individuals (deBoer et al., 2015). A major concern in the cancer survivor population is that working-aged adults with a cancer diagnosis are more than twice as likely to be unemployed compared to adults in a non-cancer cohort, at 33.8% compared to 15.2% respectively (deBoer, Taskila, Ojajärvi, Van Dijk, & Verbeek, 2009). Cancer survivors struggle with return-to-work, many citing cancer-related fatigue (CRF) as a major obstruction to their management of employment and daily activities (Nitkin, Parkinson, & Schultz, 2018).

CRF is a secondary effect of cancer and anti-cancer treatments that negatively impacts 50-90% of the cancer population (Campos, Hassan, Riechelmann, & Del Giglio, 2011). Despite rest and reduced activities, individuals may experience this overwhelming and fluctuating fatigue for months-to-years post-cancer diagnosis and anti-cancer treatment. Although the issue of CRF is well documented and known to be problematic, the assessments and interventions for CRF in work-related capacities are limited, with minimal interdisciplinary approaches from the perspective of occupational therapists and physiotherapists.

Occupational therapy is a healthcare profession rooted in meaning and function, namely the relationship between how individuals occupy their lives with meaning and the particular activities in which they engage, including productive tasks such as working (Hildenbrand & Lamb, 2013). Physiotherapy is a healthcare profession dedicated to movement and the relationship between physical mobility and wellness (Higgs, Refshauge & Ellis, 2001). Occupational therapy and physiotherapy interventions often interact, as movement and function are related; clinically, there are many instances of interdisciplinary interventions for patient care. From a research perspective, the current body of interdisciplinary cancer rehabilitation research between occupational therapy and physiotherapy is progressing, but remains limited.

Emerging evidence in cancer rehabilitation supports a positive relationship amongst participation in exercise interventions and improved physical abilities, reduced reports of fatigue, and increased functional activity engagement (McNeely, Dolgoy, Al Onazi, & Suderman, 2016). However, examples of the effects of these physical interventions applied to work-related capacities are sparse. Implementation studies focus on parallel goals of evaluating implementation an intervention into practice while also gathering data on its effectiveness (Bernet, Willens, & Bauer, 2013). In this regard, implementation studies are changing and

developing entities; they are examples of living research and, therefore, require researcher presence, awareness, and involvement at all steps throughout the research process. Given the limited interdisciplinary trials that inform physical interventions through functional (or occupational therapy) perspectives, and understanding the clinical concerns in this area of practice, the authors opted to pursue an interdisciplinary pilot study to explore CRF and work self-efficacy through the addition of tailored functional interventions to an exercise implementation study.

Project overview.

The pilot study consisted of adding an occupational therapy-informed functional intervention targeting work-related barriers in survivors with CRF. The potential clinical implications of utilizing interdisciplinary approaches for cancer rehabilitation and CRF management are significant, particularly given the limited resources of healthcare professionals. In theory, research that addresses both functional and physical needs of individuals, through cohesive interdisciplinary care and shared intervention outcomes, are relevant and beneficial from both client-centred and fiscally responsible perspectives.

The pilot study was designed as a sub-study of the Alberta Cancer Exercise (ACE) hybrid effectiveness-implementation study. ACE is evaluating the benefit of a clinic-to-community model of care with the aim to support high quality, timely, and personalized exercise for cancer survivors. As a large-scale implementation study, ACE provided a unique platform through which to explore how work self-efficacy goals and CRF symptom outcomes could be supported through an interdisciplinary exercise and occupational therapy functional intervention, and how exercise interventions could be tailored to address functional, work-related needs. The pilot focused on work self-efficacy—meaning belief in oneself—as this is a known key

component of achievement and thus an important first step in work-related cancer programming from an occupational therapy perspective (Bültmann & Brouwer, 2013).

The pilot study explored an occupational therapy-driven intervention that comprised a component of the parent-study; this involved addressing both physical and functional outcomes, as well as an individualized approach to the intervention design. The distinct aspects of the pilot compared to the parent study warranted a modified methodological approach and a unique set of assessment tools. While the ACE study used a variety of assessments including physical testing and self-reported outcome measures, the pilot study required its own evaluative components to measure changes in participant perspectives and satisfaction in order to understand their experiences with work self-efficacy.

Section summary.

- Cancer-related fatigue (CRF) remains a major consideration for cancer survivors returning to work, but little occupational therapy-driven research exists in this area of practice.
- Interdisciplinary interventions, combining occupational therapy and physiotherapy, offer opportunity to provide potentially beneficial outcomes, targeting both physical and functional concerns for CRF management and work-related considerations.
- The pilot, under the parent study of a large-scale implementation exercise study, used a single subject research design to explore functional interventions as part of exercise programs.

6.3.2. Research Design

A single subject research design was deemed most appropriate for the pilot study. A single subject design is a type of quantitative research that involves studying the behaviour of a small number of participants, typically between two and ten. The pilot was designed to easily

integrate into the parent ACE study, be simple to administer, and efficient regarding participant time and staff demands. The study took place across two community sites: a cancer rehabilitation clinic and a cancer-specific community wellness centre in Edmonton, Alberta, during the fall of 2018. The parent ACE study involves a 12-week personalized group exercise training program, 2 times per week for approximately 1-1.5 hours per session. The pilot study offered participants a condensed 6-week occupational therapy component from weeks 7-12 of the ACE study, and involved two additional testing sessions prior to and post intervention, resulting in a total of 8 weeks for the pilot intervention. The functional intervention included 3-5 functional activities added to the regular exercise programming for each participant. These functional activities were designed by an occupational therapist and were based on participant-reported functional and fatigue-related concerns regarding their work. The total time commitment for the additional activities was a maximum of 30 minutes per session. The major considerations in designing such interventions were that the activities had to be easy to explain, measure and implement. The exercise specialists managing the exercise program would therefore be able to support the pilot participants when completing their additional functional exercises, and so that participants would not be taxed with unreasonable demands on their time and energy.

Single subject designs compare an individual's original scores to his/her changes at the end of an intervention. This design was used so that the participant's change scores could be analyzed individually and then compared to group trends. The additional assessments used in the pilot were completed prior to beginning (week 6 of ACE) and shortly after completing the intervention (after week 12 of ACE). These assessments included the Canadian Occupational Performance Measure (COPM) for work self-efficacy scores of task importance, satisfaction, and performance over time, lift tests for predictability of return-to-work over time, and participation

and attendance logs (Dedding, Cardol, Eyssen, & Beelen, 2004; Matheson, Isernhagen, & Hart, 2002).

The outcome measures included work-related physical performance (lift tests), participation (logs), and work self-efficacy (COPM). These measures were used in combination with the quality of life and fatigue measures collected as a part of the parent study.

Section summary.

- The additional functional intervention was designed to be easily implementable and was tailored to support participant-reported concerns based on the Canadian Occupational Performance Measure (COPM).
- Functional interventions were designed by the occupational therapist and overseen by the exercise study trainers.

6.3.3. Research Practicalities

Planning.

The pilot study was led by an occupational therapist who conducted assessments, developed interventions, and graded/modified functional activities on a weekly basis. The pilot also received support from the ACE interdisciplinary team of physiotherapists, certified exercise physiologists, and kinesiologists who assisted with facilitating the interventions. The differences in the rehabilitative approach between physical and functional activities became apparent in the development of the pilot. Instructional phrasing, terminology, and directions had to be carefully considered in development so as to be accessible to all disciplines involved.

Recruitment.

Potentially eligible participants for the pilot study were identified after baseline testing in the ACE study. Participants who reported CRF and identified issues related to return to work were provided the option to take part in the pilot study.

The occupational therapist provided the research team with specific recruitment information to provide to potential participants regarding the purpose of the pilot study and outlining the additional time requirements.

Participants were in the working-age range of 18-65 years. A minimum sample of 5-10 participants was expected based on normative data for pilot studies of a similar nature. Of 10 potentially eligible participants, seven agreed to take part in the pilot study. (See Table 1.)

Ethics.

Ethics was granted by the Health Research Ethics Board of Alberta: Cancer Committee as a sub-study of the previously approved ACE Hybrid Effectiveness-Implementation Study. Employer and company details were not used as part of the collected data in the study. Vocation specific details were explored through the National Occupational Classification (*NOC*) database (Government of Canada, 2018).

Programming.

The functional interventions were developed based on each participant's COPM goals. The interventions created a simulated environment wherein the participant's vocation-specific needs and current ability levels were challenged. As the pilot was conducted in fitness and physical therapy settings, selection of individualized interventions required creativity and imagination to simulate a work environment yet also fit within the limited surroundings. For the

purpose of the functional interventions, gym equipment was repurposed into work equipment. For example:

- A chair with a pedal became a driver's seat for a participant whose goals included improving driving tolerance for managing work-related vehicle travel;
- An inclined treadmill used with a pushing motion on the front display to simulate moving a hospital bed down a hallway for a participant who was returning to a nurse position;
- A sandbag weight lifted on and off a chair served as a simulated transfer to work on upper body strength and endurance for a participant who worked as a paramedic.

All included functional activities were individually designed to fit the participant's specific goals and current level of physical ability, as determined from the physical lift testing and ACE exercise data. Grading and adapting—techniques to modify the challenge or scope of a task—were used by the occupational therapist in collaboration with the participants and updates from the research staff on a weekly basis. Some examples of grading include the following: for driving simulations, the range of the wheel-turning shoulder movements and the range of motion of the shoulder checking movements were increased over time; for hospital-bed-pushing simulations, the speed or incline of the treadmill was systematically progressed to increase the challenge; for paramedic transfer simulations, the weight of the sandbags and height of the lift were progressively increased as adaptation occurred. See Table 2 for an example of interdisciplinary functional activity interventions targeting fatigue and work-related concerns for a neonatal nurse.

Section summary.

- Development of interdisciplinary terminology was important to the success of the pilot as physiotherapists, kinesiologists, and exercise professionals were support personnel for the pilot intervention.
- Recruitment was carried out via the parent study.
- Ethics were obtained through the parent study, which meant that the pilot study had to fit with the criteria of the already existing parent study.

6.4. Method in Action

Over the course of eight weeks, all seven participants (100%) completed their initial assessment, 6-week intervention, and final assessment. In the initial session, all participants were able to identify three to five functional and work-related CRF concerns based on the COPM. Occupational therapy-driven functional interventions were tailored for each participant to address his/her COPM reported concerns, both physically and functionally. All participants completed weekly grading and/or modification of the functional activities as prescribed by the occupational therapist.

The development of the functional interventions proved more time consuming than was originally estimated. This discrepancy in time management resulted from the individualized nature of each activity and the time required to consider how exercise staff could best facilitate the assigned activity. For example, in the driving simulation, the instructions provided to the exercise trainers did not explain the function of a driving simulation. Rather, the instructions detailed the physical requirements of the task, such as the angles and posture for sitting; the weight and angle for the shoulder exercises with the simulated steering wheel; the position, angle, and frequency of the calf-pumping exercise simulating the gas and brake pedals. The occupational therapist's time for communication with the interdisciplinary team and translating

of the functional language (i.e. driving simulation) into physical conditions (i.e. specificity of the physical details of the task) required more time than originally planned. Overall, however, the attention to development of the interventions resulted in a relatively seamless embedding of the functional interventions into the physical exercise program.

In the week following completion of the functional interventions, final assessments were conducted. All participants (n=7/7) showed meaningful change scores (minimum 2 point difference) on their COPM scores. Essentially, the pilot achieved its goals: developing functional interventions, and embedding the occupational therapy programming within a physical exercise program. For participants, the interventions meaningfully targeted three to five of their self-identified, most important CRF work-related concerns, thereby improving their work self-efficacy. Overall, the pilot study was successfully completed.

Since the pilot was unique both in design and implementation, it provided many opportunities for learning and sharing. Despite its very small sample size, this pilot study evidenced the challenges of carrying out implementation research, particularly when the work is tailored, time sensitive, and, by nature, consistently changing to meet the demands of the study participants. Essentially, this pilot required 7 simultaneous and distinct functional interventions developed by the occupational therapist, with each intervention capable of being graded and/or modified during each week of the study.

Successes

6.4.1. Collaboration

Great insight was found into the ways in which interdisciplinary research can be effectively developed during this study. This occurred due to the opportunity to collaborate with the physiotherapists, certified exercise physiologists, and kinesiologists, seeing how they

embraced the occupational therapists' creative and functional approach to the functional interventions. For example, in the driving simulation, the collaborative efforts of kinesiologists, a physiotherapist, and an occupational therapist enabled the development of a driving simulation that also satisfied the physical exercise requirements of the general exercise program.

Moreover, the opportunity for the exercise trainers to participate in the pilot provided an opportunity to further their understanding of the personalized and functional needs of the participants.

Work self-efficacy outcomes (performance and satisfaction).

Participants reported that the opportunity to discuss their work-related concerns in a safe space helped them in both physical and mental preparations for return-to-work. However, when pilot participants took part in their individual, functional simulation activities side-by-side—one simulating the pushing of a hospital bed; another simulating the walking between desks in a classroom and the collection of items off simulated desks; and a third simulating the walking in a NICU corridor and transferring of newborn babies from incubators to beds—and engaged in work-related conversation about their increased confidence in their work capabilities, researchers clearly noted that, in the same way as participants in the general exercise program were becoming more confident in their physical abilities and the strength and endurance of their bodies, so, too, were gains being made in participants' work self-efficacy. The functional interventions and the physical exercises had become part of the same training and translation for real world task applicability.

Low cost, efficient implementation strategies.

As with many graduate research projects, this pilot had limited funding yet demanded implementation of new activities on a small budget. With a graduate studies thesis operating

grant of $4000.00 provided by the Faculty of Rehabilitation Medicine at the University of Alberta, approximately $1000.00 (CAD) was spent on supplies and $3000 on staffing costs for the study for the 6 weeks of the intervention. The creative process used to develop the simulations enhanced rapport between the research team and the participants, as increased collaboration and personalized focus were required for the effective implementation of challenging interventions for each participant while still maintaining the physical and safety guidelines of the general exercise program.

6.4.2. Challenges

Effective timing.

Time management was an issue in this pilot, as determining how much time tasks required both for planning and for facilitation was difficult to ascertain. The conception of appropriate functional activities took longer for some than others, given the limited resources for simulating work spaces. For example, creating the nursing station of an operating room, complete with fine tools to pick up, required collection of the simulated small tools, and their careful arrangement within the simulated work station, in order to target properly the fatiguing muscle groups identified by the participant. In the end, taping on the floor allowed the occupational therapist to mark the identical spot, so that the simulation could be positioned, taken down, and repositioned in the same place for all 6 weeks of the pilot.

Further, timing was an issue in a study with multiple participants and only one occupational therapist. The timing of the sessions to accommodate the general exercise programming meant that sometimes several participants were simultaneously present at the facility, while at other times, no participants were present. Staggering the intervention times

would have been beneficial for the pilot, but may not have accommodated participant needs for scheduling of the general exercise program (the parent study).

Coordination of the final testing required clear and transparent communication between all the members of the research team and the participants. This was to ensure participants were not overwhelmed by too many tests or testing sessions, for both the pilot and the general exercise program. Providing flexible schedules to participants and coordinating the limited clinic spaces proved challenging.

Determining outcome measures.

Different disciplines focus on different outcomes and endpoints. The outcomes for the pilot had to fit with those of the parent study, while still staying true to the functions-based focus. Since there is not yet a single gold standard measure for CRF, and since new endpoints were being introduced in the pilot, discussions were required concerning which assessments to use in the pilot and why. After much dialogue, the research team agreed that a physical measure, a participation measure, and a work self-efficacy measure, would be ideal for use in the pilot given the large amount of data collected as part of the parent-study. Though collection of more employment and employer details may have proven beneficial, the nature of the pilot and its time and ethical constraints did not allow exploration of this avenue. While other occupational therapy studies may have used more functional assessments, the balance between needed outcome data and the potential burden on participant's time were important considerations.

Section summary.

- While the overall outcome of the pilot can be considered a success based on the achieved results of meaningful change scores, the research journey should be considered as an outcome in its own right.

- Many teachable and learnable moments required knowledge sharing to determine how best to develop an interdisciplinary study.

6.4.3. Practical Lessons Learned

While the pilot undertook to look at functional interventions, CRF management, participant self-reports, and work self-efficacy, the unique design and implementation of the pilot offered opportunity to also consider the effectiveness interdisciplinary research, shared language, study designs and methodological processes, and communication skills. Specifically, the learning opportunities presented most clearly in determining how to (1) successfully prescribe the functional interventions without disrupting the exercise program, (2) measure the functional activities using a distinct design from the parent study, and (3) collaborate with the staff and trainers to support inclusion of functional activities as part of a physical exercise intervention.

Learning moment 1: The challenge of targeting multiple, meaningful endpoints in interdisciplinary research.

Interdisciplinary research can prove challenging, as mutual disciplinary awareness is required for effective collaboration on both common and distinct outcomes, as well as having consideration of the time and effort required by the participant. A study with too many measures or too high a demand for time or effort from the participants, is unlikely to be successful. Similarly, an interdisciplinary study that does not focus sufficiently on each discipline runs the risk of not managing meaningful outcomes for the specific disciplines involved and, therefore, not being able to deliver the interventions or to measure the targeted outcomes. In addition, other professionals' limited awareness can be an additional challenge regarding the specialized skill-set of the occupational therapist in functional activities, and how occupational therapists are trained in addressing the physical, cognitive and emotional aspects of the person and the fit with

the environment and occupations. Navigation of research from within different professional backgrounds can require adjustment to the ways in which single disciplined research might be conducted.

The successful management of interdisciplinary research requires that consensus on outcomes, development of mutually exclusive versus shared interventions, and agreement of terminology and language used within the scope of research should be reviewed and discussed as a team prior to commencement and at key points during the research continuum.

- Collaboration is required in interdisciplinary research to develop shared outcome measures.
- The time demands for an interdisciplinary study should take into consideration the commitments required by the participants.

Learning moment 2: Perspective taking and shared language.

While the goal of most patient-oriented research is better understanding and ultimately improvement of the patient experience, there are many different approaches to development and execution of studies. Consideration of which discipline is developing and carrying out the study is important, as various healthcare disciplines have unique models of practice, distinct clinical and research foci, specific terminology, and specific measurable endpoints. In this pilot, kinesiologists, certified exercise professionals, and physiotherapists were asked to adapt their routine exercise program to facilitate unique functional interventions. Specifically, the trainers conducting the exercise study were tasked to stretch the concept of their working environment in order to allow the gym spaces to encompass a "real world" applicability and simulation component. The trainers supported collaborative research by embracing the imaginative component of the functional pilot trial. For example, when asked to imagine that walking on

treadmills was actually pushing a hospital bed down a corridor, or that exercise rooms were actually busy hallways of schools, or that chairs were actually the driver seats of cars, they wholeheartedly supported the pilot interventions, and encouraged participants to do so. Were it not for that mutual respect and acceptance, the study would not have been sustained over the six week intervention timeline.

Further, were the study specific only to occupational therapy, functional language may have more routinely been used and more familiar to occupational therapy researchers. However, given that the parent study was rooted in exercise and quality-of-life outcomes, the research language focused heavily on physical outcome measures. In developing interdisciplinary functional interventions and explaining how these functional interventions were to be conducted, the occupational therapist's selection of terminology in order to be understood by physical-specific disciplines became crucial to the success of the pilot.

The ability to take the perspective of the different disciplines and to translate the needs of the occupations-based intervention into physical-measurable terms became the key to the success of the pilot. For example, in the driving simulation, seated tolerance for driving was referred to in physical terms as "forward-flexion shoulder range of motion, with calf-pumping exercise, in seated position", rather than as a functional description of "driving simulation" activity, in order to fit the perspective of the parent-study trainers and the focus of the parent-study. Successful interdisciplinary studies should consider the approach and terminology of all professionals involved and support accessible and cohesive wording and contextualization.

- Perspective taking involves consideration of how and why different disciplines might approach similar situations.

- Mutual respect for other disciplines fosters the development of more collaborative research approaches.
- The terminology used in interdisciplinary studies should reflect a consensus amongst all disciplines involved, so as to best reflect collaborative research.

Learning moment 3: The outcome benefits of well-rounded research.

The development of a methodological approach is very time consuming, specific, and detailed. The development of a distinct methodological approach for a pilot that is different from its parent-study is very specific and time consuming. While the benefits to interdisciplinary healthcare research are known—namely that it is timely, relevant, and clinically applicable—the commitment required by all team members to support research of a shared nature is crucial. Teams must work together to promote and support the development and biased-free implementation of well-rounded, interdisciplinary research.

The goal of the parent-study was primarily to improve physical outcomes, whereas the pilot focused on functional outcomes. In this regard, participants in this pilot brought their professional work-related narratives into the physical exercise program, and in doing so, provided the trainers with opportunity to address physical challenges in relation to specific individualized functional goals. This amalgamation of functional and physical endpoints is an example of how an interdisciplinary scope offers a potentially effective means of truly connecting with client-driven or client-centred practice in a way that uni-disciplinary research cannot necessarily tackle. Since humans are multifaceted, increased knowledge and understanding of an individual's background and priorities can be foundational in supporting his/her specific functional outcomes, in ways that are personally relevant and meaningful.

This pilot came to exist following patient-reported and clinically perceived need for services, which were not yet well addressed in the literature. The pilot provided a learning opportunity to prove that seeking out gaps in clinical practice and research, and pursuing developing areas of practical health-based research, offer researchers a space in which to develop research with clinical applicability and potential that can truly improve the scope of patient care.

- Research that provides insight into how humans engage, participate, and interact within their environments may offer opportunity for progressing client-centred clinical care.
- The pursuit of areas of study that remain under represented and/or are developing offer opportunity for emerging healthcare research to engage and progress clinical practice standards.

6.5. Conclusion

Conducting interdisciplinary research within implementation study provides a novel and exciting research opportunity with unique challenges. In this pilot, the authors often reflected on the team-based approach to research, the importance of implementation, and the vast prospects that functional and occupations-based research can contribute to physical-based research, and vice versa.

The single subject design and utilization of the COPM link the individual participant experiences to quantifiable outcome data. This unique approach to the study design has implications for better understanding the participant experience during the intervention and, in the future, for increased opportunities to adjust the interventions even more as participants engage in similar studies.

An interdisciplinary design needs to consider the terminology, assessments, and interventions used to ensure that the work is, in fact, reflective of the multiple disciplines involved. Further, in future tailored interventions that explore CRF and work-related functional considerations, the ease of implementation, the fiscal accessibility, and the time efficiency for the participants should be considered.

If a successful study is one that contributes interesting and unique outcomes to the body of research, this pilot certainly offers preliminary work self-efficacy endpoints that are relevant to both physical and functional domains. If a successful study also entails making the researchers question their practice and choices, this pilot provides a place for researcher growth and learning about interdisciplinary roles and the significance of collaboration and teamwork in the interdisciplinary research process.

Table 6-1. Demographics (*n*=7).

Variable	**Value**
Age: Mean (±SD)	44.3
Range	26–62
Sex:	
Female	5
Male	2
Employment status	
Return to work/partial work within 3 months prior to study	2
Return to work/partial work during study	2
Return to work/partial work within 1 month post study	1
Not working during study or 1 month post study	2
Time since diagnosis	
Within the first year	4
>1 year	3
Vocations	
Neonatal nurse	1
Acute care nurse	1
Operating room nurse	1
Paramedic	1
Yoga instructor	1
School teacher	1
Clinic nurse coordinator	1

Table 6-2. Example of interdisciplinary functional activity interventions targeting fatigue and work-related concerns for a neonatal nurse.

Fatigue work-related concern	Intervention	Implementation and time commitment	Grading	Approx. cost (CAD)	COPM initial score	COPM reassessment score
Lift, carry, and transfer infants (at 8 lbs, for approx. 10 min)	Use of sandbag weights to simulate infants (8 lbs max) Use treadmill for 10-min moderate-fast paced walking Transfer infants to planks on railings on treadmill	Use as part of cardiovascular section of general exercise program. 15 min maximum	Adjust time, weight, frequency of transfers, speed of walking	Sandbag weight (approx. $10.00 CAD); plank pieces (approx. $15.00 CAD)	Performance: 3 Satisfaction: 1	Performance: 6 Satisfaction: 8
Maintain stamina to rush to patient emergency (sprint 1 city block)	Use of treadmill with increased speed for 1 min as part of walking intervals	Use as part of cardiovascular section of general exercise program. 15 min maximum	Adjust incline of treadmill, frequency of intervals, speed of walking	No added cost	Performance: 5 Satisfaction: 2	Performance: 6 Satisfaction: 9
Manage repeated forward bend for positioning of patients	Standing forward squatting, bending, and lifting to waist level with sandbag weights	As part of exercise program. 5 min maximum	Adjustment of weight, depth of squat and bend, endurance	Sandbag weight (approx. $10.00 CAD)	Performance: 3 Satisfaction: 2	Performance: 8 Satisfaction: 10

Chapter 7

Discussion

Chapter 7

Discussion

7.1. Introduction

This closing chapter connects the relevance of the preceding chapters and concludes the dissertation. In line with an implementation-focus, this chapter discusses the dissertation work from both research and clinical perspectives. First, this chapter reflects on the researcher positionality with respect to the approach to CRF and work-related considerations, models, and frameworks used in the dissertation research as compared to standard practice. Second, this chapter re-introduces the two pillars of this dissertation, summarizing the major considerations of current management of CRF, and CRF with respect to work-related issues. Third, this chapter highlights the major achievements of the work, in addition to the challenges and limitations. Finally, this chapter proposes potential areas for future research.

7.2. Researcher Positionality

In completing this dissertation and satisfying the requirements for my doctoral degree, I can reflect on all that this research has afforded me, both professionally and personally. Were it not for the patients who encouraged me, and the researchers who educated me, and the frontline clinicians who supported me, I would not have been in a position to accomplish this work. Certainly, the mix of clinical and research opportunities enabled me to approach the subject of CRF and work-related outcomes from many vantage points. When I reflect on my position regarding research, I default to a middle ground of using a multi-methods approach to answer research questions through the scope of implementation practice. My position is that research in cancer rehabilitation ought to be clinically relevant, patient-progressive, and relatable/scalable (Sacristan, 2013).

This dissertation work took advantage of opportunities that presented along my journey through graduate studies, with each study informing the next. Because so little research has been done (de Boer, Taskila, Ojajarvi, Van Dijk, & Verbeek, 2009; Nitkin, Parkinson, & Schultz 201) and the need is great (Bijker et al., 2018; Gehrke & Feuerstein, 2017), the field offered unlimited research opportunities. The challenge for me was where to best start. Thus, as a first step, I sought to explore, describe, and better understand the cancer survivors' perspectives on CRF and later its impact on work-related outcomes. My rationale was that this groundwork needed to be established before I could consider investigating the complex and multi-faceted nature of implementing return-to-work (RTW) programming (Harvey & Kitson, 2015). As there was also a lack of an accepted methodology to guide targeted research on RTW programming, and no guiding evidence to direct interventions, I problem solved, as I would do in the clinical setting when working with cancer survivors. I appreciate that this 'thinking outside of the box' meant that my research deviated from traditional research approaches, and thus may appear somewhat unorthodox. I strongly feel this type of practical-focused research—research that stems from my clinical implementation lens (thinking clinically and being present-focused, while also thinking about future implementation at the outset of research)—is what is needed to start to tackle this large gap in care related to CRF in the context of cancer survivor workability. Figure 7-1 depicts the clinical relevance, problem-solving, and progression across the two pillars of research in this dissertation.

My hopes for this research endeavor are three-fold. First, I hope that this work can be seen as a first step in engaging both occupational therapy and physiotherapy in CRF and work-related outcomes in a practical and efficient manner. Through a shared rehabilitative approach we can critically examine how we define and label issues surrounding cancer sequelae based on

the functional and quality of life outcomes, and not just on the medical and physiological determinants. Second, I hope that this work will be meaningful and motivational to other researchers and healthcare professionals, and can serve as a bridge between research and clinical practice. For frontline clinicians who wish to pursue research endeavours, I hope that this work serves to encourage such pursuits. It is my deep belief that cancer rehabilitation will only continue to grow if we integrate research and practice, recognizing the importance of both aspects of our profession. Finally, I hope that this work leads to positive outcomes for those negatively impacted by issues of CRF and workability.

7.3. Dissertation Pillars

7.3.1. Pillar I. Exploration of CRF (from experiential and clinical perspectives)

The examination of CRF-specific issues from the perspectives of cancer survivors provides new opportunity to enhance our understanding of the condition as it manifests at the level of the individual. On critical examination of the current approach to CRF-management, it is obviously medically focused, addressing CRF as a condition comprising (1) consistent low energy, and/or misuse of the term 'tiredness' to explain fatigue, (2) limited activity engagement, and (3) impairments in physical strength and endurance (Dolgoy, Krishnasamy & McNeely, 2019). Despite the identified need for increased rehabilitative supports, the number of published functional interventions and occupational therapy-focused interventions in this area remain scarce (Polo & Smith, 2017). The findings of the studies in this dissertation exploring CRF suggest the need for a change in the way in which CRF is characterized; the research of this dissertation found CRF to be a condition (1) involving fluctuating and unpredictable energy levels, (2) negatively affecting cognitive and physical functioning, and impacting activity engagement, and (3) responsive to cohesive physical exercise and functional conditioning.

7.3.2. Pillar II: CRF in the Context of Work-Related Rehabilitative Opportunities (using the platform of a cancer-specific physical activity program)

The establishment of rehabilitative guidelines and protocols for services specific to the functional, physical, and cognitive impacts of CRF on workability remain a necessary future goal for best practice (Stout et al., 2016). The ACE@Work study presented in chapters Four, Five and Six offered opportunity to first explore CRF in context and then implement programming, as a primary step towards addressing the development of concrete and ongoing rehabilitation throughout the cancer trajectory. While further research and development of the rehabilitative and functional understanding of CRF and its impacts on work-related outcomes remains essential in informing and progressing both clinical practice and the work-specific supports available to cancer survivors, this study was able to address timely issues through the final product of proof-of-concept implementation (Chapter Five). Given the knowledge that CRF continues to impact working-aged cancer survivors makes developing rehabilitation to address issues in a functional and efficient manner all the more imperative.

The majority of the published research that describes the issue of unemployment for cancer survivors looks at the individual statistics from an economic standpoint, specifically focusing on missed days of work and lost revenues (Silver, Baima, Newman, Galantino, & Shockney, 2013; Seifart, & Schmielau, 2017; Guy et al., 2013; Jagsi et al., 2014). Through the second pillar, this dissertation offers a different vantage point by looking at CRF and work-related outcomes through (1) the perspective of the individual experience, and (2) the opportunities for functional interventions that target CRF, and that make use of a shared physical and functional approach to care. Given the complexity of CRF and the range of its effects,

physical exercise programs that transition to functional outcomes—thus bridging the cancer survivor from exercise activities into real-world engagement—have the potential to offer beneficial outcomes, while making efficient and effective use of existing rehabilitative resources and the cancer survivor's energy (Fauser et al., 2019; Stubblefield, Schmitz, & Ness, 2013). While previous studies, such as a high resistance exercise program, found benefits in exercise alone for reducing the time-frame for returning to previous work, there was no long-term follow up with participants to know whether they continued to see improvements as their work tasks increased (Thijs et al. 2012). The work of this dissertation suggests that reliance on rehabilitation through physical exercise alone may limit the scope of interventions.

7.4 Study Achievements

Two achievements arose from the dissertation research. First, an understanding of the need for a paradigm shift in the current approach to CRF, and second, an understanding of the feasibility and potential for implementation of programming relating to CRF and work-specific activities.

7.4.1. A Paradigm Shift in the Current Thinking on CRF

The exploratory findings highlight distinctions between how CRF was/is typically managed (what we do now), and also, the potential opportunities for change (what can be done). Four important aspects of the need for a paradigm shift in the current approach to CRF will now be described.

7.4.1.1. CRF language and descriptors. The studies presented in Pillar I, Chapters Two and Three (namely the JARS study, and the TARGETing CRF study), point to the language and descriptors used in addressing CRF. Key findings of Chapter Two include the reported inconsistencies in the manner in, and degree to which energy fluctuations impacted cancer

survivors' usual activity engagement, and the degree to which CRF affected each individual's sense-of-self. The two novel targets that emerge from the data in this study are the themes of "uncertainty" and "sense-of-self". These two constructs are not addressed in the typical screenings, basic education, or treatment for CRF (National Comprehensive Cancer Network [NCCN], 2020). Key findings in Chapter Three reveal cancer survivors reported CRF in terms of its impact on function and daily life. The findings of this study, similar to the findings of the JARS study (Chapter Two), point to the importance of assessing function and considering functional engagement in the approach to CRF rehabilitation.

At the systems level, CRF is viewed through the medical definition of a steady-state of low energy or tiredness (NCCN, 2020; Dolgoy, Krishnasamy & McNeely, 2019). In contrast to this medical definition of CRF, the participants reported inconsistent and fluctuating nature of CRF symptoms, suggesting the need for an approach that acknowledges and works with the unpredictable manifestation of the condition. Of the current self-reported tools commonly used to screen for CRF symptoms, neither the Functional Assessment of Cancer Therapy-Fatigue (FACT-F) nor the Edmonton Symptom Assessment Scale (ESAS), target the uncertainty (unpredictability and fluctuations in symptoms) or sense-of-self (impact on identity, or life roles) (Yellen, Cella, Webster, Blendowski, & Kaplan, 1997; Richardson & Jones, 2009). Thus, these screening tools do not utilize the necessary terminology to adequately capture these nuances that are critical to inform interventions.

7.4.1.2. Tiredness distinct from CRF. From the findings in Pillar I, together with the findings of the ACE@Work interview study (Chapter Four) in Pillar II, the terms "tiredness", "fatigue", and "exhaustion" all presented as different, but related constructs on the symptom continuum. The Fatigue Adaptation Model describes a continuum of energy states, which

includes tiredness, fatigue, and exhaustion; these states adapt to symptoms of limited energy second to behavioural patterns (Olson, 2007). In contrast to Olson's (2007) findings, the ACE@Work interview thematic findings indicate that rather than using behavioural patterns as markers, participants reported their severity of CRF symptoms in terms of functional outcomes and activity engagement, calling for support to transition between levels of activity performance. The functional effects of being tired are arguably distinct from the functional effects of being fatigued or exhausted; namely, a tired state is remedied by sleep. CRF does not respond positively to sleep alone, but does respond to activity engagement, and specifically exercise interventions (Bower, 2014). While the Fatigue Adaptation Model provides a straight continuum of fatigue states, the findings for CRF would warrant a different shaped model; a model that accounted for the highs, lows, and changes in activity tolerance that are part of the CRF continuum. With CRF, ongoing fluctuation does not indicate a lack of condition management, rather, awareness and response to these fluctuations would be the goal for interventions to manage symptoms.

Given the different multifactorial and systematic effects of cancer and cancer treatments on the state of being tired, the findings from the ACE@Work interviews with past-exercise program participants from the ACE study, also reflect the differences in CRF compared to other types of fatigue. Frustration was frequently described with respect to slow and lengthy recovery timelines, and in regard to limited healthcare and work-related rehabilitative services.

7.4.1.3. Energy cultivation. Through the work in Pillar I, the concepts of energy cultivation versus energy depletion emerged as a novel approach to facilitate balancing and nourishing energy through activity engagement. The findings of this dissertation point to the need for a shift in the perspective of CRF screenings and management from one of energy

allocation as ‘energy usage’ to a focus on energy usage as a structuring of ‘energy cultivation versus depletion’ in activity engagement. Table 7-1 identifies the current and proposed approaches to CRF, as a culmination of the exploration of CRF in Pillar I.

The current and long-standing practices of CRF management use approaches that manage current energy levels, including energy conservation, energy allocation, and energy maximization (NCCN, 2020); these approaches inherently assume that baseline energy is low and limited, such that energy output should be used to maximize activity engagement during peak energy times (Vatwani & Margonis, 2019; Barsevick, et al., 2004). While these methods focus on usage of the energy a person currently has, they do not offer the functional- and engagement-focused approach to progressing, or increasing, the baseline of fluctuating energy levels that an ‘energy cultivation versus depletion’ perspective allows.

As such, the energy cultivation versus depletion approach considers that the more opportunity an individual has to gain awareness and autonomy over how their activities impact their fatigue and vice versa, the more opportunity they should have to control and manage the awareness around their fatigue symptoms, if not the actual manifestations of some symptoms. With a consideration of cultivation of energy, human energy is likened to a natural resource, wherein regrowth, development, and increase of that resource occurs through functional rehabilitation and a combined focus on occupational and physical endpoints. Facilitating growth or cultivation of energy occurs through a combination of factors, including physical activity, nutrition, hydration, positive social interactions, productive activity engagement, and healthy mental wellness practices. From a clinical perspective, these findings speak to the need for further research and development of programming and tools that enhance awareness of energy levels, and, through self-awareness, appropriate amounts of activity engagement, second to

available energy allowances. As a preliminary self-rating Likert scale, Figure 7-2 depicts a clinically relevant tool developed from the findings of Pillar I applied to Pillar II's exploration of CRF in context of work-related consideration. The scale can be used as part of an energy cultivation approach, to support a cancer survivor in describing and understanding energy, symptom management, and activity engagement; the intention would be to trial the use of this tool in future research.

7.4.1.4. Consideration of activity and timing in CRF symptom presentation. In considering both the exploration of CRF in Pillar I, and the exploration of CRF in a work-specific context in Pillar II, issues around functional management and transition of activities across continuums from healthcare settings to community settings were evident. From a clinical perspective, the implications of an inconsistent presentation for CRF, and the manner in which healthcare and/or work stakeholders comprehend the behaviours associated with CRF also have an impact on the professional assessments and approach to work-related outcomes. For example, if a cancer survivor who participates in functional RTW testing experiences symptoms that change throughout the day or week, he/she may appear to be inconsistent in his/her reported abilities and functional presentation, which can lead to the mislabeling of these individuals as malingerers (Islam et al., 2014). Other chronic, flaring conditions (such as auto-immune disorders) are known to have negative impact on activity engagement, identity, and workability (Hoving, van Zwieten, van der Meer, Sluiter, & Frings-Dresen, 2013). Currently, CRF is often compared to chronic fatigue, although the mechanisms driving the two conditions are vastly different—CRF being solely the result of cancer—and the manifesting symptoms are also distinct—CRF not responding positively to increased sleep, general activity reduction, or routine planning, as does chronic fatigue (Park, Jeon, Bang, & Yoon, 2019). Further, the cognitive and

physiological symptom combinations of CRF are concretely different from those of chronic fatigue, particularly when the medical and pharmaceutical components of CRF specific to cancer care are taken into account (Park et al., 2019). The target of uncertainty points to rehabilitative interventions that focus on the inconsistent and unpredictable nature of CRF symptoms.

The current approach to CRF management follows stages similar to the medical model of care for cancer—specifically acute care, routine activity, and ongoing maintenance—and falls short in supporting cancer survivors in the transition from acute to routine activity engagement (Mehnert, 2011; Silver, Baima & Mayer, 2013). Participants of the ACE@Work interviews (Chapter Four) were calling for care during times of transition and/or activity changes. Drawing on Courneya & Friedenreich's Physical Activity in Cancer Care (PACC) framework (2007), and with consideration of Silver, Baima & Mayer's concept of rehabilitative opportunities at each point in the cancer trajectory (2013), Figure 7-3 depicts a model of the proposed energy cultivation approach as it would apply to workability contexts. Note that in the current approach to CRF, the predominant failures in RTW interventions occur in early stages of returning to work (Feuerstein et al., 2010). Participants of the ACE@Work interviews noted similar concerns, and some even proposed work-related rehabilitation options that would be similar to physical training they underwent in the ACE study, and progressive in nature. This finding regarding a need for functional and practical interventions in the transitional period prior to returning to work led the research team to cogitate on combining physical and functional programming. To the research team's knowledge, there are no published studies that utilize combined and individualized functional and physical training programs for cancer survivors with work-related barriers secondary to CRF.

7.4.2. Feasibility and Implementation of CRF Interventions

Pillar II of this dissertation focused on the feasibility and implementation of an intervention for CRF and work-related outcomes. The ACE@Work interview study, ACE@Work proof-of-concept study and the knowledge translation exploration chapter (Chapters Four, Five, and Six) present the progressing from exploration to implementation of tailored functional work-related activities as augmentations in an existing physical exercise program in advance of formal RTW programs and functional simulations.

7.4.2.1. Embedded program design. Embedding the additional work-related activities into the already existing and scheduled exercise program offered an efficient way to include functional work-related outcomes in the physical exercise program, without overloading the participants (as demonstrated by the adherence and patient-reported COPM outcomes) (van Egmond et al., 2016; deBoer et al., 2015).

7.4.2.2. Measurement: lift tests. From a work-related perspective, the lift tests used in this study must account for several factors, including the individual fitness level, the type of job, and the specifics of the cancer itself. Risk factors for cancer sequelae (such as chronic edema) should be considered when developing physical testing in this population (Berger, Gerber, & Mayer, 2012). Survivors with vocations that are physically demanding and involve heavy lifting are less likely to have successful workability outcomes (Feuerstein, et al., 2010). Further, physical conditioning through exercise programming is known to support work-related outcomes in cancer survivors; therefore a combined approach of the physical and functional activities may offer the potential for a more effective and efficient rehabilitation outcome (Feuerstein, et al., 2010; Mehnert, 2011).

7.4.2.3. Measurement: work self-efficacy, through satisfaction and performance self-ratings. Self-efficacy is a known determinant of task and goal achievement (Bültmann & Brouwer, 2013). In cancer and work-related research, the connection between workability and work self-efficacy has been established, but has not been extensively explored (Wolvers, Leensen, Groeneveld, Frings-Dresen & De Boer, 2018). Determining which measure to use for work self-efficacy in implementation was challenging. Use of individualized assessments for this study was important, based on the outcomes of the study presented in Chapter Four. The Canadian Occupational Performance Measure (COPM) was selected, although its use was shortened to fit the specific needs of this study. While the COPM is a well-known assessment in occupational therapy, it is typically used in its entirety (all three sections of activities of self-care, leisure, and productivity) (Dedding, Cardol, Eyssen, & Beelen, 2004). When the COPM was applied to the proof-of-concept study in Chapter Five, only the productivity section was utilized (for work-related considerations), making the questionnaire very effective and efficient in targeting and capturing issues of importance relating to work-specific targets for the participants of this study. In the absence of other individualized, cancer-specific, functional outcome measures related to work self-efficacy, the COPM offers an option for determining and measuring work-related components of self-efficacy, specifically performance and satisfaction. Meaningful improvements for each participant and for the group in general were seen across the measured domains of performance and satisfaction for productivity. The use of the productivity section of the COPM, while unique, offered opportunity to enhance understanding of the participant experience before and after the intervention. Measuring performance and satisfaction through the COPM provides insight into the manner in which the participants rated their work-related activity outcomes based on their self-perception. The improvements in performance and

satisfaction are consistent with work-related self-efficacy literature, which suggests that self-perception and self-belief are key components of positive task outcomes (Wolvers et al., 2018).

7.5. Study Challenges & Limitations

In consideration of the research as a whole, there are several challenges and limitations that impacted the research process. The issues I faced as a clinician (see Introduction, Positionality) were actually very similar to the barriers faced in this research. Specifically, incongruent timelines, limited applicable research, and problematic models and guidelines.

7.5.1.Challenges

7.5.1.1. Incongruent timelines. In terms of timelines, ensuring that research could be conducted that would suffice the end goal of an implementation project was challenging and required high levels of organization, flexibility, and team support. It was difficult to coordinate the multifactorial systems working to support patient care, while also considering the complex health needs and CRF symptoms of participants. At each opportunity to reflect on positionality, I continued to focus on a patient/participant-centred approach and used study designs strategically to be as inclusive as possible. The time-sensitive considerations of this practically focused approach, reflect the reality of implementation practice research.

7.5.1.2. Limited applicable research. There was minimal guidance from the literature to inform structures in which to situate the studies (ie. models and frameworks). Without applicable assessments, flexibility in design was paramount. Content and thematic analysis were employed across the studies with a purpose that differed from classical qualitative perspectives and typical methods of analysis. While implementation research utilizes aspects of qualitative research, the focus is practical, and aims to facilitate quality implementation of effective programs within a specific context (Estabrooks, Brownson, & Pronk, 2018).

7.5.1.3. Problematic practice models and guidelines. It was challenging to have access to so many models and guides but none that were sufficient for a cancer population with CRF and work-related considerations. This really speaks to the limited scope of rehabilitation-focused (separate from physical exercise) research in this area of clinical relevance. In overcoming this challenge, broader models were employed to effectively explore the issue in context.

7.5.2. Limitations

7.5.2.1. Practicality. The practical limitations in this study relate primarily to the timeliness and opportunities of conducting clinically relevant research. The tight timelines of a doctoral degree and the added pressures of a semester of research exchange, certainly created catalysts to complete the research efficiently. In implementation research, knowing the healthcare system and services in place is helpful to understanding the contextual factors. For the research in Chapter Two of this dissertation, conducted while on research exchange in Melbourne, Australia, it was at times challenging to set up the study, and required external support to understand the healthcare system in Victoria, Australia. In working through the limitations of time and knowledge in this study, I gained insight into the important differences in care options and services throughout different healthcare regions. In managing this limitation, the approach to research was consistently targeted to obtain practical outcomes; this experience supported the clinically-relevant results-focused designs of subsequent studies in the dissertation. In this regard, all of the research studies took advantage of timely opportunities to explore novel issues, with practical approaches being at the forefront of the approaches.

7.5.2.2. Discussion on theory and model selection. The theory and models used in this dissertation are broad, and therefore are not specific to cancer nor work contexts. The broader framing of the studies in this dissertation may be seen as a limitation given the specificity of the

issues being explored. However, in the absence of more appropriate models and theories, the models used to guide the work—the Person Environment Occupation (PEO) model and the Social Ecological (SE) model—were selected to work together in exploring the unique perspectives of each of the study participants within the levels of social systems in which they function (Strong, Rigby, Stewart, Law, Letts, & Cooper, 1999; Golden & Earp, 2012). Overall, the studies appropriately made use of framework and models that aligned well with the scopes of exploration and description, without confining the research to ill-fitting, yet more cancer specific options. Social theory allowed for exploration of CRF from a new vantage point, particularly being able to consider outlying information that didn't fit the currently accepted norms, and in doings so, allowed for exploration of new practice opportunities.

By using a content analysis approach with social theory and the two models, the study findings could be mapped to the implementation strategies, and therefore, the theories and models selected, together with the analysis process, allowed the findings to be made very relevant to implementation programming in cancer care.

The limited space allotted in publications made it difficult to fully describe the relationship among theory, models, and approaches in the exploratory chapters/studies; limiting the opportunity to describe and link theoretical underpinnings more explicitly to the research.

7.5.2.3. Use of the Canadian Occupational Performance Measure (COPM). The COPM measures self-perceived importance, performance, and satisfaction in task engagement. However, the COPM is not an accepted measure of self-efficacy nor work self-efficacy, and does not explicitly explore task/activity readiness nor self-belief in task/activity success. Thus, the use of this measure was exploratory in nature and requires further research to validate appropriateness of use in this research context.

7.5.2.4. Chosen study designs. Many of the limitations and challenges of this research lay in the progressive (less conventional) designs of the studies. Each study was approached with consideration of the participant group and their specific needs, the timely opportunity, as well as the potential for clinically relevant outcomes from a targeted approach.

In the study presented in Chapter Three, a major consideration of the design was in the choice not to use verbal communication, in order to enhance the accessibility of participation for head and neck cancer survivors. Given the rich data that emerged from the findings of that study, it was determined that the design appropriately fit the participants' needs and provided a timely opportunity to gather findings from an under-represented subject group (Simcock & Simo, 2016).

In the final study, presented in Chapter Five, there was ample consideration of using a pre- and post-test design, which can be viewed as a limitation given that formal assessment only happens at two critical points in the research. In embedding new programming within an existing research program, in the case of this pilot study, the pre- post-test design was determined to be a manageable design, showing feasibility of participant participation, which has been previously reported in past literature as a challenge of implementation studies in similar areas of research (van Egmond et al., 2016). While embedding the study within a parent-study ensured there were limitations based on having to engage in research within the parameters of an existing study, the parameters of the parent-study are contextually relevant to how clinical practice is often limited in services, spaces and equipment. Thus using the two points of measure and the fixed-parameters of the parent-study ensured that the research targeted: (1) successful prescription of the functional interventions, without disrupting the physical exercise program, (2) ongoing and accurate measurement of the functional activities, and (3) collaboration with the staff and trainers

to support inclusion of functional activities into the physical exercise intervention. Given cancer care is working towards this goal of interdisciplinary interventions for cancer survivors (NCCN, 2020), the study design effectively focused on the research while demonstrating clinically relevant feasibility.

7.6. Recommended Clinical Practice

The statistical narrative for many cancers has evolved from a focus on mortality, to consideration of cancer as a chronic disease. Thus, issues around economical impacts and individual wellbeing associated with cancer survivorship are now of increased importance (Stubblefield et al., 2013; Jagsi et al., 2014; Islam et al., 2014). The concept of recovery in cancer is also shifting focus; a disease that was once the sole jurisdiction of physicians now calls for the involvement of rehabilitation experts to manage complex and ongoing multifactorial issues. The findings of this dissertation point to the importance of multiple disciplines—occupational therapy, physiotherapy and exercise physiology—working together in the management of cancer rehabilitation—specifically of CRF and work-related functional outcomes—utilizing a shared approach that considers both the physical and the functional needs of an individual.

The sequential studies in this dissertation point to an important end: the lexicon, including the definition of CRF, needs to change if we are to refine our approach to the rehabilitation of the condition. Once a more functional awareness of CRF as a condition involving fluctuating energy, unpredictable symptom triggers, uncertainty, challenges with life participation, and issues of sense-of-self is established, rehabilitation can focus on function, engagement, and—most importantly—workability.

This work has shown that involvement of occupational therapists, together with physiotherapists and exercise physiologists, in a shared approach to managing both the functional and physical aspects of CRF is feasible. Greater involvement of the interdisciplinary team in CRF management ensures functionality to any rehabilitative approach and may better transition and bridge survivors from physical exercise rehabilitative sessions to practical, real-world applicability (Gagliardi, Dobrow & Wright, 2011; Dolgoy et al., 2020 - in press).

7.7. Future Directions

The findings of this dissertation suggest that further research is needed that considers an individualized approach to CRF management in the context of work-related outcomes.
I propose the following areas of future research:

- Continued research into the terminology and lexicon of fatigue from an implementation and quality improvement perspective. Research geared at using tools developed through this dissertation (such as those included in this chapter) in healthcare and community settings. In clinical settings, there are distinct differences in service delivery and patient care. Further exploration of how language impacts the patient experience in the cancer care pathway would be relevant to both implementation and quality improvement.
- Further exploration of the issues regarding RTW, in particular, the complex terminology used in work-specific fields of rehabilitation, and the trajectory of cancer care from acute treatment to the eventual RTW interventions. I intend to achieve this research aim, in part, through development of a breast cancer work-specific online module that shares functional and physical care opportunities, and

will provide a platform to collect data on terminology and communication specifics relating to workability and returning to work.

- Further research of combined programming of exercise with other functional therapeutic programming. Specifically, I am currently completing an Alberta Cancer Foundation grant funded study exploring cognitive interventions for work-focused issues of CRF as part of a physical exercise program for cancer survivors.
- Finally, I intend to look at community partnerships on a larger scale, in particular with mapping out the needs of cancer survivors with respect to rehabilitation from treatment ongoing.

7.8. Summary

This dissertation explores CRF and work-related outcomes, beginning with descriptors of CRF and culminating with a pilot study that examined work-related programming for CRF management of work-specific outcomes. The exploratory research in this dissertation used a social theory framework in order to shed light on current healthcare practices. The issue of CRF and workability were viewed through an individualized lens, using the PEO model, and through a service within systems consideration, using the SE model; there is a clear emergence of the negative effect of CRF on work-related outcomes.

This dissertation serves as a starting point for further investigation into functional approaches with respect to CRF and work-related outcomes in particular. Going forward, clinical practice and research need to address the particulars of CRF for the individual, while considering the protocols and overall management of the condition from a systems approach. Further research exploring management options is warranted, as work-related outcomes continue to be a primary concern of survivors with CRF.

Table 7-1. CRF: Current Approach & Proposed Approach

CRF: Current Approach & Proposed Approach		
	Current Approach	Proposed Approach
Definition	An unusual, persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning	The condition of having limited and fluctuating energy required for everyday function, following a cancer diagnosis
Assumptions/symptoms	Low energy, tiredness, mood and mental health issues, lack of motivation.	Fluctuating and inconsistent energy, considerations of identity and sense-of-self, emotional considerations (frustration), desire to and barrier with activity engagement.
Care plans / focus of interventions	Medical/pharmaceutical primary focus to manage sleep and mental health issues; physical exercise for increasing energy; psychosocial interventions for self-awareness and mindfulness; increase to sleep; decrease to activity	Rehabilitative primary focus to manage functional activity demands and address issues of importance to identity; medical/pharmaceutical interventions as appropriate to manage contributing factors; combined physical and functional interventions to address physical status and real-world transition of activity to everyday contexts; rest and mindful time allocation rather than sleep.
Energy demands	Steady state low energy	Fluctuating and inconsistent energy
Interventions for energy	Energy allocation	Enhance energy cultivating activities (mindfulness, social engagement, exercise, nutrition, hydration, sleep) and reduce energy depleting activities

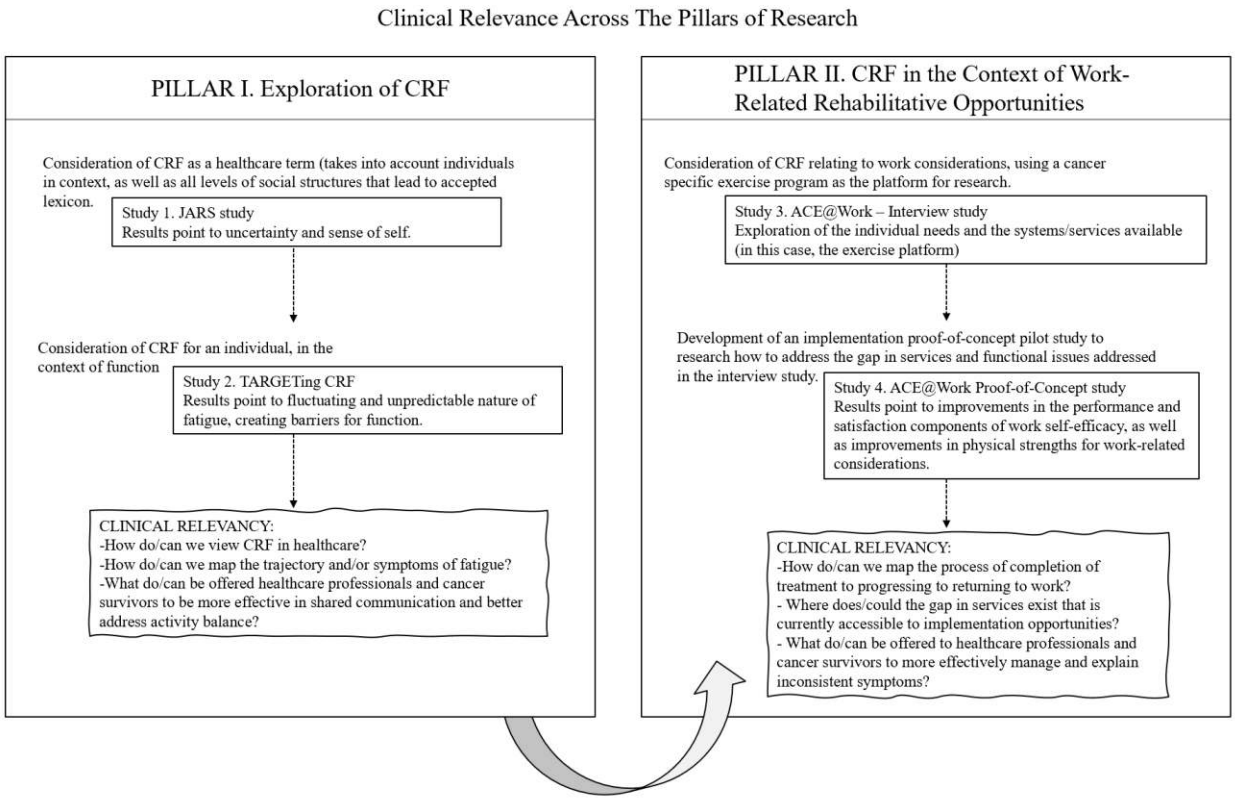
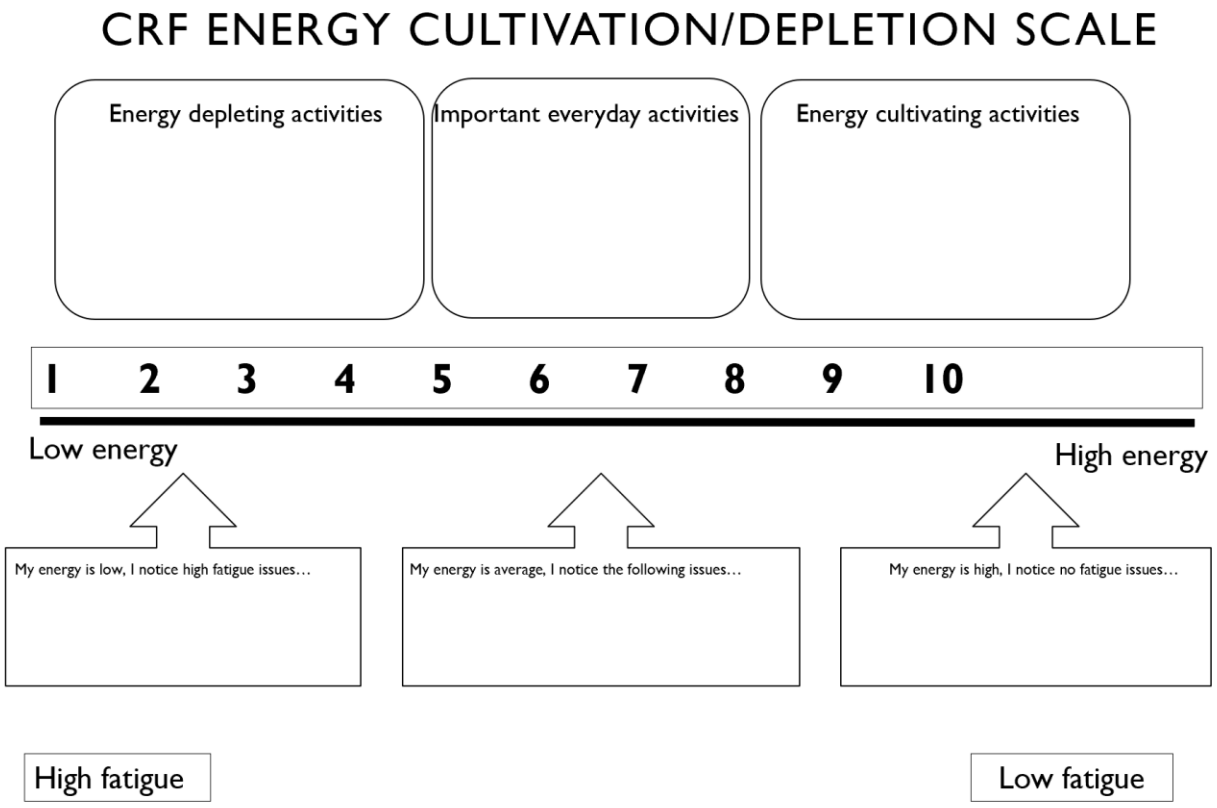
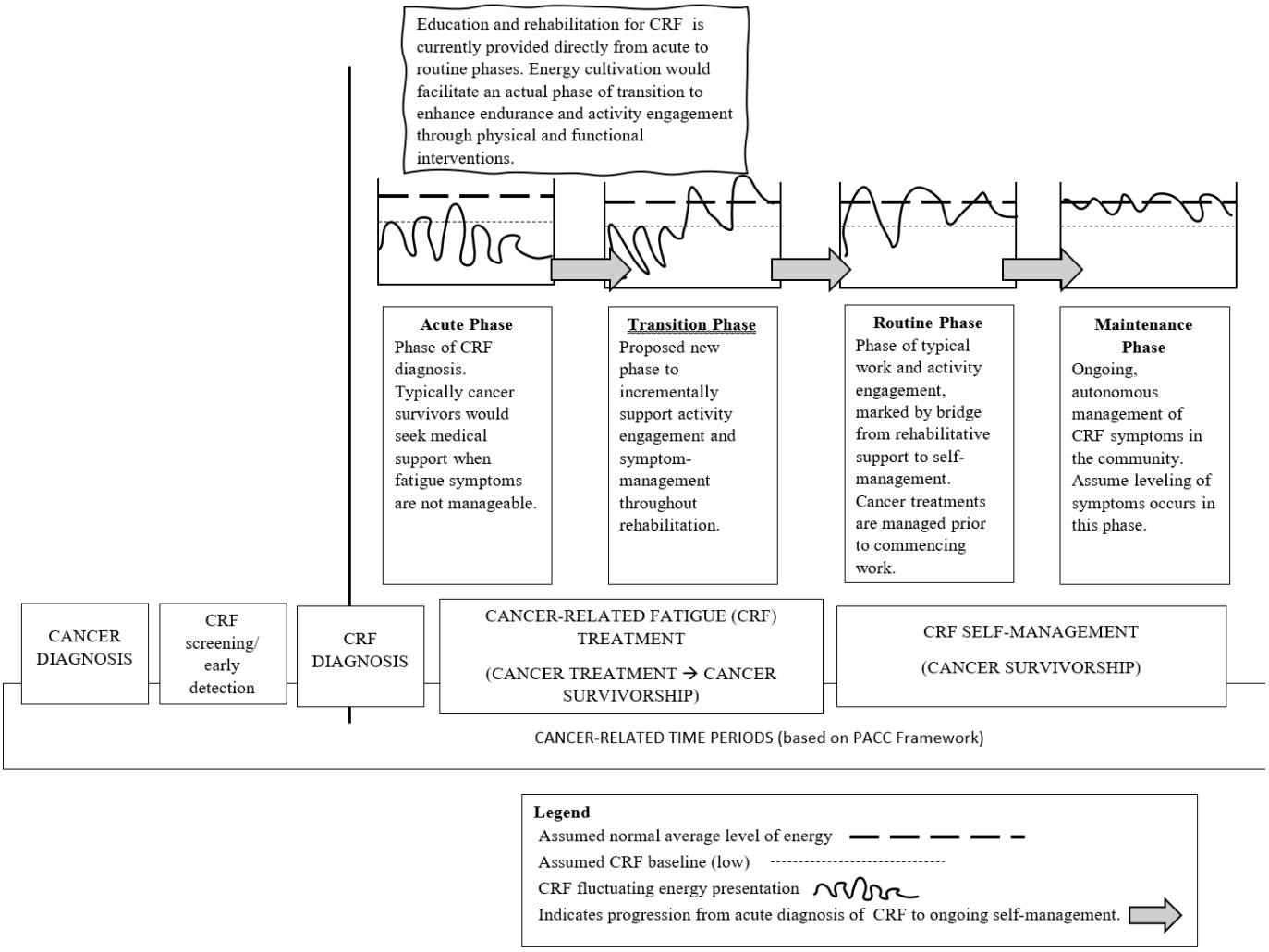


Figure 7-1. Clinical Relevance Across the Pillars of Research



1. Developed based on current distress and fatigue tools that use inorganic measures (such as thermometers and batteries) to rate current issues.
2. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Distress Management Version 2.2018, 02/23/18. The NCCN Clinical Practice Guidelines (NCCN Guidelines®) are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network www.nccn.org.
3. Use of individualized and functional rating/Likert scales have been used in return-to-work contexts and in other areas of occupational therapy (Matheson, R., & Associates Inc. (2008). Functional Capacity Evaluation (FCE) Certification Program. Keene NH: Roy Matheson and Associates; Canadian Association of Occupational Therapists, (1997; 2002). Enabling Occupation: An Occupational Therapy Perspective (Revised Ed.). Ottawa, ON: CAOT Publications ACE.)

Figure 7-2. CRF Energy Cultivation/Depletion Scale



1. Developed using the timeframes from the PACC framework in Courneya, K. S., & Friedenreich, C. M. (2007). Physical activity and cancer control. In Seminars in oncology nursing (Vol. 23, No. 4, pp. 242-252). WB Saunders. Assumes that CRF is not experienced by cancer survivors as a consistent state of low energy, rather CRF may present as inconsistent and uncertain (Dolgoy, N. D., Krishnasamy, M., & McNeely, M. L. (2019). Uncertainty and sense-of-self as targets for intervention for cancer-related fatigue. European journal of cancer care, 28(4), e13048.)
2. The work-focused component was developed with consideration of gaps in service, with use of the models amalgamated in Mehnert, de Boer, & Feuerstein, 2013.

Figure 7-3. CRF Energy Cultivation Model

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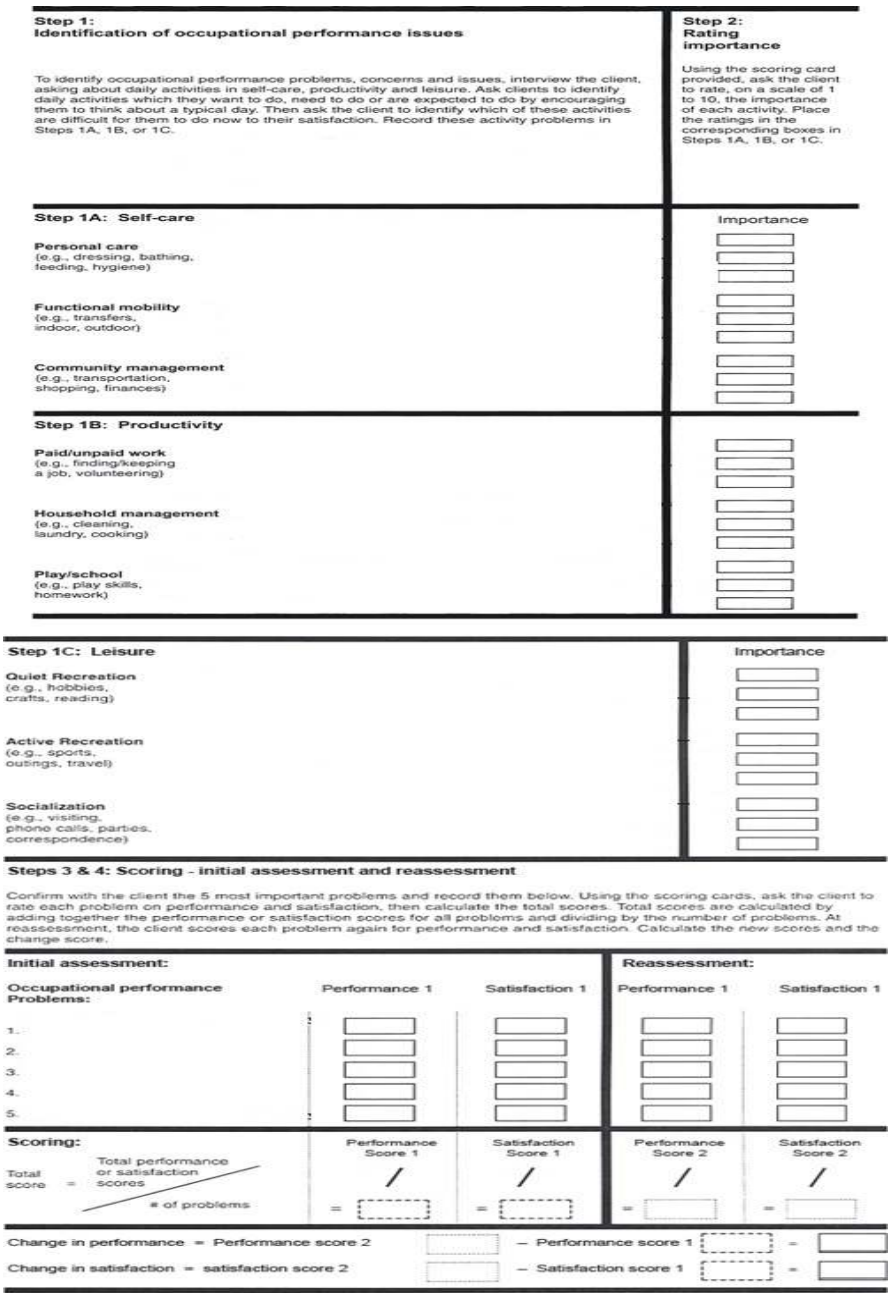
APPENDIX 1. CANADIAN OCCUPATIONAL PERFORMANCE MEASURE (COPM)



Step 1: Identification of occupational performance issues

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

Step 2: Rating importance

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

Step 1A: Self-care — Importance

- **Personal care** (e.g., dressing, bathing, feeding, hygiene)
- **Functional mobility** (e.g., transfers, indoor, outdoor)
- **Community management** (e.g., transportation, shopping, finances)

Step 1B: Productivity

- **Paid/unpaid work** (e.g., finding/keeping a job, volunteering)
- **Household management** (e.g., cleaning, laundry, cooking)
- **Play/school** (e.g., play skills, homework)

Step 1C: Leisure — Importance

- **Quiet Recreation** (e.g., hobbies, crafts, reading)
- **Active Recreation** (e.g., sports, outings, travel)
- **Socialization** (e.g., visiting, phone calls, parties, correspondence)

Steps 3 & 4: Scoring - initial assessment and reassessment

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

Initial assessment: Occupational performance Problems:	Performance 1	Satisfaction 1	Reassessment: Performance 1	Satisfaction 1
1.				
2.				
3.				
4.				
5.				
Scoring: Total score = Total performance or satisfaction scores / # of problems	Performance Score 1 / =	Satisfaction Score 1 / =	Performance Score 2 / =	Satisfaction Score 2 / =

Change in performance = Performance score 2 — Performance score 1 =

Change in satisfaction = satisfaction score 2 — Satisfaction score 1 =

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APPENDIX 2. FUNCTIONAL ASSESSMENT OF CANCER THERAPY – FATIGUE (FACT-F)

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

	PHYSICAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

An5	I have energy	0	1	2	3	4
An7	I am able to do my usual activities	0	1	2	3	4
An8	I need to sleep during the day	0	1	2	3	4
An12	I am too tired to eat	0	1	2	3	4
An14	I need help doing my usual activities	0	1	2	3	4
An15	I am frustrated by being too tired to do the things I want to do	0	1	2	3	4
An16	I have to limit my social activity because I am tired	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	EMOTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Yellen SB, Cella DF, Webster K, Blendowski C, Kaplan E. (1997) Measuring fatigue and other anemia-related symptoms with the Functional Assessment of Cancer Therapy (FACT) measurement system.J Pain Symptom Manage,13(2):63-74.

APPENDIX 3. EDMONTON SYMPTOM ASSESSMENT SCALE (ESAS)

Edmonton Symptom Assessment System: (ESAS-R) Likert Scale 0-10
- No Pain --- Worst Possible Pain
No Tiredness (Tiredness = lack of energy) --- Worst Possible Tiredness
No Drowsiness (Drowsiness = feeling sleepy) --- Worst Possible Drowsiness
No Nausea --- Worst Possible Nausea
No Lack of Appetite --- Worst Possible Lack of Appetite
No Shortness of Breath --- Worst Possible Shortness of Breath
No Depression (Depression = feeling sad) --- Worst Possible Depression
No Anxiety (Anxiety = feeling nervous) --- Worst Possible Anxiety
Best Wellbeing (Wellbeing = how you feel overall) --- Worst Possible Wellbeing

Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. (1991). The Edmonton Symptom Assessment System (ESAS): a simple method of the assessment of palliative care patients. Journal of Palliative Care, 7:6-9.

APPENDIX 4. CANADIAN PROBLEM CHECKLIST (CPC)

Canadian Problem Checklist:

Please check all of the following items that have been a concern or problem for you in the past week including today:

Emotional:	Informational:	Social/Family:
❒ Fears / Worries	❒ Understanding my illness and/or treatment	❒ Feeling a burden to others
❒ Sadness	❒ Talking with the health care team	❒ Worry about family / friends
❒ Frustration/Anger	❒ Making treatment decisions	❒ Feeling alone
❒ Changes in appearance	❒ Knowing about available resources	❒ Relationship difficulties
❒ Intimacy / Sexuality	❒ Quitting smoking	
❒ Coping	❒ Medications	
❒ Change in sense of self		
❒ Loss of interest in everyday things		
Practical:	**Spiritual:**	**Physical:**
❒ Work / School	❒ Meaning/Purpose of life	❒ Concentration/Memory
❒ Finances	❒ Faith	❒ Sleep
❒ Getting to and from appointments		❒ Weight
❒ Accommodation		❒ Constipation / Diarrhea
❒ Child/Family/Elder care		❒ Swallowing
		❒ Falling/Loss of balance

Howell, D., S. Keller–Olaman, T. K. Oliver, T. F. Hack, L. Broadfield, K. Biggs, J. Chung et al. "A pan-Canadian practice guideline and algorithm: screening, assessment, and supportive care of adults with cancer-related fatigue." *Current oncology* 20, no. 3 (2013): e233.

APPENDIX 5. LIFT TEST

As per of functional testing in return-to-work, lifting ability is tested. Typically, a lift test will use wooden or plastic crates of varying weights for testing.

The weight of the box is to be deducted from the weight put into the box for testing.

For example, the weights of the following items need to be considered when using them in lifting tasks:

-Wooden Functional Testing Box = 4kg

-Wooden Bolt Box = 6kg

-Milk Crate = 0.5kg

Several tests of listing, carrying, and placement are performed.

Matheson, L. N., Isernhagen, S. J., & Hart, D. L. (2002). Relationships among lifting ability, grip force, and return to work. Physical therapy, 82(3), 249-256.

APPENDIX 6. CONSENT FORMS – TARGETing CRF

June 2016

Evaluating Outcomes from a Combined Supervised Therapeutic and Resistance Exercise Program for Survivors of Head and Neck Cancer:
A Randomized Controlled Trial

(A study to evaluate outcomes from a combined therapeutic and resistance exercise program for survivors of head-and-neck cancer)

CONSENT FORM

This form is part of the process of informed consent. It is designed to explain this research study and what will happen to you if you choose to be in this study. If you would like to know more about something mentioned in this consent form, or have any questions at anytime regarding this research study, please be sure to ask your doctor, nurse or physical therapist. Read this consent form carefully to make sure you understand all the information it provides. You will get a copy of this consent form to keep. You do not have to take part in this study and your care does not depend on whether or not you take part. This study is being conducted by researchers at the University of Alberta, Cross Cancer Institute and University of Alberta Hospital. The study is funded by the University of Alberta.

Your doctor has referred you to the study. You are being asked to participate in this study because you have indicated that you are interesting in participating in a therapeutic exercise program for survivors with head and neck cancer.

Your participation in this study is entirely voluntary. Please take your time to make your decision. It is recommended that you discuss with your friends and/or family about whether to participate in this study.

"WHY IS THIS STUDY BEING DONE?"

You are being asked to take part in this study because you have received treatment for your head and neck cancer and you have expressed an interest in taking part in a therapeutic exercise program that is specifically designed to address the needs of survivors of head and neck cancer.

"WHAT DO WE HOPE TO LEARN?"

We hope to learn more about the outcomes from offering this type of combined program for survivors of head and neck cancer. We want to see whether survivors are interested and able to take part in the program and if outcomes are better than seen from current standard of care. If the program is acceptable to survivors and shows benefit for symptoms, physical fitness and quality of life outcomes, we hope to investigate the program in a larger multi-centre study.

"WHAT IS INVOLVED IN THIS STUDY?"

In this study, you will receive one of two treatments. You will be "randomized" into one of two groups. Randomization means the treatment to which you are assigned is determined by chance. It is like flipping a coin. You will have an equal chance of being assigned to group 1 or 2. You will be told which treatment you will be receiving.

Group 1

Therapeutic Exercise Alone (Standard Care) Group. If you assigned to this group, you will take part in 10-week specialized therapeutic exercise program twice per week at the University of Alberta. The therapeutic exercise program involves range of motion, stretching and strengthening exercises to address shoulder and neck dysfunction due to cancer treatment. You will have the option to attend a second 10-week session for maintenance. The exercise sessions will be offered in a group of 2-5 cancer survivors. Each exercise session will take 45 minutes to complete.

You will also be provided with information on how to increase your overall day-to-day activity level through general physical activities such as walking, gardening, and yoga. You will be asked to carry out the physical activity program on your own at home over the 24-week study period.

Group 2

Combined Therapeutic and Lower Body Resistance Exercise Group: If you are assigned to this group, you will take part in a 10-week combined therapeutic and lower body resistance exercise program twice per week at the University of Alberta. The therapeutic exercise program involves range of motion, stretching and strengthening exercises to address shoulder and neck dysfunction due to cancer treatment. You will also be given exercises for your lower body to help restore muscle mass and improve your overall body strength. You will have the option to attend a second 10-week session for maintenance. The exercise sessions will be offered in a group of 2-5 cancer survivors. Each exercise session will take 60 to 75 minutes to complete.

You will also be provided with information on how to increase your overall day-to-day activity level through general physical activities such as walking, gardening, and yoga. You will be asked to carry out the physical activity program on your own at home over the 24-week study period.

"HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?"

About 50 people will take part in this study.

"WHAT WILL MY PARTICIPATION INVOLVE?"

If you want to take part in this study you will be required to sign the consent form.
We will collect your relevant medical history and demographic information.

You will have the following tests and procedures:

- Body composition measurement: We will measure your height and body weight. These measurements take about 2 minutes to complete.

- A physical therapist will measure your neck and shoulder movement, flexibility, balance, as well as your upper and lower body strength. This examination will take about 30 minutes to complete.

- You will complete a 6-minute walk test in a hallway on a flat surface. In this test, you are asked to cover as much distance as you can while walking at a comfortable pace for 6 minutes. This test takes about 10 minutes to complete.

- You will also be asked to complete a self-administered questionnaire. The questionnaire will tell us about the affect of your cancer treatment on your neck and shoulder, and on your day-to-day life. As well, the questionnaire will tell us about your past and current physical activity level, your fatigue and current quality of life. The questionnaire will take about 15 to 20 minutes in total to complete.

The above measurements will be done at the beginning of the study, at week 12, week 24 and at one year.

Optional tests (one time only):

- You will have the option to complete a questionnaire that asks you about fatigue you may have experienced as a result of your cancer treatment. This questionnaire will take around 3-5 minutes to complete.

- You will have the option to undergo additional tests to determine the status of your spinal accessory nerve and trapezius muscle function. A neurologist will perform a nerve conduction test to see how well your nerve is functioning. This test will be done only one time and will take place in the Neurophysiology laboratory in the Faculty of Medicine. We will also examine your shoulder position and the strength of your trapezius muscle. This additional testing will take 20 to 30 minutes to complete.

"HOW LONG WILL I BE INVOLVED IN THE STUDY?"

You may be in this study for one year. Each testing session will take around an hour and a half (90 minutes) to complete.

"WHAT ARE THE SIDE EFFECTS?"

The main side effect from exercise testing and training is secondary muscle soreness. You may notice that your muscles are sore for a couple of days after the testing session and during the first week or so of the exercise program. We expect that these symptoms will get better as you get used to exercise. As well, the exercise program will be personalized for you to minimize excessive soreness and modified if you experience any excessive muscle soreness or fatigue from your exercise sessions.

Every medical treatment including the standard treatment has side effects, which your doctor will explain to you. It is important that you know and understand the possible side effects of the treatments given in this study. The main risk associated with exercise is injury to the muscles,

tendons, joints or bones. Your exercise sessions will be supervised and your program designed to minimize this risk by slowly increasing the amount and intensity of your exercise over time.

There is also a very small risk of heart issues (such as chest pain, irregular heart rate, heart attack) should you exercise too intensively. To avoid any risks associated with exercise, you will be screened to ensure it is safe and appropriate for you to take part in the exercise program. All exercise will be of a low to moderate intensity level to minimize the stress on the heart and body. As well, we will monitor your vital signs (e.g., heart rate, blood pressure) during the exercise testing and if needed, when you exercise. If any concerns are identified at any time, you will be referred back to your doctor for further evaluation. If any issues develop during the study period, your exercise sessions may be held or discontinued.

If you have any side effects, you should call the study coordinator/ physical therapist in charge of the study. The telephone numbers are on the last page of this form.

"WHAT ARE MY RESPONSIBILITIES?"

You must be willing to attend all scheduled study visits, undergo all of the testing described above and complete the questionnaires. It is very important that you inform the study research coordinator of any injuries, side effects or health problems that you may be experiencing as well as any medications (prescribed or holistic/herbal/naturopathic) that you are taking while on this study.

"WHAT ARE MY ALTERNATIVES?"

You may choose not to participate in this study. Your healthcare provider will discuss lifestyle issues for survivors with you. Right now, the usual treatment at the Cross Cancer Institute is to receive counseling about physical activity and a therapeutic home exercise program for the neck and shoulder.

"ARE THERE ANY BENEFITS TO PARTICIPATING IN THIS STUDY?" Participation in this study may or may not be of personal benefit to you. Possible benefits from the exercise program may include improved mobility of your neck and shoulder, increased overall upper and lower body strength and decreased fatigue. Based on the results of this study, it is hoped that patient care can be improved in the long-term.

"CAN I WITHDRAW FROM THIS STUDY?"

In discussion with you, your doctor at the Cross Cancer Institute, either at his/her own initiative or at the request of the sponsor of this study, may withdraw you from the study at any time if it is in your best interests. Taking part in this study is voluntary; you may withdraw from the study at any time if you wish to do so. If you decide to stop participating in the study, we encourage you to talk to your doctor first. The researchers may withdraw you for reasons such as:

- You are unable to tolerate the exercise.
- You sustain an injury as a result of participation.
- You experience an adverse effect during or after exercising.
- Your doctor no longer feels your participation is in your best interests.

No matter which group you are randomized to, even if you stop treatment early, we would like to keep track of you and your health for the 52-week study period to look at the long-term effects of the study treatments. Should you decide to withdraw from the study at any time, information collected on you up until that point would still be provided to the researchers.

"ARE THERE COSTS TO ME FOR TAKING PART IN THIS STUDY?"

You will not have to pay for participating in the exercise programs. We will cover the costs of your parking for sessions at the University of Alberta. There may be additional costs to you for taking part in this study such as:

- transportation
- meals
- babysitting, etc.

"WHAT ARE MY RIGHTS AS A PARTICIPANT?"

If you suffer an injury or become ill as a result of participating in this research, you will receive all medical treatments (or services) recommended by your doctors. No compensation will be provided beyond this point. However, it is important to note that nothing said in this consent form alters your legal rights to recover damages (e.g. legal action). If new information becomes available or there are changes to the study that may affect your health or willingness to continue in the study, you will be told in a timely manner.

"WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?"

Identifiable health information will be collected from you during this study. This information may be used by the researchers who are carrying out this study, and may be disclosed to others as described below. Any research proposal to use information that identifies you for a purpose other than this study must be approved in advance by the Health Research Ethics Board of Alberta-Cancer Committee. Direct access to your identifiable health information collected for this study will be restricted to the researchers who are directly involved in this study except in the following circumstances: Your identifiable health information may need to be inspected or copied from time to time for quality assurance (to make sure the information being used in the study is accurate) and for data analysis (to do statistical analysis that will not identify you). The following organizations may do this inspection:

- Health Research Ethics Board of Alberta-Cancer Committee, the institutional review board at this centre
- Members of the Regulatory/Audit team at the Cross Cancer Institute, for quality assurance purposes
- Health Canada

Any disclosure of your identifiable health information will be in accordance with the Alberta Health Information Act. As well, any person from the organizations listed above looking at your records on-site at the Cross Cancer Institute will follow the relevant Alberta Health Services and the relevant Alberta Innovates-Health Solutions Health Research Ethics Board of Alberta-Cancer Committee policies and procedures that control these actions. Any disclosure of your identifiable health information to another individual or organization not listed here will need the approval of

the Health Research Ethics Board of Alberta-Cancer Committee. Your identifiable health information collected as part of this study, which includes records of your progress, your responses to the questionnaires and your diaries will be kept confidential in a secure University of Alberta facility.

The researchers who are directly involved in your study may share information about you with other researchers, but you will not be identified in that shared information except by a number. The key that indicates what number you have been assigned will be kept secure by the researchers directly involved with your study and will not be released.

Although absolute confidentiality can never be guaranteed, Alberta Health Services will make every effort to keep your identifiable health information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information in accordance with the Alberta Health Information Act and other regulatory requirements. The information collected during this study will be used in analyses and will be published and/or presented to the scientific community at meetings and in journals, but your identity will remain confidential. It is expected that the study results will be published as soon as possible after completion.

A description of this clinical trial will be available on http://www.ClinicalTrials.gov, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

This study's registration ID number to use on this web page is: NCT02647021

"WHO DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?"

For information about your disease and/or research related injury/illness, you may contact the Principal Investigator, Margie McNeely at 780-432-8716 or 780-248-1531 or page her through the Cross Cancer Institute Switchboard at 780-432-8771 to answer any questions you have about this study. If your doctor or physical therapist has not been able to answer or resolve your questions and/or concerns about this study, or if you feel at any time that you have not been informed to your satisfaction about the risks, benefits, or alternatives to this study, or that you have been encouraged to continue in this study after you wanted to withdraw, you can call the Alberta Health Services Patient Concerns Department at 780- 432-8585 or toll free at 1-877-753-2170.

UNDERSTANDING OF PARTICIPANTS

I can refuse to take part or withdraw from this study at any time without jeopardizing my health care. If I continue to take part in the study, I will be kept informed of any important new developments and information learned after the time I gave my original consent. I also give consent for the Principal Investigator and Alberta Health Services (the Custodian) to disclose identifiable health information, as per the Alberta Health Information Act, to the organizations mentioned on the previous pages. I have read and understood all of the information in this consent form. I have asked questions, and received answers concerning areas I did not understand. I have had the opportunity to take this consent form home for review and discussion. My consent has not been forced or influenced in any way. I consent to participate in this research study. Upon signing this form I will receive a signed copy of the consent.

(PRINT NAMES CLEARLY)

_____ _____ _____

Name of Patient Signature of Patient Date

_____ _____ _____

Name of Person Signature of Date

Obtaining Consent Person Obtaining Consent

Patient Study Number or Hospital Number: _____

Was the patient assisted during the consent process in one of the ways listed below?

□ Yes □ No

If yes, please check the relevant box and complete the signature space below:

□ The consent form was read to the patient, and the person signing below attests that the study was accurately explained to, and apparently understood by the patient.

□ The person signing below acted as a translator for the patient during the consent process.

_____ _____

Signature of person assisting Date

in the Consent Discussion

Please note: More information regarding the assistance provided during the consent process should be noted in the medical record for the patient if applicable.

APPENDIX 7. CONSENT FORMS – ACE@Work Qualitative Interview

March 1 2018

ADDENDUM TO

PARTICIPANT INFORMATION & CONSENT

Title of Program: Exploration of a Functional Fatigue Intervention to Support Return to Work Among Cancer Survivors

Principal Investigator: Margaret McNeely, PT, PhD

Research/Study Coordinator: Naomi Dolgoy, M.OT, PhD candidate

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Before beginning the Albert Cancer Exercise (ACE) study, you signed an Information & Consent Form describing the ACE program and your rights as a participant. At that time, it was explained that you would be informed of any changes to the ACE program. An additional optional component has been added to the outcomes associated with the ACE program. If after discussing the new information with the coordinators, you would like to take part in this optional component, please sign this Consent Form Addendum. The original consent form, signed at the beginning of the ACE study, is still applicable above and beyond the information contained in this addendum.

Optional components (one time only):

- Post-ACE Retrospective Follow up: For those who have completed the ACE program, there is an option to take part in a semi-structured interview about your experience returning to work and managing cancer related fatigue symptoms. The interview will take approximately 1 hour to complete, either in person or over the telephone. The information collected from this interview will support future research and program development around cancer related fatigue and return-to-work.

ADDENDUM TO CONSENT FORM

Title of Study: Exploration of a Functional Fatigue Intervention to Support Return to Work Among Cancer Survivors

Principal Investigator: Margaret McNeely, PT, PhD 780-248-1531

Research/Study Coordinator: Naomi Dolgoy, M.OT, PhD candidate 587-216-2522

I understand and appreciate the new information in this addendum concerning the study I already consented to participate in.

I have been given the opportunity to discuss the information contained in this addendum. All of my questions have been answered to my satisfaction.

This signature on this Information & Consent Form Addendum means that I agree to complete one or both of the optional components. I understand that I remain free to withdraw at any time.

Signature of Participant	Name (Printed)	Date

Signature of Person Obtaining Consent	Name (Printed)	Date

A SIGNED COPY OF THIS ADDENDUM MUST BE GIVEN TO THE RESEARCH PARTICIPANT

APPENDIX 8. CONSENT FORMS – ACE@Work Intervention

Informed Consent Form for Participation in a Research Study

The Alberta Cancer Exercise "ACE" Program for Cancer Survivors Supporting Community Based Exercise Participation for Health Promotion and Secondary Cancer Prevention

(A study to evaluate the benefit of a community-based exercise program for cancer survivors)

Protocol ID: *HREBA.CC-16-0905*

Principal Investigator: Dr. Margaret McNeely, PT, PhD

Department of Physical Therapy/ Department of Oncology

University of Alberta & Cross Cancer Institute

Phone: 780-248-1531

Sponsor/Funder(s): Alberta Innovates Health Solutions

Emergency Contact Number (24 hours / 7 days a week):

Cross Cancer Institute Telephone Triage Nurse:

780-432-8919 or 1-877-707-4848 (toll free)

You are being invited to participate in a research study because you have you have indicated that you are interested in participating in a community-based exercise program for survivors of cancer. This consent form provides detailed information about the study to assist you with making an informed decision. Please read this document carefully and ask any questions you may have. All questions should be answered to your satisfaction before you decide whether to participate.

The study staff will tell you about timelines for making your decision. You may find it helpful to discuss the study with family and friends so that you can make the best possible decision within the given timelines.

Taking part in this study is voluntary. You may choose not to take part or, if you choose to participate, you may leave the study at any time without giving a reason. Deciding not to take part or deciding to leave the study will not result in any penalty or any loss of medical or health-related benefits to which you are entitled.

The principal investigator or site project coordinator, who is one of the researchers, will discuss this study with you and will answer any questions you may have. If you do consent to participate in this study, you will need to sign and date this consent form. You will receive a copy of the signed form.

WHAT IS THE BACKGROUND INFORMATION FOR THIS STUDY?

The growing population of cancer survivors in Alberta has brought attention to the long term toll of cancer and its treatment on the body, mind and overall health of survivors. Exercise is an effective intervention that can optimize the health and wellbeing of cancer survivors and possibly reduce rates of cancer recurrence and secondary cancers. Currently standard care at the Cross Cancer Institute is to receive counseling on the value of physical activity and healthy living after the completion of cancer treatments.

The Health Research Ethics Board of Alberta – Cancer Committee (HREBA-CC), which oversees the ethical acceptability of research involving humans, has reviewed and granted ethics approval for this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to evaluate the relative benefit of a community-based exercise program for cancer survivors – the Alberta Cancer Exercise (ACE) Program. Our aim is to support persons who have been diagnosed with cancer to adopt an active lifestyle to improve their health outcomes. We want to see whether survivors are interested and able to take part in the program and if outcomes are similar to those seen in supervised clinic and hospital based programs. We also plan to study how best to implement the program in community-based exercise facilities across Alberta.

WHAT ARE OTHER OPTIONS IF I DECIDE NOT TO PARTICIPATE IN THIS STUDY?

You do not have to take part in this study in order to receive continued medical care. You may choose not to participate in this study. Your healthcare provider will discuss lifestyle recommendations with you. Right now, the usual treatment at the Cross Cancer Institute is to receive counseling on the value of physical activity and healthy living after the completion of cancer treatments.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 1000 people across Alberta will take part in this study. We plan to enroll about 350 people at the Cross Cancer Institute.

WHAT WILL HAPPEN DURING THIS STUDY?

STUDY INTERVENTION

If you agree to take part in this study, you will undergo screening and fitness testing and will be referred to a suitable exercise program. The exercise program will take place at selected sites including Edmonton YMCAs and municipal fitness centres. You will take part in a twice weekly exercise program for a 12-week period and will be followed for outcomes for up to a year. The exercise program will be tailored to your fitness level and be designed to address your personal fitness or lifestyle goals.

All participants will have measurements taken at the start of the study, at 12-weeks , 24 weeks and at one year to see the effect of exercise on their physical fitness and quality of life. Participants taking part in the study in the first year will have the option to receive a follow-up questionnaire after the exercise program each year for up to 5 years.

STUDY PROCEDURES

Established Procedures

The following established procedures will be done as part of this study. Some of these procedures may be done as part of your standard care, in which case the results may be used. Some may be done more frequently than if you were not taking part in this study. Some of these procedures may be done solely for the purpose of the study. If the results show that you are not able to continue participating in the study, the principal investigator will let you know.

- Body composition measurement: We will measure your height and body weight. As well, we will take a measurement of your waist and hip size with tape measure. These measurements take between 2 and 3 minutes to complete.

- Aerobic endurance measurement: We will have you perform a 6-minute walk test in a hallway on a flat surface to determine your fitness level. This is a submaximal test, meaning that you will exercise at a moderate level for the specific 6-minute time period. The aerobic fitness testing takes around 10 minutes to complete.

- Musculoskeletal fitness measurement: we will measure your grip strength, measure your lower body endurance (30s Sit to Stand), and assess your flexibility using a sit-and-reach test and shoulder elevation measure. We will also assess your balance using a one-legged stance balance test. These tests take around 20 minutes to complete.

- Optional fitness tests: Depending on your interests and the location of your exercise program you may have the option to undergo additional fitness testing including the following: Push-up test (upper body muscular endurance); Plank test (core endurance); a submaximal strength test for your arms (bench press) and your legs (leg press); a submaximal cycle or treadmill test (meaning that you will exercise at a moderate level until you reach a specific heart rate. This helps us to better estimate your fitness).

Questionnaires

You will be provided with a questionnaire package at the start of the study, at 12 weeks, at 24 weeks and, at one year. For those enrolled in the study in the first year, you will have the option to complete a follow-up questionnaire package each year for the duration of the study (up to 5 years). The purpose of the questionnaire is to understand how the program affects different aspects of your life.

- The revised Edmonton Symptom Assessment Scale: this questionnaire asks you to rate symptoms related to your cancer and cancer treatment. This questionnaire is usually administered as part of your standard care. This questionnaire takes about 5 minutes to complete.
- Stage of Change (at start of study only): This questionnaire asks about your readiness to take part in exercise. This questionnaire takes 1 minute to complete.
- Exercise preferences questionnaire (at the start of the study only): This questionnaire asks about your exercise goals and the type of exercises you would like to take part in. This questionnaire takes 1 minute to complete.

- Physical activity level: We will assess asking you about your physical activity level using the Godin Exercise Leisure-time Questionnaire. This 6-item questionnaire asks specific questions about the type, intensity, frequency and duration of your average weekly physical activity. This questionnaire takes around 2-3 minutes to complete.
- Cancer-related Quality of Life: We will assess your quality of life using the Functional Assessment of Cancer Therapy-Fatigue Scale. This 39-item questionnaire asks specific questions about your physical wellbeing, social/family wellbeing, emotional wellbeing, functional wellbeing and fatigue. This questionnaire takes around 10 minutes to complete.
- Health-related Quality of Life: We will assess your quality of life using the RAND short form (SF)-36. This 36-item questionnaire asks specific questions about your physical functioning, pain, limitations, emotional wellbeing, social functioning, energy, general health perception and perceived change in health. This questionnaire takes around 10 minutes to complete.
- Cost effectiveness: We will assess the cost effectiveness of the program using the EQ5D. This 5-item questionnaire aske specific questions about your mobility, self-care, usual activities, pain/discomfort and anxiety/depression. This questionnaire should take 2-3 minutes to complete.

The information you provide is for research purposes only and will remain strictly confidential.

Some of the questions are personal; you may choose not to answer them.

Even though you may have provided information on a questionnaire, these responses will not be reviewed by individuals not involved in this study, e.g., your health care practitioner/team. If you would like them to know this information, please bring this to their attention.

Participant Diaries

You will be asked to keep a diary of your daily physical activity during the 12 week exercise program. This will include recording the type of physical activity, the duration and intensity of each session and any symptoms before or after each session. You will be asked to return the diary to the cancer rehabilitation clinic in Corbett Hall, University of Alberta or submit an electronic copy to the researchers.

OPTIONAL RESEARCH

The researchers doing this study are interested in doing additional optional research. You will be given a separate optional study consent form(s) to read and sign if you wish to give permission to this. You may decide not to participate in the "optional" study and still participate in this main study.

The *ACE at Work* pilot study is an optional added component to the ACE program. In *ACE at Work*, the researchers are examining return to work issues in cancer survivors with cancer-related fatigue. If you choose to take part in *ACE at Work* you will need to attend an extra session each week from weeks 7-12 of the ACE study. This will involve an added time commitment for you of 10-15 hours or approximately 1-2 more hours per week.

Please initial if you wish to be contacted for further discussion on this optional study component _____.

WHAT ARE THE POTENTIAL SIDE EFFECTS FROM PARTICIPATING IN THIS STUDY?

You may experience side effects from participating in this study. Some side effects are known and are listed below, but there may be side effects that are not expected. You should discuss these with the principal investigator or project coordinator. The risks and side-effects of the standard or usual treatment will be explained to you as part of your standard care. These risks are not included in this consent form.

The main side effect from exercise testing and training is secondary muscle soreness. You may notice that your muscles are sore for a couple of days after the testing session and during the first week or so of the exercise program. We expect that these symptoms will get better as you get used to the exercise. As well, the exercise program will be personalized to you to minimize excessive soreness and modified as needed if you experience any excessive muscle soreness or fatigue from your exercise sessions.

Every medical treatment including the standard treatment has side effects, which your doctor will explain to you. It is important that you know and understand the possible side effects of the treatments given in this study. The main risk associated with exercise is musculoskeletal injury (injury to the muscles, tendons, joints or bones). Your exercise sessions will be supervised and your program designed to minimize this risk by slowly increasing the amount and intensity of your exercise over time.

There is also a very small risk of heart issues (such as chest pain, irregular heart rate, heart attack) should you exercise too intensively. To avoid any risks associated with exercise, you will be screened to ensure it is safe and appropriate for you to take part in the exercise program. All exercise will be of a low to moderate intensity level to minimize the stress on the heart and body. As well, we will monitor your vital signs (e.g., heart rate, blood pressure) during the exercise testing and if needed, when you exercise at the participating facilities. If any concerns are identified at any time, you will be referred back to your doctor for further evaluation. If any issues develop during the study period, your exercise sessions may be held or discontinued.

If you have any side effects, you should call the study coordinator/ physical therapist in charge of the study. The telephone numbers are on the last page of this form.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

Participation in this study may or may not be of personal benefit to you. Possible benefits include improved physical fitness and better energy. Based on the results of this study, it is hoped that in the long-term, patient care can be improved.

WHAT ARE MY RESPONSIBILITIES AS A STUDY PARTICIPANT?

If you choose to participate in this study, you will be expected to:

- Tell the study research coordinator about your current medical conditions;
- Tell the study research coordinator about all prescription and non-prescription medications and supplements, including vitamins and herbals, that you may be taking and check with the research coordinator before starting, stopping or changing any of these. This is for your safety

as these may interact with the intervention you receive on this study;
- Tell the study research coordinator if you are thinking about participating in another research study;
- Attend all scheduled study visits, undergo all of the procedures described above and complete the questionnaires.
- Inform the study research coordinator of any injuries, side effects or health problems that you may be experiencing

HOW LONG WILL I BE PARTICIPATING IN THIS STUDY?

The study exercise program will last for about 12 weeks, with the option to continue with a 12-week fee for service maintenance program. You will be asked to come back to the Cancer Rehabilitation Clinic in Corbett Hall at the University of Alberta for follow-ups at 12-weeks, 24 weeks and one year. Each follow-up testing session will take around an hour and a half (90 minutes) to complete. In addition, questionnaires are to be completed once a year for up to 5 years.

WILL THERE BE ANY LONG-TERM FOLLOW-UP INVOLVED WITH THIS STUDY?

If you stop receiving the study intervention early, we would like to keep track of your health for up to the 1 year study period to look at the long term effects of the study treatments of your participation on the study. We would do this by having you come back to the Rehabilitation Clinic in Corbett Hall at the University of Alberta for the fitness assessments or by completing online questionnaires.

In the event it is necessary to further evaluate the safety or efficacy of the community-based cancer and exercise program it may be necessary to have access to additional information about your health status. The study team may attempt to obtain study-related information about your health from you or from other private sources, including your care physician. This may include contacting you again by phone or letter, but only if you have not withdrawn your consent for future contact. However, contacting you, your care physician or using other private sources of information, is optional, please indicate your decision using the check boxes below.

You give permission to the study research coordinator or member of the study team to attempt to obtain study-related information about your health status to further evaluate the safety or efficacy of the clinic-to-community-based cancer and exercise program. This may include contacting your care physician, or by contacting you by phone or letter (i.e., future contact).

☐ Yes ☐ No Participant's Initials: _____

Name/phone number of care physician: _____

CAN I CHOOSE TO LEAVE THIS STUDY EARLY?

You can choose to end your participation in this research (called early withdrawal) at any time without having to provide a reason. If you choose to withdraw early from the study without finishing the intervention, procedure or follow-up, you are encouraged to contact the principal investigator or study staff. If you decide to stop participating in the study, we encourage you to

talk to your doctor first. You may be asked questions about your experience with the study intervention.

You may withdraw your permission to use information that was collected about you for this study at any time by letting the study research coordinator know. However, this would also mean that you withdraw from the study. Information that was recorded before you withdrew will be used by the researchers for the purposes of the study, but no additional information will be collected or sent to the sponsor after you withdraw your permission.

CAN MY PARTICIPATION IN THIS STUDY END EARLY?

In discussion with you, your doctor at the Cross Cancer Institute, either at his/her own initiative or at the request of the sponsor of this study, may withdraw you from the study at any time if it is in your best interests. The principal investigator may stop your participation in the study early, and without your consent, for reasons such as:

- You are unable to tolerate the exercise.
- You sustain an injury as a result of participation.
- You experience an adverse effect during or after exercising.
- Your doctor no longer feels this is the best treatment for you.
- The sponsor decides to stop the study;

If this happens, it may mean that you would not receive the study intervention for the full period described in this consent form. If you are removed from the study, the principal investigator will discuss the reasons with you and plans will be made for your continued care outside of the study.

HOW WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the principal investigator and study staff will only collect the information they need for this study.

Records identifying you, including information collect from your medical files/records, such as your Electronic Medical Records (EMR), Netcare, charts, etc., will be kept confidential to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Authorized representatives of the following organizations may look at your identifiable medical/clinical study records at the site where these records are held for quality assurance purposes and/or to verify that the information collected for the study is correct and follows proper laws and guidelines:

- The Health Research Ethics Board of Alberta – Cancer Committee, which oversees the ethical conduct of this study
- Members of the Regulatory/Audit team at the Cross Cancer Institute, for quality assurance purposes

Authorized representatives of the above organizations may **receive** information related to the study from your medical/clinical study records that will be kept confidential in a secure location

and may be used in current or future relevant health research. Your name or other information that may identify you will not be provided (i.e., the information will be de-identified). The records received by these organizations will be coded with a number. The key that indicates what number you have been assigned will be kept secure by the researchers directly involved with your study and will not be released. To protect your identity, the information that will be on your assessment forms and questionnaires will be limited to your study ID and initials.

Any disclosure of your identifiable health information will be done in accordance with federal and provincial laws including the Alberta Health Information Act (HIA). The organizations listed above are required to have organizational policies and procedures to protect the information they see or receive about you, except where disclosure may be required by law. The principal investigator will ensure that any personal health information collected for this study is kept in a secure and confidential AHS facility as also required by law.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during the study will be used in analyses and will be published and/or presented to the scientific community at meetings and in journals, but your identity will remain confidential. It is expected that the study results will be published as soon as possible after completion. This information may also be used as part of a submission to regulatory authorities around the world to support the approval of this intervention.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated. Every effort will be made to keep your identifiable information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information.

Data collected will be entered into the secure REDCap server held at the University of Alberta and data will only be used for research purposes.

Studies involving humans sometimes collect information on race and ethnicity as well as other characteristics of individuals because these characteristics may influence how people respond to different interventions. Providing information on your race or ethnic origin is voluntary.

WILL MY HEALTHCARE PROVIDER(S) BE INFORMED OF MY PARTICIPATION IN THIS STUDY?

Your family doctor/health care provider will be informed that you are taking part in a study so that you can be provided with appropriate medical care. If you do not want your family doctor/health care provider to be informed, please discuss with your study team to find out your options.

WILL THERE BE ANY COSTS INVOLVED WITH PARTICIPATING IN THIS STUDY?

You will not have to pay for the exercise program you receive in this study. We will provide a parking pass to cover your parking costs at the University of Alberta when you come for any tests or procedures associated with the study. Costs associated with attending the 12-week exercise program in the community will be covered. You will have to pay if you wish to continue to take part after the 12-week program. The cost to continue in the program for a 12-week

maintenance period will be subsidized; however, the cost may vary among facilities (fee for service). There may be additional costs to you for taking part in this study such as:

- transportation
- parking costs at the YMCA or municipal fitness centres
- meals
- babysitting, etc.

Possible Costs After the Study is Complete

You may not be able to receive the study intervention after your participation in the study is completed. There are several possible reasons for this, some of which are:

- Your caregivers may not feel it is the best option for you;
- You may decide it is too expensive and insurance coverage may not be available;
- The intervention, even if approved in Canada, may not be available free of charge.

The principal investigator will discuss these options with you.

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

You will not be paid for taking part in this study. However in the case of research-related side effects or injury, as a direct result of participating in this research, you will receive all medical treatments or services recommended by your doctors.

Although no funds have been set aside to compensate you in the event of injury or illness related to the study treatment or procedures, you do not give up any of your legal rights for compensation by signing this form.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of these results, please contact the principal investigator.

The results of this study will be available on a clinical registry; refer to the section titled “Where can I find online information about this study?”. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the hospital, investigators, sponsor, involved institutions for compensation or their agents, nor does this form relieve these parties from their legal and professional responsibilities.

IS THERE CONFLICT OF INTEREST RELATED TO THIS STUDY?

There are no conflicts of interest declared between the principal investigator and sponsor of this study.

WHAT IF RESEARCHERS DISCOVER SOMETHING ABOUT ME AS A RESEARCH PARTICIPANT?

During the study, the researchers may learn something about you that they didn't expect. For example, the researchers may find out that you have another medical condition.

If any clinically important information about your health is obtained as a result of your participation in this study, you will be given the opportunity at that time to decide whether you wish to be made aware of that information.

WHERE CAN I FIND ONLINE INFORMATION ABOUT THIS STUDY?

A description of this clinical trial will be available on http://www.clinicaltrials.gov, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

The study registration number to use this website is: NCT02984163

WHO DO I CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, or if you suffer a research-related injury, you should talk to the project coordinatior or principal investigator. These person(s) are :

Dr. Christopher Sellar, PhD (Project Coordinator)	780-492-6007
Name	Telephone
Dr. Margaret McNeely, PT,PhD	780-432-8716 or 780-248-1531
Name	Telephone

Dr. Margaret McNeely can also be paged through the Cross Cancer Institute Switchboard at 780-432-8771

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta – Cancer Committee at:

Telephone: 780-423-5727 Toll Free: 1-877-423-5727

If you have any questions about the optional *ACE at Work* component, please contact Dr. McNeely or Naomi Dolgoy at 780.432.8716 or via email at dolgoy@ualberta.ca

Part 1 - to be completed by the potential participant.

Yes **No**

Do you understand that you have been asked to take part in a research study?	☐	☐
Do you understand why this study is being done?	☐	☐
Do you understand the potential benefits of taking part in this study?	☐	☐
Do you understand the risks of taking part in this study?	☐	☐
Do you understand what you will be asked to do should you decide to take part in this study?	☐	☐
Do you understand the alternatives to participating in this study?	☐	☐
Do you understand that you are free to leave the study at any time, without out having to give reason and without affecting your future health care?	☐	☐
Do you understand who will see your records, including health information that identifies you?	☐	☐
Do you understand that by signing this consent form you are giving us permission to access your health information and specimens if applicable?	☐	☐
Do you understand that by signing this consent form that you do not give up any of your legal rights?	☐	☐
Do you understand that your family doctor/health care provider will/may be informed of your participation in this study?	☐	☐
Have you had enough opportunity to ask questions and discuss this study?	☐	☐

By signing this form I agree, or *allow the person I am responsible for*, to participate in this study.

Signature of Participant /*Substitute Decision-Maker*	PRINTED NAME	Date

(As a Substitute Decision-Maker, you are being asked to provide informed consent on behalf of a person who is unable to provide consent for him/herself. If the participant gains the capacity to consent for him/herself, your consent for them will end.)

Part 2 - to be completed by the principal investigator or designee who conducted the informed consent discussion. Only compete this section if the potential participant has **agreed** to participate.

I believe that the person signing this form understands what is involved in the study and has freely decided to participate.

Signature of Person Conducting the Consent Discussion	PRINTED NAME	Date

Part 3 - to be completed only if the participant is unable to read or requires assistance of an oral translator/interpreter.

- The informed consent form was accurately explained to, and apparently understood by the participant*/substitute decision maker.*
- Informed consent was freely given by *or on behalf of* the participant.

Signature of Impartial Witness/Interpreter	PRINTED NAME	Date

APPENDIX 9. ETHICS APPROVAL – TARGETing CRF

HREBA Health Research Ethics Board of Alberta Cancer Committee

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 4A7
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

June 28, 2016

Ethics IDHREBA.CC-15-0167_MOD1

Margaret McNeely

Dear Margaret McNeely :

**RE: Evaluating Outcomes from a Combined Supervised Therapeutic and Physical Exercise Program for Survivors of Head and Neck Cancer:
A Randomized Controlled Trial**

Approved by Delegated Review on 28 June 2016

The following information was received in reference to the modification for the above named study:

- Consent Form Version June 18 2016 clean, June 22, 2016
- Consent Form Version June 18 2016 track changes, June 22, 2016
- Testing sheet_ Nerve Conduction and Trapezius Function , June 18, 2016, June 22, 2016
- Optional Cancer related fatigue qualitative questionnaire, June 18, 2016, June 22, 2016
- TARGET Proposal_June 18 2016 Amended Version, June 18, 2016, June 22, 2016

This submission was reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC) approval is granted for the following:

Consent Form Version June 18 2016 clean, June 22, 2016
Testing sheet_ Nerve Conduction and Trapezius Function , June 18, 2016, June 22, 2016
Optional Cancer related fatigue qualitative questionnaire, June 18, 2016, June 22, 2016
TARGET Proposal_June 18 2016 Amended Version, June 18, 2016, June 22, 2016

All modifications to the protocol or informed consent form(s) must be submitted for ethics approval prior to implementation and adverse events reports provided in accordance with Committee reporting requirements.

The membership of this Committee complies with the membership requirements for Research Ethics Boards defined in Part C Division 5 of the *Food and Drug Regulations*. This Committee carries out its functions in a manner consistent with Good Clinical Practices and has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted to by the Qualified Investigator named above at the specified clinical trial site. This approval and the views of this Committee have been documented in writing.

Members of the Committee who are named as investigators or co-investigators in research studies do not participate in discussion related to, nor vote on, such studies when they are presented to the Committee. It is not our policy to release the names of the Committee membership, however, an outline of its composition can be provided.

12/10/2019 https://iriss.ucalgary.ca/IRISSPROD/Doc/0/0T0VKUT1UEQK1AS7UTP1E16H6C/fromString.html

Please accept the Committee's best wishes for success in your research.

Sincerely,

Raul Urtasun , HREBA-CC

APPENDIX 10. ETHICS APPROVAL – ACE@Work (Qualitative Interview)

HREBA Health Research Ethics Board of Alberta Cancer Committee

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

Modification of Ethics Approval

This is to acknowledge that the modification to the research indicated below has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC), I am pleased to advise that approval has been granted.

Ethics ID:	HREBA.CC-16-0905_MOD5
Principal Investigator:	Margaret McNeely
Co-Investigator(s):	Kerry Courneya Nicole Culos-Reed Jacob Easaw Anil Abraham Joy Harold Lau Albert Murtha Matthew Parliament Edith Pituskin Jeff Vallance Janice Yurick
Student Co-Investigator(s):	There are no items to display
Study Title:	The Alberta Cancer Exercise "ACE" Program for Cancer Survivors: Supporting Community-based Exercise Participation for Health Promotion and Secondary Cancer Prevention
Sponsor:	Alberta / Innovation and Science

Effective: Tuesday, December 12, 2017 **Expires:** Tuesday, December 11, 2018

Modification reviewed by delegated review on 20 May 2018.

The following documents have been approved:

- Addendum Consent Optional Interview Return to Work , May 1, 2018, May 14, 2018
- Consent form for optional in-clinic brief physical assessment , May 1, 2018, May 14, 2018
- Neuro-Oncology In-Clinic Assessment , May 1, 2018, May 14, 2018
- ACE at Work Phase I, May 1, 2018, May 14, 2018

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical

Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health Canada's *Food and Drug Regulations* (FDR), Part C, Division 5 and is registered with the U.S. Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

Members of the HREBA-CC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

Please note that the approval of this modification does not change the effective or expiry dates of this study as indicated above.

Please accept the Committee's best wishes for success in your research.

Approved on behalf of CC by, **Date:**

Raul Urtasun , HREBA-CC Thursday, May 24, 2018

Note: This correspondence includes an electronic signature (validation and approval via an online system).

APPENDIX 11. ETHICS APPROVAL – ACE@Work (Implementation Study)

HREBA Health Research Ethics Board of Alberta Cancer Committee

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

Modification of Ethics Approval

This is to acknowledge that the modification to the research indicated below has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC), I am pleased to advise that approval has been granted.

Ethics ID:	HREBA.CC-16-0905_MOD6
Principal Investigator:	Margaret McNeely
Co-Investigator(s):	Kerry Courneya Nicole Culos-Reed Jacob Easaw Anil Abraham Joy Harold Lau Albert Murtha Matthew Parliament Edith Pituskin Jeff Vallance Janice Yurick
Student Co-Investigator(s):	There are no items to display
Study Title:	The Alberta Cancer Exercise "ACE" Program for Cancer Survivors: Supporting Community-based Exercise Participation for Health Promotion and Secondary Cancer Prevention
Sponsor:	Alberta / Innovation and Science

Effective: Tuesday, December 12, 2017 **Expires:** Tuesday, December 11, 2018

Reviewed and approved by delegated review on 18 October 2018

The following documents have been approved:

- Consent Addendum, October 11, 2018, October 11, 2018
- ACE at Work Pilot Proposal , August 28, 2018, October 11, 2018

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health Canada's *Food*

and Drug Regulations (FDR), Part C, Division 5 and is registered with the U.S. Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

Members of the HREBA-CC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

Please note that the approval of this modification does not change the effective or expiry dates of this study as indicated above.

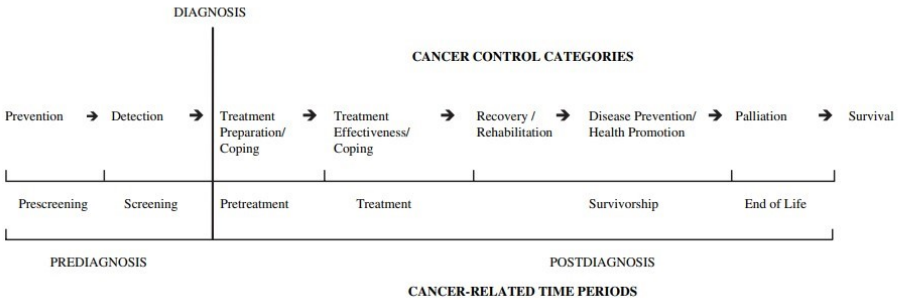
Please accept the Committee's best wishes for success in your research.

Approved on behalf of CC by, **Date:**

Raul Urtasun , HREBA-CC Tuesday, October 23, 2018

Note: This correspondence includes an electronic signature (validation and approval via an online system).

APPENDIX 12. PHYSICAL ACTIVITY IN CANCER CONTROL (PACC) FRAMEWORK



Courneya KS, Friedenreich CM. (2007). Physical activity and cancer control. Semin Oncol Nurs. 23(4):242-252.