CANWELL: USING EXERCISE TO EMPOWER PEOPLE WITH CANCER

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ABSTRACT

People with cancer face many challenges related to their disease and its associated treatments. There is an increasing number of survivors living in the community who are looking for strategies to manage the sequelae of their condition. This dissertation consists of two studies directly evaluating the effects of exercise on cancer survivors who participated in a community-based exercise program (CanWell program) and a measurement paper that evaluated a measure of symptom burden.

The first study outlines the development of the CanWell program, including its theoretical underpinning the effect of the 12-week exercise program on function, as measured using the 6-minute walk test and the STEEP treadmill test. Additionally the effects of exercise on health-related quality-of-life and cancer disease burden were measured using the Functional Cancer Therapy Assessment – General and the Edmonton Symptom Assessment System (ESAS), respectively. This study found that participants in the CanWell program have significantly improved the physical abilities as measured by the distance they can walk in six minutes and the time they can walk/run on a treadmill. Furthermore, participants reported improved in quality-of-life and lower levels of cancer disease burden. As no adverse events occurred during the exercise program, it was concluded that the CanWell program was effective and safe.

The second study was conducted to evaluate the long-term exercise compliance of those who graduated from the CanWell program, as well as facilitators and barriers to continuation of exercise routines as a regular daily activity. In addition to the outcome measures used in the first study described above, a survey that was based on the theory of

behaviour change, explored facilitators and barriers to exercise. The results of this study found that while CanWell graduates were able to maintain the functional levels (no change in 6-minute walk test compared to the end of the CanWell program), there were significant reductions in exercise aerobic abilities (statistically significant reduction in time spent on a treadmill). The main barriers to continuation of exercise following completion of CanWell were fatigue, cost, and return to work.

In the last study, the measurement properties of the ESAS were investigated using Rasch analysis leading to a revised scoring algorithm to meet unidimensionality and interval scaling. The ESAS scores from study #1 were re-analyzed using the new interval-level scoring scheme. This Rasch-based scoring resulted in different conclusions than the traditional ordinal scaling.

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This dissertation is dedicated to those who could not be here: My mother who only knew that I had potential, but did not get to see it harvested. To Sela, who died too young and would have loved to see me reach this milestone.

This thesis is also dedicated to all the CanWell participants, those who are here and those who have passed. Seeing you exercise, sweat, improve, and smile makes all the work (and political challenges) worth it. Thank you for being part of this dissertation.

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To my children, Golan and Eden. My schooling, work, and research are important, but never forget that you are more important! Thank you for making me happy and helping with the chores so I can type away.

To my wife, Deborah Tsui. Thank you for all your support and keeping the “unit” going. Now that I am finished with my studies, it is your turn!

PREFACE

Below is the description of the Student's contribution to each of the manuscripts.

For the three manuscripts: Oren Cheifetz conceptualized the research questions, study designs, data collections and data analyses, and writing the drafts of the manuscripts.

Dr. Linda Woodhouse provided required expertise for the design and implementation of the first study, assisted with refining objectives and design, and editing the manuscript.

Dr. Joy MacDermid provided required expertise for the design and implementation of the second and third studies, assisted with refining the objectives and design, and editing the manuscripts of the three studies enclosed.

Dr. Julie Richardson and Professor Paul Stratford assisted with reviewing the study objectives, providing content expertise, and editing the manuscripts.

Mrs. Jan Park Dorsay is a co-investigator of the first two studies and contributed to conceptualization of the research questions, study designs, and editing the manuscripts.

Contents

List of Abbreviations

6-MWT	Six-minute Walk Test
ACSM	American College of Sports Medicine
ANOVA	Analysis of Variance
BMI	Body Mass Index
CI	Confidence Intervals
cm	Centimeter
CTT	Classical Test Theory
E&T	Exercise and Thrive
EORTC-QLQ-C30	European Organization for Research and Treatment of Cancer – Quality of Life Questionnaire
ESAS	Edmonton Symptom Assessment System
EWB	Emotional Well-being
FACIT	Functional Assessment of Chronic Illness Therapy
FACT-G	Functional Assessment Cancer Therapy - General
FWB	Functional Well-being
HHS	Hamilton Health Sciences
HR-QoL	Health-Related Quality of Life
ID	Imputed Data
IRT	Item Response Theory
JCC	Juravinski Cancer Center
JPD	Jan Park Dorsay
Kg	Kilogram
MD	Mean Difference
MI	Multiple Imputation
MNSQ	Mean Squares
MSAS	Memorial Symptom Assessment Scale
OC	Oren Cheifetz
PWB	Physical Well-being
QOL	Quality of Life
RCT	Randomized Controlled Trial
RMSE	Root Mean Square Error
SD	Standard Deviation
SPSS	Statistical Package for the Social Science
STEEP	Standardized Exponential Exercise Protocol
SWB	Social Well-being
TPB	Theory of Planed Behavior
WB	Well-being
WHOQOL-BREF	World Health Organization Quality of Life BREF
ZSTD	Z-Standardized

Chapter 1. Background

Statement of Research Problem

The primary objectives of this thesis work were to develop and measure the impact of a community-based exercise and education program designed to maximize the physical health of people with cancer. A secondary objective was to evaluate the validity of the Edmonton Symptom Assessment System (ESAS), a tool designed to measure disease burden in people diagnosed with cancer.

The thesis objectives listed above aim to contribute information to the question: “Is it feasible to provide a safe, effective, and efficient exercise program that maximizes the physical health of people with cancer in the community? Additionally, what are long-term exercise barriers for cancer survivors who participated in supervised exercise programs?

The CanWell program was founded through a partnership between an acute care hospital, Hamilton Health Sciences (HHS), an educational institute (McMaster University), and a community not-for-profit exercise facility (Les Chater YMCA of Hamilton/Burlington/Brantford). CanWell is a community-based, supervised, exercise and education program for cancer survivors. Two studies were conducted to evaluate the short and longer term outcomes of this program.

The ESAS can be used to measure cancer, and cancer treatment, related symptoms such as pain, fatigue, nausea, and shortness of breath in order to provide patients, care providers, and researchers with an easy-to-use scale to evaluate disease burden (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). The ESAS was used in the CanWell program as a measure of cancer disease burden and it is currently used by all Regional

Cancer Centers in Ontario, Canada. However, it required stronger evidence on its clinical measurement properties. Thus, in this thesis the reliability of the ESAS was examined using a Rasch Analysis approach.

Epidemiology of Cancer

It is estimated that approximately two out of every five Canadians will develop cancer at some point throughout their lives (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). It is anticipated that almost 190,000 new cancer diagnoses will be made in 2013 with over half of them lung, breast, colorectal and prostate cancers (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). The trend towards observed increases in the incidence of cancer are attributed primarily to improvements in cancer detection, as well as, a growing and aging population (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013).

While the incidence of cancer is increasing, significant improvements have been achieved in cancer survival. The five-year relative survival from all forms of cancer has improved from 56% (1992-1994) to 63% (2006-2008) (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). Five-year relative survival ratios are the highest for thyroid, testicular, and prostate cancers (98%, 97% and 96%, respectively) while cancers with the poorest prognosis include pancreatic (8%), esophageal (14%), and lung (17%) (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). As survival from cancer has improved, it is also been observed that the relative survival ratio is higher for women compared to men diagnosed with melanoma, breast, oral, and lung cancers. Factors that affect cancer survival rates include time to cancer diagnosis (i.e. diagnosis at a earlier stage of cancer leads to improved survival), tumor type (i.e. aggressiveness of the tumor), as well as, available diagnostic and treatment services, age at diagnosis, socio-economic status, and lifestyle (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). It is estimated that improvements in technology and medical management will contribute to on-going improvements in cancer survival.

Prevalence refers to the number of people living with cancer in a given population at a specific date (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). However, the Canadian Cancer Society's Advisory Committee on Statistics emphasizes the importance of considering tumor prevalence vs. person prevalence when considering the diagnosis of cancer (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). They emphasize that, as the medical management of cancer improves and the population ages, some people may be diagnosed with more than one type of cancer. As such, it was identified that at the beginning of 2009 839,291 cancers were recorded (compared to 838,724 people diagnosed with cancer alive at the same time, 10-year based prevalence, i.e. approximately 1,000 more tumors diagnosed than people) (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). The growing number of people living with cancer provides a challenge to the health care system. In 2000, cancer was rated as the fourth-costliest condition in Canada, costing approximated $17.4 billion in direct and indirect (e.g. loss of productivity) costs (Institute of Health Economics, 2008).

Effects of cancer on body, structure, and function

The effects of cancer on patients depend on a variety of factors including the cancer location, type, and stage. For example, patients with cancer of the head and neck will often have balance problems, possibly cognitive problems, and sometimes effects on levels of consciousness. The following section is a brief review of complications related to three types of cancer including head and neck, breast, and colon. However, since there are over 200 types of cancer (www.cancer.gov), the purpose of this section is to highlight the unique challenges each of the three cancer diagnoses present in order to emphasize the importance of appreciating the distinctive challenges that may affect patients.

In a systematic review by So and colleagues (So et al., 2012) 31 studies were found that discussed cancer-related side-effects for people with head and neck cancers. In their study, So et al, found that 12-months following treatment patients reported overall reductions in global quality of life (QOL) (So et al., 2012). Although they found that one year after cancer treatment the majority of patients recovered their emotional well-being (compared to the time of diagnosis and time during treatment), these were long lasting reductions in physical function that persisted (So et al., 2012). Emphasizing the importance of cancer location, So et al. also found that patients who had cancers of the larynx or hypopharynx had poorer QOL than those diagnosed with oral cavity or oropharynx cancers (So et al., 2012).

In women undergoing treatment for breast cancer, cancer treatment impairments are common at one-year, and longer, following treatment (Hayes, Rye, Battistutta, DiSipio, & Newman, 2010; Karki, Simonen, Malkia, & Selfe, 2005). Karki et al. found that six-months following breast cancer treatment scar tightness, axilla swelling, and shoulder-neck pain were common impairments reported by patients (Karki et al., 2005). Despite that, while scar tightness and swelling improved by 12-months, upper limb pain continued. That study also found that the presence of impairments, such as shoulder pain, affected patients' activities including lifting, carrying, and reaching out (Karki et al., 2005). They also found that women in their study reported restrictions in participation identified by reduced attendance in leisure activities and reduced ability to work (Karki et al., 2005). A prospective study by Hayes et al. (Hayes et al., 2010) found that while upper-body function improved over time following breast cancer surgery, up to 41% of patients exhibited on-going reduced function between six- and 18-months following treatment. The factors contributing to the on-going impairments and reduced function included older age, lower socio-economic status, involvement of the dominant side, more extensive surgery, and the complication lymphedema (Hayes et al., 2010). Hayes and colleagues concluded that the persisting adverse effects of cancer and its treatment negatively affect the QOL of breast cancer survivors (Hayes et al., 2010).

Similar to those diagnosed with breast or head and neck cancers, people diagnosed with colon cancer have unique impairments depending on the tumor location. For example, patients with rectal cancer experience higher levels of diarrhea compared to those with cancer elsewhere in the colon (Caravati-Jouvenceaux et al., 2011). The challenges associated with these cancers were directly related to poorer scores in physical and social well-being (WB) scores reported in QOL surveys (Caravati-Jouvenceaux et al., 2011). Appreciatively, as cancer progresses and spreads to the bone (i.e. metastasizes) there are further reductions in QOL and increased risk for bone fractures (Resnick & Penson, 2012; Walker et al., 2013).

When considering the effects of cancer on patients it is also important to appreciate the variety of symptom experience that may also be caused by the cancer treatment. The next section gives a brief review of the effects of common cancer treatments on body structures.

Effects of cancer treatments

The three most common types of cancer treatments include surgery, radiation, and chemotherapy. The decision as to which treatments are selected for each patient is dependent on their unique disease characteristics (e.g. cancer type, stage, aggressiveness of the tumor, etc.). The treatment options depend on the location of the cancer. Treatment-related sequelae will be determined by the type of medical management used. For example, all people with cancer that have surgery as part of their management are at risk for wound infections. However, those that have abdominal surgery will have different physical limitations compared to those who have lower extremity surgery due to sarcoma. To further complicate the recovery trajectory, it is not uncommon for some patients to receive two, or more, types of cancer treatment. For example, most women diagnosed with Stage 2 breast cancer and above will have adjuvant therapy consisting of chemotherapy and/or radiation therapy (Chew, 2001).

Cancer surgery can be used to diagnose the disease, remove the tumor, or help prevent cancer in some cases (American Cancer Society, 2011a). Side-effects related to surgery are often divided into two groups including those that can occur during surgery (e.g. bleeding, damage to internal organs or other tissues, reactions to medications used, and other complications in other organs such as heart tissue) and those that take place after surgery is completed (e.g. pain, bleeding, and infections) (American Cancer Society, 2011a). For women with cancer, a common side-effect associated with surgery includes secondary lymphedema (Cheifetz, Haley, & Breast Cancer, 2010). Pain and shoulder dysfunction are common complications for those who have undergone surgery for head and neck cancers (McNeely et al., 2008).

Radiation therapy is a form of cancer treatment that may be used as the primary treatment modality, either in isolation or combined with other therapies such as chemotherapy or surgery (American Cancer Society, 2011b). Most radiation therapy treatments also have localized side-effects that depend on the area targeted (American Cancer Society, 2011b). For most patients local swelling, skin color changes, loss of hair (alopecia), and fatigue are common adverse effects experienced (American Cancer Society, 2011b). For example, people who receive radiation therapy to their head often experience swelling in the head, cognition changes, and hair loss (American Cancer Society, 2011b; Butler, Rapp, & Shaw, 2006). Men who are receiving radiation therapy for prostate cancer often report difficulties with bladder function, such as incontinence, as well as sexual dysfunction, both negatively affecting participation and QOL (R. C. Chen et al., 2012; McCammon, Kolm, Main, & Schellhammer, 1999). While most radiation therapy treatments are performed through an external beam and thus lead to primarily local side-effects. However, there are other forms of radiotherapy, such as internal radiation where radioactive sources are implanted, or systemic radiation (using radioactive drugs) (American Cancer Society, 2011b). It is important to appreciate that all three types of radiation treatment can lead to whole body adverse effects, especially systemic (or whole body) radiation.

Compared to cancer-related surgery and radiation therapy, chemotherapy is a form of cancer management that is often administered using medications or intravenous access, and thus affects the whole body. There are many types of chemotherapy regimens and their associated adverse effects are as varied as the treatment protocols. However, common side-effects include nausea and vomiting, hair loss, anemia, and fatigue (American Cancer Society, 2013). Fernandez-Ortega et al. (2012) have summarized that while most cases of chemotherapy-induced vomiting can be prevented with antiemetic medications, nausea continues to be an important challenge (Fernandez-Ortega et al., 2012). In their study, it was found that even while using antiemetic mediations, almost 45% of the patients experienced nausea during cancer treatment that were associated with negative impacts on patient-reported QOL (Fernandez-Ortega et al., 2012).

Fatigue is another significant chemotherapy-related complication. Depending on the study reviewed, the incidence of chemotherapy-, or cancer-related fatigue ranges from 17%-100% (Ahlberg, Ekman, Gaston-Johansson, & Mock, 2003). Unlike being tired, cancer-related fatigue does not resolve with rest or sleep (American Cancer Society, 2013). There are many factors associated with the development of cancer-related fatigue including physiological and psychosocial parameters (Ahlberg et al., 2003). Chemotherapy is known to have a negative effect on red-blood cells leading to anemia and a reduced ability of the body to carry oxygen to different body structures (Ahlberg et al., 2003). Some chemotherapy treatments such as steroids, for example prednisone and methotrexate, are known to cause proximal muscle weakness (Batchelor, Taylor, Thaler, Posner, & DeAngelis, 1997), further contributing to the development of fatigue.

Advances in the medical management of people with cancer have led to improvements in cancer survival, and hence, the number of people now living with the long-term sequelae of the disease and its treatments is continuing to rise. In the following section the benefits of exercise on the common side-effects of cancer treatment will be reviewed.

Benefits of Exercise

There is a growing interest in the benefits of exercise and increased physical activity for people with cancer. This is evidenced in recent publications of several systematic reviews and meta-analyses (McNeely et al., 2006; Schmitz et al., 2005; Speck, Courneya, Masse, Duval, & Schmitz, 2010), as well as, two publications from the Cochrane Collaboration (Mishra et al., 2012). The American College of Sports Medicine (ACSM) has also developed and published exercise guidelines for cancer survivors (Schmitz et al., 2010).

The benefits of exercise for cancer survivors may also relate to the disease affecting the person. For example, research has shown that women who increase physical activity will benefit from improved cardiorespiratory fitness (C. J. Kim, Kang, Smith, & Landers, 2006; Schneider, Hsieh, Sprod, Carter, & Hayward, 2007b), body composition (i.e. reduced fat and increased lean body mass), physical functioning (McNeely et al., 2006), reduced fatigue (Kirshbaum, 2007; Schneider, Hsieh, Sprod, Carter, & Hayward, 2007c), and improved quality of life (Fitzgerald, 2007; Milne, Gordon, Guilfoyle, Wallman, & Courneya, 2007; Schneider, Hsieh, Sprod, Carter, & Hayward, 2007a). In addition to the physical and psychological improvements (Galantino, Cannon, Hoelker, Iannaco, & Quinn) described in the literature, increased physical activity by women with breast cancer is also associated with primary prevention of cancer (Batty & Thune, 2000; Cummings, 2007) and improved survival (Barbaric, Brooks, Moore, & Cheifetz, 2010; X. Chen et al., 2011; Ibrahim & Al-Homaidh, 2011).

It is important to appreciate that people with cancer who are receiving active cancer treatment can also benefit from exercise. Courneya and Friedenreich (2007) have summarized the benefits of exercise, and increased physical activity, during treatment included a reduction of cancer-treatment toxicities, maintenance of physical functioning, improved mood and QOL, prevention of muscle loss and fat gain, as well as, facilitating completion of difficult cancer treatments and increasing the effectiveness of some cancer treatment regimens K. S. Courneya and Friedenreich (2007). It is important to appreciate that while the benefits of exercise may be greater following the completion of cancer treatment (Conn, Hafdahl, Porock, McDaniel, & Nielsen, 2006; McNeely et al., 2006), exercising during cancer treatment should also be encouraged in order to maintain physical function, maintain muscle strength, and other benefits (Schmitz et al., 2010).

When considering exercise for people with cancer, it is important to consider exercise prescription parameters. Exercise types, such as aerobic and resistance, have shown to have different benefits for cancer survivor. A summary of the benefits of exercise, organized by the main body systems, is presented in Table 1. In this table, it is highlighted if endurance or resistance exercise were the primary beneficial contributing exercise types. In a randomized control trial (RCT) by Kim et al. (S. H. Kim et al., 2011), women participated in an 8-week, moderate-intensity, aerobic program. In this study the intervention group had a significantly reduced resting heart rates, reduced systolic blood pressure, and increased exercise capacity (measured by VO_2 peak) compared to the control group (no exercise). In a RCT by Courneya et al. (K. S. Courneya et al., 2007) that compared resistance exercises to aerobic exercises it was demonstrated that aerobic exercises were superior in improving aerobic fitness and percent body fat, while resistance exercises were superior in improving muscle strength, lean body mass, and chemotherapy completion rates.

While there is agreement that both strength and endurance exercise routines should be included for people with cancer, there is no consensus on exercise intensity or frequency. However, the ACSM guidelines recommend that cancer survivors should exercise at the same level as the general population with individualized exercise prescriptions modifications based on each persons' cancer diagnosis, their cancer treatment, and other unique considerations (Schmitz et al., 2010). It has also been demonstrated that both home-based exercise programs (Demark-Wahnefried et al., 2007; Ingram, 2006) and supervised exercise programs (K. S. Courneya et al., 2007; Schneider et al., 2007b) are beneficial for cancer survivors. Regardless of the type of exercise prescribed, it is important to address exercise barriers that are unique to cancer survivors. The following section describes some of the unique exercise barriers reported by cancer survivors.

Table 1: Effects of Exercise on Cancer Toxicities (Campbell & McTiernan, 2007; Kisner & Colby, 2007; Schneider, Dennehy, & Carter, 2003)

Cancer Treatment Toxicity	**Exercise Type**	**Benefits**
Immune suppression	Moderate aerobic	Enhance immune function (increase number and function of cytotoxic T lymphocytes and macrophages).
Cardiovascular	Aerobic & Resistance	Generalized vasoconstriction. Improved cardiac output. Increased capillary beds in muscles. Generalized vasoconstriction: will improve blood shunting from nonworking organs/muscles to those that are.
Pulmonary	Aerobic	Improve oxygen extraction from arteries. Larger lung volumes. Increase epinephrine release.
Gastrointestinal	Aerobic	Improved gastrointestinal motility.
Musculoskeletal	Aerobic & Resistance	Improved bone density (weight bearing exercises). Reduce body fat and improve lean body mass.
Neuroendocrine	Aerobic & Resistance	Improve insulin sensitivity and increase glucose uptake by skeletal muscle. Reduced systemic inflammation markers (C-reactive protein, Serum amyloid A, interleukin-6, and tumor necrosis factor-α).
Hepatic	Unknown	Unknown
Nephrotoxicity	Unknown	Unknown

Barriers to Exercise

In spite of increasing evidence that regular physical activity decreases the risk of certain cancers, as described above, Canadians in general are not meeting the basic recommendations for physical activity. Within Southern Ontario, only 50% of males and females self-report engaging in 30-45 minutes of moderate activity on most days of the week (Gilmour, 2007), and nationally, only 5% of adults accumulate 150 minutes, or 30 minutes five days a week of moderate to vigorous exercise (Statistics Canada, 2011). Cancer survivors face specific barriers to meeting targets for exercise and activity. Barriers include pain and symptoms related to cancer and its treatments, body image issues, lack of information about exercise and exercise safety, lack of supervised exercise programs. It is estimated that only 10% of cancer survivors exercise at their pre-diagnosis level during cancer treatment. An additional 20-30 % of cancer survivors resume their pre-diagnosis level of exercise post treatment (K.S. Courneya, Karvinen, & Vallance, 2007). Additional discussion of exercise barriers for cancer survivors is presented in Chapter 3 of this thesis.

In order to address several exercise barriers of cancer survivors, Hamilton Health Sciences together with McMaster University and Hamilton/Burlington/Brantford YMCA supported the development of the CanWell program. CanWell is an evidence-based, exercise and education program for people with cancer. The following section presents the objectives of the thesis and provides an overview of the chapters in this dissertation with their relationship to the incorporation of exercise as an integral component of cancer care.

Objectives of the Thesis Work

The overarching objective of this thesis was to measure the impact of a community-based exercise and education program on the rehabilitation and recovery process of cancer survivors, including how the intervention is sustained in the longer term. Three specific studies were done out to address this objective.

The specific objectives of each manuscript are presented below:

Objectives for Manuscript 1:

- To describe the development and implementation of an evidence-based, theory driven, community-informed exercise and education program for people with cancer (CanWell program).
- To evaluate the effectiveness of the CanWell program as measured by physical and QOL measures.

Objectives for Manuscript 2:

- To evaluate the long-term physical and health-related quality of life changes expressed by cancer survivors who participated in a 12-week community-based exercise and education program (CanWell)?
- To investigate exercise barriers that exist for CanWell graduates who did not continue to exercise.

Objectives for Manuscript 3:

- To evaluate the psychometric properties of the Edmonton Symptom Assessment System (ESAS) using a Rasch Analysis approach.
- To compare the conclusions made using ESAS scores in the initial CanWell study with conclusions drawn using Rasch-proposed ESAS scoring approach.

Review of Included Manuscripts

The first manuscript (Chapter 2) entitled “CanWell: Meeting the psychosocial and exercise needs of cancer survivors by translating evidence into practice.” In this chapter a description of the CanWell program is provided. CanWell, an evidence-informed, community-based, exercise and education program for people with cancer was developed to meet a gap identified by a survey of cancer survivors at the Juravinski Cancer Center (Cheifetz & Park Dorsay, 2007). In this survey, cancer survivors reported that they wanted to learn about exercise, felt they could exercise, wanted the exercise program to be in the community, and that the program be associated with the cancer center. This led to the development of CanWell which represents a partnership between Hamilton Health Sciences (HHS), McMaster University, and Hamilton/Burlington/Brantford YMCA. It was designed by a physiotherapist specializing in oncology care and a Nurse Practitioner with rehabilitation oncology experience. CanWell was implemented at the Les Chater YMCA in Hamilton, Ontario in 2009 as a pilot research project and became an integral component of the YMCA programing in January 2010. Unique to the CanWell program is that it is accessible to people with any cancer diagnosis, at any stage of the disease, and during any time of the cancer care continuum. Furthermore, the program is supervised by HHS professional health-care staff and implemented by YMCA fitness staff with input from the university. Following participation in CanWell, participants reported significant improvements in health-related quality-of life (HR-QoL), were able to ambulate a greater distance during a six-minute walk test, and increase their total minutes on a treadmill. Furthermore, no increases in disease burden were identified using the Edmonton

Symptom Assessment System. Importantly, no exercise related injuries were reported by CanWell participants during the 12-week supervised exercise program.

The functional and HR-QoL benefits achieved by CanWell participants have demonstrated that the program is feasible. As funding for the CanWell research has been completed, the ability of the program to continue and grow has demonstrated that CanWell is also sustainable as an ongoing partnership between the establishing institutions.

The second manuscript (Chapter 3) is titled "Identifying exercise adherence and barriers following participation in a community-based exercise and education program for cancer survivors." Participants who completed their 12-week supervised exercise regimen as part of the CanWell program were recruited for a long-term follow-up. During this second study, participants repeated the same evaluations completed at the end of the CanWell program with the addition of a survey investigating their current exercise levels facilitators and barriers limiting exercise participation. For this study, it was hypothesized that CanWell graduates are more likely to continue exercising following completion of the program since they have received guidance with safe exercise programs, have access to an exercise facility, and can consult with hospital-based health care providers at the community facility. Interestingly, the 57 CanWell graduates who participated in the second study exhibited statistically significant reductions in total minutes on the treadmill ($t_{22} = -2.24$, $p < 0.05$) with a trend towards improvements in 6-MWT distance.

Participants reported no significant changes in total HR-QoL or disease burden scores. However lower physical well-being ($t_{36} = -2.15$, $p < 0.05$) and higher social well-being ($t_{36} = 2.84$, $p < 0.01$) scores were reported in the HR-QoL measurement tool subdomains. Participants also reported fatigue, gym cost, and return to work as the top three barriers to exercise. Important knowledge to improve CanWell was learned from participants who reported that while they believed they can exercise independently (86%), only 60% thought they could progress their exercise programs without advice. This information is important to health-care providers who plan and implement exercise programs for cancer survivors to ensure maximal exercise adherence and progression for participants.

The third manuscript (Chapter 4) is titled "Rasch analysis of the Edmonton Symptom Assessment System (ESAS) and its research implications." The ESAS was developed by Bruera et at. (2001) as a simple tool to evaluate common symptoms reported by patients who are admitted to a palliative care setting (Bruera et al., 1991). Since its development, the ESAS has become a standard measurement tool used both in clinical and research settings to evaluate specific cancer-related symptoms, as well as, overall cancer disease burden (Richardson & Jones, 2009). The psychometric properties of the ESAS have been studied in several studies, all using statistical methods associated with the Classical Test Theory (CCT). The first goal of the third study presented in this dissertation was to investigate the psychometric properties of the ESAS using Rasch analysis, which is grounded in the Item Response Theory (IRT) (Streiner D.L. & Norman G.R., 2008). A secondary goal was to apply the findings of the Rasch analysis, specifically using Rasch-proposed ESAS scoring to re-analyze the effects of exercise on cancer disease burden in the CanWell cohort who participated in the study reported in

Chapter 2 of this thesis. The current study has yielded two important results. The first is that the ESAS, in the studied format, did fit the Rasch model suggesting it is a reliable tool, and that it is appropriate to use the ESAS to measure overall cancer disease burden. The second important conclusion was that, when analyzing overall ESAS scores, different conclusions could be made if the traditional scoring system is used (i.e. using summed scores, which have ordinal-level properties) or if Rasch-proposed scores are utilized (Chapter 4, Appendix 1), as they have interval-level properties.

In summary, this chapter highlights the challenges affecting people with cancer, such as the side-effects associated with the disease and its related treatments. The effects of exercise, as a modality to assist in the management of cancer, or cancer treatment, related complications were also described. The reader was also provided with a brief overview of each of the studies that comprise this dissertation. The following three chapters provide a comprehensive review of each study described above. The final section of this thesis (Chapter 5), consists of a discussion which describes how the overall dissertation contributes to meeting the physical and psychological needs of people with cancer in order to empower them throughout their cancer journey.

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Chapter 2: CanWell: Meeting the psychosocial and exercise needs of cancer survivors by translating evidence into practice.

Title: CanWell: Meeting the psychosocial and exercise needs of cancer survivors by translating evidence into practice.

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Abstract

Background

As more evidence emerges to support the incorporation of exercise for cancer survivors to positively affect physical, emotional, and social health it is imperative that health-care providers use current knowledge to develop evidence-based exercise programs for these patients. Our purpose is to describe the development, implementation, and effectiveness of the CanWell program, an evidence-based, community and partnership-based, exercise and education program for all people with cancer.

Methods

Exercise and cancer research was reviewed, summarized, and utilized to develop CanWell. A 12-week, supervised, community-based, exercise and education program established in collaboration between an acute care hospital, academic center, and a not-for-profit YMCA facility. CanWell participants completed physical and health-related quality of life measures (HR-QoL) prior to initiating the program and repeated them at six-, and 12-weeks.

Results

Following the exercise program participants reported significant improvements in HR-QoL, recorded distance ambulated during a six-minute walk test, and total minutes on a treadmill recorded using the STEEP treadmill test. Furthermore, no increases in disease burden were identified using the Edmonton Symptom Assessment System. In addition, no exercise related injuries were reported by CanWell participants.

Conclusions

As the body of evidence supporting the incorporation of exercise as a standard of care for cancer survivors, it is imperative that care providers use current knowledge to provide opportunities for their patients to exercise in effective exercise programs. CanWell is an example on how collaboration between hospital, university, and community institutions can be used to move research into practice and meet the needs of cancer survivors.

Keywords: Cancer, Oncology, Exercise, Community, evidence-based.

Introduction

Cancer is a major public health concern in North America and many other parts of the world (Jemal, Siegel, Xu, & Ward, 2010). It is estimated that approximately 1,638,900 new cases of cancer will be diagnosed in the United States in 2012, with an estimated 577,190 cancer related deaths (American Cancer Society, 2012). It has been estimated that approximately one-third of these deaths are related to obesity, lack of physical activity, and poor nutrition and therefore may have been prevented (American Cancer Society, 2012). On a positive note, the overall incidence of cancer in the US decreased for both men (1.3% per year) and women (0.5% per year) from 2000 to 2006 along with decreased death rates (21.0% for men and 12.3% for women) over the last 15 years (Jemal et al., 2010). Depending on the cancer type, 5-year survival rates continue to improve primarily due to progress in earlier cancer detection and improvements in the medical management of cancer (American Cancer Society, 2012). However, with the increased number of people living with cancer there is a growing burden on health care systems in terms of medical management, cancer surveillance, and supportive care (American Cancer Society, 2012; Canadian Cancer Society's Steering Committee, 2009; Jemal et al., 2010).

Improved cancer survival is welcomed; however, the untoward short and long term treatment side-effects commonly experienced by cancer survivors lead to decreased quality of life and increased costs of cancer care (Barbaric, Brooks, Moore, & Cheifetz, 2010; Breastcancer.org, 2009; Early Breast Cancer Trialists Collaboration Group, 1998). The short-term side-effects include low blood counts, nausea and vomiting, fatigue, cognitive dysfunction, pain, and others (Courneya & Friedenreich, 2007; Courneya, McKenzie, et al., 2008; Friendenreich & Courneya, 1996). Cancer and its treatments are also associated with muscle wasting and cachexia, and reduced physical function (Courneya & Friedenreich, 2007; Courneya, McKenzie, et al., 2008; Friendenreich & Courneya, 1996; McNeely et al., 2006; Montazeri, 2008). Long-term side-effects include increased body mass index, ongoing cognitive deficits, persistent fatigue, cardiomyopathies, neuropathies, mood disturbances, bone loss and pulmonary damage (MacMillan Cancer Support, 2009; Schmitz & Speck, 2010; Silver, 2007). A survey conducted by cancer support groups reported that 71% of cancer survivors experienced at least one of these problems for more than 10 years following their cancer treatment (MacMillan Cancer Support, 2009). The risk of psychological distress for cancer survivors relates more strongly to their level of physical disability than it does to the diagnosis, stage or treatment of cancer (Banks et al., 2010).

The benefits of increased physical activity and exercise for people with cancer are well documented (Courneya & Friedenreich, 2007) and known to counteract many of the side-effects listed above (McNeely et al., 2006; Milne, Wallman, Gordon, & Courneya, 2008). High levels of physical activity and exercise training are also associated with improved survival, prevention of new cancers, earlier detection of some types of cancer (Barbaric et al., 2010; Ibrahim & Al-Homaidh, 2011; Irwin et al., 2011), and are known to last five years following participation in the programs (Mutrie et al., 2012).

While the benefits of exercise for people with cancer have been well documented, there are barriers to cancer survivors' adoption of exercise as part of their lifestyle.

Commonly reported barriers include cancer and treatment related side-effects, predominantly cancer related fatigue. The experience of treatment side-effects challenges self-efficacy, the belief of the person in their ability to perform exercise (Blaney et al., 2010). Health system-related barriers to exercise include availability of exercise programs for cancer survivors. The majority of studies investigating the effectiveness of exercise programs for cancer survivors have been hospital or university based, and of limited duration due to available space and resources. Thus, interest is growing in community-based exercise programs for cancer survivors (De Smedt, De Cocker, Annemans, De Bourdeaudhuij, & Cardon, 2012; Haas & Kimmel, 2011; Murray et al., 2012; Rajotte et al., 2012; Ross et al., 2011). The theoretical and evidence underpinning these community-based exercise programs, as well as, the staffing models supporting them, vary significantly. However, these programs are aligned with the preferences of cancer survivors who want home- (Jones & Courneya, 2002; Karvinen, Courneya, Venner, & North, 2007) or community-based (Karvinen et al., 2006) exercise programs.

The purpose of this paper is to describe the development, implementation, and effectiveness of an evidence-based, theory driven, community-based exercise and education program for people with cancer that was developed in collaboration between a university, acute care hospital, and a not-for-profit healthy lifestyle organization.

Materials and Methods

The CanWell Program Philosophy

The theoretical construct underpinning the CanWell program, for both participants and program providers, is based in self-efficacy. Self-efficacy is the most visible construct of Social Cognitive Theory (Bandura, 1986; Rogers et al., 2005; Stone, 1998) and refers to a person's belief in their ability to manage a specific task, or behavior (Bandura, 1986; Rogers et al., 2005). While cancer survivors report interest in exercising, they have concerns about knowing how to do so safely and successfully (Cheifetz & Park Dorsay, 2007). CanWell provides education, support and an individualized program designed to enhance participants' self-efficacy in their ability to modify their lifestyle with exercise. Similarly, care providers who have the skills and knowledge, and believe that they can work with cancer survivors; are most likely to do so. Care providers' lack of knowledge regarding cancer and exercise is considered a barrier to cancer survivors' access to evidence based exercise programs (Cristian, Tran, & Patel, 2012). As many years are required to build clinical competence to treat people with cancer who have divers medical conditions (Silver, Baima, & Mayer, 2013), health care providers may feel lack of confidence (i.e. self-efficacy) in their abilities to prescribe safe exercise programs.

The CanWell Program addresses a current gap focusing on YMCA fitness staff knowledge and skill (Appendix 1), thereby enhancing their self-efficacy in working with cancer survivors.

Participants and Setting

CanWell (www.canwellprogram.ca) was established in 2009 at the Les Chater Family YMCA in Hamilton, Ontario, Canada. The program was established as a partnership between Hamilton Health Sciences (HHS), McMaster University, and the YMCA. CanWell was designed using available exercise and cancer evidence by HHS staff (OC and JPD). YMCA staff participated in a 12-hour training session that included topics such as cancer pathophysiology, review of cancer treatments, exercise prescriptions for people with cancer, and more (Appendix 1). YMCA staff were also trained in data collection and enjoyed ongoing on-site mentoring by the Physiotherapist and Nurse Practitioner.

Eligible participants are adults diagnosed with cancer, living in the community, and those who are considered "well." For the purpose of CanWell, a "well participant" is defined as a cancer survivor who is living at home, able to ambulate independently, has no acute medical conditions (e.g. no angina or active pneumonia), and who passes pre-exercise safety screening (Appendix 2). In addition, a cancer survivor is defined as a person living with cancer at any stage of care throughout the cancer care continuum; from diagnosis to palliative. Participants were required to purchase YMCA membership, with generous financial assistance available based on self-identified fiscal needs.

CanWell received approval from the HHS/McMaster University Research Ethics Board and is registered with ClinicalTrials.gov. Written informed consent is obtained prior to initiating study activities. Data from non-consenting participants is excluded from outcome analysis.

CanWell is a prospective, pre/post, cohort study that consists of a 12-week supervised exercise and education program. Participants are required to participate in supervised exercise twice a week and to exercise independently a third time. Prescribed exercises are individualized based on baseline testing, unique cancer type and stage, and person specific precautions and contraindications (Appendix 1). Exercise prescriptions include aerobic endurance (target heart rate 50%-80% of maximal heart rate, depending on abilities), muscle strength (target is muscle fatigue following 2-3 sets of 12 repetitions), and flexibility exercises based on established guidelines (Anonymous, 1998; Heyward, 2006; Klika, Callahan, & Drum, 2009; Kraemer et al., 2002; Mutrie et al., 2007). Peer support is encouraged during the individualized exercise programs and during group classes. Details on the free CanWell education sessions, YMCA staff training, and exercise safety guidelines are available in Appendix 1.

Study Procedures

Participants are referred to CanWell through their physician (oncologist or family practitioner), Nurse, Psychologist, or by self-referral. During the intake session a Physiotherapist, Nurse Practitioner, or CanWell-trained Kinesiologist review participants' relevant medical history, establish exercise safety guidelines, and obtain written consent by those interested in participating in the program research. Measurements are completed prior to initiating the exercise program and repeated at six-, and 12-weeks.

Outcome Measures

Physical Performance Measures

Aerobic fitness is evaluated using the standardized exponential exercise protocol (STEEP). The STEEP was developed to evaluate aerobic fitness using either a cycle ergometer or a treadmill, and found to be useful for participants of varying capabilities (Northridge et al., 1990). The STEEP was designed to begin at low workloads and increases exponentially between ramp and speed (Northridge et al., 1990). It has been shown to produce similar peak VO_2 measurements as the modified Bruce treadmill test, but in shorter timeframes (Riley et al., 1992). The STEEP has been used in healthy

(Northridge et al., 1990) participants, patients with congestive heart failure (Riley et al., 1992), and patients with lung cancer (Win et al., 2005).

The 6-minute walk test (6-MWT) is a functional walk test recommended for use in both research and clinical settings (Solway, Brooks, Lacasse, & Thomas, 2001). The 6-MWT has excellent test-retest reliability (ICC 0.82-0.99) (Portney & Watkins, 2000), and has been used to assess walking performance in people with cancer (Cheville, Troxel, Basford, & Kornblith, 2008) and administered according to a standardized protocol (ATS Committee on Proficiency Standards for Clinical Pulmonary Function Laboratories, 2002).

Self-Reported Quality of Life Measures

Health related - Quality of Life (HR-QoL) is measured using the Functional Assessment of Cancer Therapy Scale – General (FACT-G) (Cella et al., 1993). This scale has been rigorously investigated for use in assessing HR-QoL of people with different types of cancers and found to have a large effect size when used in both cross-sectional and longitudinal designs (Cheung, Goh, Thumboo, Khoo, & Wee, 2005). The FACT-G (version 4) is a 27-item self-report measure yielding a total score ranging from zero (0, worst HR-QoL) to 94 (best HR-QoL). This scale also consists of four subscales evaluating physical, emotional, functional, and social well-being. The validity and reliability of FACT-G subscales has been established and the scores are commonly reported in cancer-related literature (Cella et al., 1993).

The Edmonton Symptom Assessment System (ESAS) is used to evaluate the burden of symptoms commonly associated with cancer including pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). The ESAS has been shown to be valid and reliable, and has been extensively used throughout the cancer care continuum (Nekolaichuk, Watanabe, & Beaumont, 2008; Philip, Smith, Craft, & Lickiss, 1998; Richardson & Jones, 2009; Watanabe, Nekolaichuk, Beaumont, & Mawani, 2009). Program satisfaction is evaluated utilizing a YMCA modified program satisfaction survey and long-term compliance with exercise are measured using an Exercise adherence and barriers survey (based on the Theory of Planned Behavior) (Blanchard, Courneya, Rodgers, & Murnaghan, 2002; Courneya, Segal, et al., 2008; Courneya, Stevinson, et al., 2012; Lowe, Watanabe, Baracos, & Courneya, 2012) and Godin Leisure-Time Exercise Questionnaire (Godin, Jobin, & Bouillon, 1986; Godin & Shephard, 1985). The results of satisfaction and long-term compliance will be reported in a future manuscript.

Statistical Analysis

Descriptive statistics were used for description of participants' baseline demographics and physical characteristics. One-way repeated measures ANOVA was used to evaluate change in HR-QoL and physical function over time (i.e. baseline, 6-weeks, and 12-weeks) with appropriate post-hoc analyses (Bonferroni correction for multiple comparrisons) (Portney & Watkins, 2000). Results are presented as mean ± standard deviation. All statistical tests are 2-sided withsignificance level set at $p<0.05$ (Portney & Watkins, 2000). Analysis was also repeated with multiple imputation (MI) of missing data to minimize potential bias of missing data (Mayo et al., 2011). One-way repeated measures ANOVA was calculated a second time for the imputed data

(Raghunathan & Dong, 2011) and compared to results from the raw data. Statistical analyses were performed using IBM SPSS Statistics (IBM Corp. Released 2011; IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.) and SAS 9.2 (SAS Institute, Cary NC).

Results

All of those referred to the program met the research inclusion criteria and were deemed eligible to participate in CanWell with the exception of one cancer survivor who was deemed ineligible related to their unstable cardiac status. Participant flow and reasons for research non-completion are presented in Figure 1.

A total of 139 cancer survivors participated in CanWell between program initiation and July 2012. Of these 115 (82.7%) consented to participate in the research component (Table 1). Of the 115 participants who started the exercise program, 85 (74%) completed the 6-week measurements and 65 (56.5%) completed the final assessments (Figure 1). There were no exercise related injuries that affected program completion.

Performance Measures

Forty participants were able to complete all three STEEP measurements and demonstrated significant increases in time on the treadmill following the exercise training ($F_{(2, 78)} = 22.5$, $p < 0.001$, power = 1). Participants exhibited significant improvement between baseline and both 6- and 12-weeks measurements (mean difference, MD, pre to 6 week = 1.11 95%CI = 0.52-1.69 and pre to 12-week = 1.5 95%CI = 0.86 – 2.15, $p < 0.001$). No significant improvement was observed between the 6- and 12-week measurements.

On the six-minute walk test (Table 2) participants were able to walk significantly further following the exercise program ($F_{(2, 110)} = 9.82$, $p < 0.001$, power = 0.98). Post hoc analyses revealed that 6-MWT distance increased significantly between baseline measurement and the 6-week evaluation (mean difference, MD = 31.9, p <0.05, 95%CI -53.1 to -10.6). While there was significant improvements between baseline and 12-week measures (MD = 26.8, p <0.05, 95%CI, -47.3 to -6.4), there was no significant increase in distance ambulated between the 6- and 12-week measures (MD = 5.0, $p = 0.79$).

Self-Report HR-QoL Measures

CanWell participants reported significant improvements in overall health-related QoL (Table 2) using the total FACT-G score ($F_{(2, 94)} = 6.97$, $p < 0.01$, power = 0.9). Post Hoc analysis revealed no significant improvements between pre-CanWell measurements and 6-weeks (MD = 1.9, $p = 0.3$), however significant change was calculated between pre-CanWell and 12-weeks measurements (MD = 4.78, $p < 0.01$, 95% CI = 1.2-8.4). Change in FACT-G total scores from 6- to 12-weeks approached significance (MD = 2.85, $p = 0.054$). Analyses of the FACT-G sub-domains (Table 3) demonstrated significant improvements in physical well-being (PWB, Greenhouse-Geisser correction $F_{(1.76, 98.33)} = 7.72$, $p < 0.01$, power = 0.9), functional well-being (FWB, Greenhouse-Geisser correction $F_{(1.68, 82.4)} = 3.37$, $p < 0.05$, power = 0.6), and emotional well-being (EWB, Greenhouse-Geisser $F_{(1.56, 76.46)} = 6.99$, $p < 0.01$, power = 0.87). There were no significant changes in the social well-being sub-scale.

While there was a significant reduction in ESAS scores over the 12-weeks of the exercise program ($F_{(2, 102)} = 3.37$, $p < 0.05$, power = 0.6), Post Hoc analysis did not find significant differences between each measurement sessions (MD pre-CanWell to 12-weeks = 3.97, p = 0.67).

Multiple Imputation Analysis

Multiple imputations were employed to impute the missing values at baseline and the two follow-up measurement sessions for the primary outcomes (6MWT, FACT-G, ESAS, and STEEP). Under the assumption that data was missing at random, we generated the missing values by patients' gender, age at referral, age at diagnosis, type of diagnosis, weight, height, body mass index, and available outcome measurements at the three time points (Tables 2 and 4). We used the Markov Chain Monte Carlo method to impute 10 replications of the missing values (Robert & Casella, 2004; Schafer, 1999). The majority of the results did not change between the analysis of the raw and imputed data with the exception of the ESAS where the second analysis identified a statistically significant improvement between pre-CanWell and the end of the program (Tables 2 and 4) and changes in FACT-G scores identifying a significant change between pre-CanWell and six-week measurements, and well as no significant differences between six-weeks and 12-weeks evaluations (Table 4).

Discussion

CanWell is a community-based, individualized exercise and education program for people with cancer that demonstrates benefits in physical function and well-being. Furthermore, this program demonstrates the use of multi-agency collaboration to implement known exercise and cancer research into a community setting.

Due to the known deleterious effects of cancer and its treatment on muscle function, aerobic fitness, and physical abilities of people with cancer (Thorsen, Gjerset, Fossa, & Loge, 2011), it was expected that a supervised exercise program would result in improvements in measures of physical fitness and function as this has demonstrated in previous studies (Courneya, Stevinson, et al., 2012; McMillan & Newhouse, 2011; Mishra et al., 2012). However since participants in CanWell are a heterogeneous cohort with mixed types and stages of cancer, it was assumed that the effects of the exercise program may be diminished compared to studies of homogeneous cohorts (Courneya, Sellar, et al., 2012; Peddle-McIntyre, Bell, Fenton, McCargar, & Courneya, 2012; Thorsen et al., 2012). Analysis of results of the CanWell program show significant improvements in aerobic fitness as evidenced by increased duration on the treadmill STEEP test after both 6- and 12-weeks of exercise training. This translated into improved walking ability with significant increases in distance ambulated during the 6MWT after just 6 weeks in the program. These findings are consistent with those reported in two systematic reviews (Knols, Aaronson, Uebelhart, Fransen, & Aufdemkampe, 2005; McNeely et al., 2006) confirming that a community-based exercise intervention designed for a heterogeneous group of cancer survivors can produce significant improvements in function.

Considering the length of the CanWell program, participants plateaued on the 6MWT after 6-weeks in the program suggesting that 6-weeks of a supervised exercise program may be sufficient for functional improvements. However, participants exhibited significant improvements in their aerobic testing during the 12-week STEEP testing, indicating that improvements continue beyond the 6-weeks. Further support for maintaining the current 12-week length of CanWell is that HR-QoL changes required the entire program to demonstrate significant improvements. This suggests that the physical abilities improve prior to changes in HR-QoL which is important when educating participants of what to expect when exercising and emphasizes the importance of setting long-term goals and adhering to the exercise programs. A potential explanation of this finding is that participants may need time to gain confidence in their increased physical capability and apply these to a wider range of meaningful life activities. Interestingly, the difference in improvement in function and HR-QoL may also be explained by the "disability paradox" where people with severe physical disabilities report unexpected high levels of quality of life (Albrecht & Devlieger, 1999) suggesting that while improvements in function were observed, exercising with other cancer survivors may have allowed participants time to reflect on their current situation and adjust their view on life. Support for this concept is the positive levels of HR-QoL reported by people with cancer who are exercising while in the palliative stage of their care (Gulde, Oldervoll, & Martin, 2011; Lowe, 2011; Oechsle et al., 2011).

Several factors may have contributed to the improved aerobic fitness and walking, including improved blood biochemistry (e.g. increased hemoglobin) (Dolan et al., 2010), improved muscular performance (strength and/or endurance), increased stride length, improved cardiovascular function (Kavazis, Smuder, Min, Tumer, & Powers, 2010), or oxygen exchange (ATS Committee on Proficiency Standards for Clinical Pulmonary Function Laboratories, 2002). Psychological factors such as increased confidence, familiarity with the outcome measure, familiarity with the exercise equipment, and decreased apprehension related to the physical challenge of exercise may have also attributed to these findings. An unexpected finding was the regression in meters walked during the 6MWT between 6-12 weeks in the program. A possible explanation may be that participants reached the maximum distance (i.e. ceiling effect) they are able to ambulate within the six-minutes without running. As this study included individuals during active treatment, or progressive disease, cumulative treatment effects or the natural progression of cancer may have contributed to the decline in aerobic function throughout this time frame, however since participants significantly improved on the STEEP test, this is less likely.

The significant improvements in ESAS scores throughout CanWell suggest that the exercise program helped resolve some cancer-related symptoms. However, the lack of the ability to identify statistically significant changes between each of the measurement (i.e. between baseline, six-, or 12-week) session may be attributed to the mixed group of participants who had different oncological conditions, different stages of cancer, a combination of participants on or off treatment, or any combinations of the factors listed above.

Unique aspects of CanWell include the location for delivery of the exercise program, the collaborative interagency partnership involved in designing and delivering the program, and the emphasis on knowledge translation. In a systematic review of 14 exercise programs for cancer survivors (McNeely et al., 2006), 64% were supervised and conducted within universities or hospitals and 36% were non-supervised exercise programs conducted in the participants' homes. Rajotte et. al. (2012) reported on a community-based exercise program at YMCA facilities in the United States (Rajotte et al., 2012). The YMCA/LIVESTRONG^{TM} Exercise and Thrive (E&T) exercise is similar to CanWell in that it is located at a YMCA and is 12- weeks long (Rajotte et al., 2012). While the E&T program has many similarities with CanWell and has resulted in significant improvements for cancer survivors (Rajotte et al., 2012), there are important differences from our program. The E&T program excluded people who are on active treatment for cancer and those with advanced metastasized cancer, an important difference from the current study. Furthermore, the on-going link between an acute care hospital where regulated health-care providers work was not reported, as well as the level of interaction between the health professionals and program participants. Hass and Kimmel (2011) reported on a community-based exercise program for cancer survivors, however their published work provides limited information regarding their program limiting the ability to compare their program to CanWell (Haas & Kimmel, 2011). Unique aspects of CanWell include the link to an acute care hospital, emphasis on participants' safety using the expertise of a Physiotherapist and Nurse Practitioner with experience in Oncology Rehabilitation to provide on-going mentorship to the YMCA Kinesiologists and Fitness Trainers, and the combination of exercise and formal education sessions in the community.

Limitations

CanWell was developed as a combined knowledge translation project implementing current understanding regarding exercise and cancer, while collecting data from the enrolled cohort. Beyond the E&T program described above, direct comparison with other published work is challenging since the program is unique. While similar programs may exist, publications describing them were not found when preparing this manuscript. To assess the effects of exercise for people with cancer, a randomized controlled trial is often considered the gold standard for clinical research (Portney & Watkins, 2000). However, when designing CanWell the researchers rationalized that current “standard care,” of not providing access to such a program, is not supported by the evidence, and hence, does not meet the goal of developing an evidence-base program. In the absence of a control group, it is possible that other factors, such as time since treatment, could have contributed to the observed results. Future subgroup analysis comparing exercise effects for those who are on treatment and those who completed treatment may address this limitation. As a pure knowledge translation project, a greater emphasis should have been put on evaluating the knowledge of the YMCA staff. While an evaluation of YMCA staff around knowledge evaluation and skills acquisition was completed following the initial training, a future project may evaluate how fitness staff learn from, and interact with, the hospital staff with a view to identifying challenges and strategies to provide ongoing support for programs such as CanWell.

While 139 cancer survivors started the CanWell program only 56% completed it. This can be considered a high drop-out rate compared with other research evaluating the effects of exercise on cancer survivors where dropout rates varied from 50% (Haas & Kimmel, 2011), 78% (Jones et al., 2009), to 88% (Rajotte et al., 2012). The majority of published research reporting high adherence rates have enrollment restricted to people with certain types of cancer (e.g. breast), or at specific stages of the cancer journey (e.g. post treatment). In comparison, CanWell was designed to meet the needs of cancer survivors during and after cancer treatment, those with limited or advanced cancer, and those who maybe palliative. The diverse nature of cancer survivors in the CanWell program may explain the lower program completion rate. As CanWell data accumulates, further analysis maybe possible on sub-groups of participants to identify potential predictors of exercise program completion. Considering the results of the MI, and their consistency with the raw data analysis, it may be safe to assume that the high dropout rate did not negatively impact on the results of this study.

In the current report, three quarters of the CanWell participants are women, potentially biasing the generalizability of the results. The imbalance in the gender and diagnosis group (mostly women with breast cancer) is probably indicative of this patient population being more educated regarding the benefits of exercise. It may also indicate that health-care providers should enhance the education they provide to all cancer survivors regarding the benefits of exercise. As the CanWell project continues to accumulate data, it may become possible to perform sub-group analysis on different cancer survivor groups.

Conclusions

The benefits of exercise for people living with cancer have been well documented. The most effective delivery method that meets cancer survivors needs, interests, and exercise safety concerns remains unknown. CanWell is an example of a unique partnership that developed an effective, community-based, individualized exercise program that address a gap in health care for people living with cancer.

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Conflict of Interest

None declared. The authors have full control of all primary data and agree to allow the journal to review data if requested.

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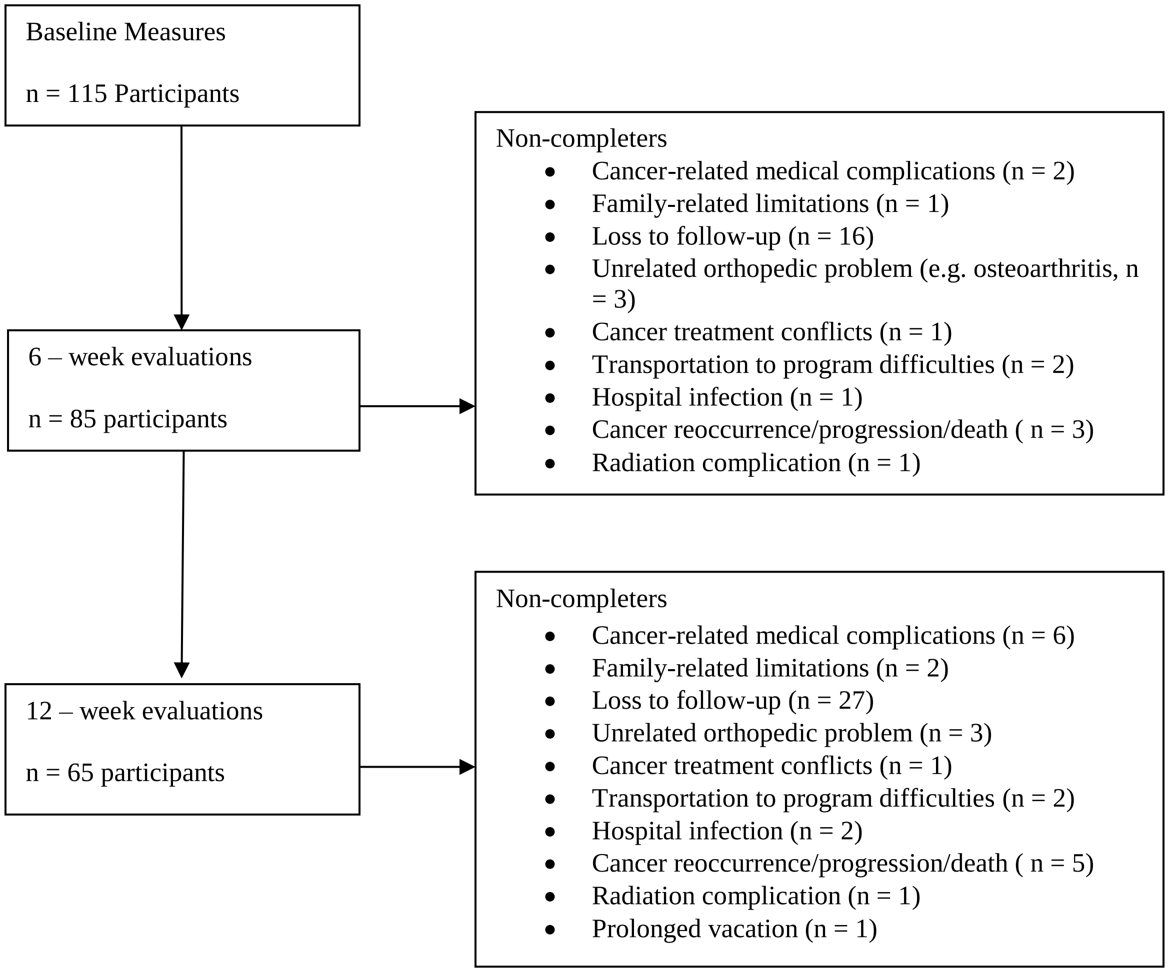

Figure 1 CanWell Program Participants' Flow

Table 1: Participant characteristics at baseline (n = 115)

Characteristics	**Mean**	**SD**	**Min**	**Max**
Age at start of CanWell (years)	54.9	9.97	32	78
Time from cancer diagnosis to CanWell referral (months)	23.2	25.64	0	141
Mass (kg)	78.3	16.94	49	119
Height (cm)	168.8	8.90	152	193
BMI (kg/m^2)	27.43	5.21	18	42
	Frequency	**% of Total**		
Gender (female)	84	73		
Cancer Diagnosis				
Breast	60	52.2		
Lymphoma	9	7.8		
Multiple Myeloma	8	7.0		
Leukemia	5	4.3		
Brain	5	4.3		
Prostate	5	4.3		
Pancreatic	4	3.5		
Colon	4	3.5		
Lung	3	2.6		
Ovarian	2	1.7		
Other*	10	8.7		
Metastatic cancer**	7	6.1		
Cancer stage†				
1	12	10.4		
2	24	20.9		
3	19	16.5		
4	10	8.7		
unknown	50	43.5		
Cancer Treatments††				
Chemotherapy	103	74.1		
Radiation	81	58.3		
Surgery	94	67.6		
Other	21	15.1		

SD, standard deviation; BMI, body mass index
* Other cancers included anal, astrocytoma, bladder, cervical, kidney, melanoma, peritoneal, stomach, thymoma, uterine, and vulvar
** does not include systemic diseases such as lymphoma, leukemia, or multiple myeloma
† Includes participants who did not know their disease stage, see study limitation section
†† Other treatments included primarily hormone therapy and stem cell transplants

Table 2: Physical Function and HR-QoL outcome measure results (raw and imputed data).

	Pre-CanWell			6-Weeks			12-Weeks		
	Raw Data		ID	Raw Data		ID	Raw Data		ID
	n	Mean (SD)	Mean (SD)†	n	Mean (SD)	Mean (SD)†	n	Mean (SD)	Mean (SD)†
STEEP	40	6.8 (2.3)	6.4 (2.14)	40	7.8 (2.3) ***	7.4 (3.22)	23	8.1 (2.4) ***	7.8 (3.22)
6MWT	56	440.6 (106.6)	430.7 (105.1)	56	472 (100.1) **	460.8 (98.66)	56	467 (93.7)	456.0 (96.51)
FACT-G	48	81.2 (14.1)	77.8 (13.9)	44	83 (14.9)	81.7 (16.09)	48	86 (15.3) **	83.3 (20.38)
ESAS	52	18 (13.7)	20.1 (13.9)	52	15 (13.4)	18.0 (13.94)	52	12 (11.8)*	16.3 (15.01)

ID, Imputed data; SD, standard deviation; STEEP, standardized exponential exercise protocol; 6MWT, 6-minute walk test; FACT - G, Functional Assessment of Cancer Therapy Scale – General; ESAS, Edmonton Symptom Assessment System

Significant improvements compared to baseline * $p<0.05$, ** $p < 0.01$, and *** $p < 0.001$

† n = 115 for multiple imputed data

Table 3: FACT-G sub-domains scores.

	Baseline	6-Weeks	12 – Weeks
	Mean (SD)	Mean (SD)	Mean (SD)
Physical WB (n = 57)	20.9 (4.83)	22.4 (4.55)**	22.7 (4.61)*
Functional WB (n = 50)	17.8 (5.98)	18.4 (6.79)	19.5 (5.92)**
Emotional WB (n = 50)	18.0 (3.96)	19.0 (3.28)	19.5 (3.55)**
Social WB (n = 56)	23.6 (5.13)	22.9 (4.95)	23.6 (5.76)

WB, well-being

* Significant improvements compared to baseline *$p < 0.05$ and **$p < 0.01$

Table 4: Raw and imputed data comparisons.

	Raw data			Imputed data		
	F value	DF	*p* value*	F value	DF	*p* value*
STEEP	22.5	(2,78)	<0.01	49.4	(2,228)	<0.01
STEEP1 vs. STEEP2	22.3	(1,39)	<0.01	48.7	(1,114)	<0.01
STEEP1 vs. STEEP3	33.8	(1,39)	<0.01	87.5	(1,114)	<0.01
STEEP2 vs. STEEP3	3.9	(1,39)	0.16	7.0	(1,114)	0.03
6MWT	9.8	(2,110)	<0.01	16.4	(2,228)	<0.01
6MWT1 vs. 6MWT2	13.6	(1,55)	<0.01	22.7	(1,114)	<0.01
6MWT1 vs. 6MWT3	10.5	(1,55)	0.01	19.3	(1,114)	<0.01
6MWT2 vs. 6MWT3	0.7	(1,55)	0.99	1.3	(1,114)	0.77
FACT-G	7.0	(2,94)	<0.01	19.9	(2,228)	<0.01
FACT-G vs. FACT-G2	2.4	(1,47)	0.37	21.5	(1,114)	<0.01
FACT-G1 vs. FACT-G3	10.9	(1,47)	0.01	33.5	(1,114)	<0.01
FACT-G2 vs. FACT-G3	6.0	(1,47)	0.05	4.1	(1,114)	0.13
ESAS	3.4	(2,102)	0.04	5.9	(2,228)	<0.01
ESAS1 vs. ESAS2	2.5	(1,51)	0.36	3.0	(1,114)	0.25
ESAS1 vs. ESAS3	5.5	(1,51)	0.006	10.1	(1,114)	0.01
ESAS2 vs. ESAS3	1.2	(1,51)	0.86	3.9	(1,114)	0.15

DF, degree of freedom; STEEP, standardized exponential exercise protocol (STEEP1, Pre-CanWell testing, STEEP2, 6-week testing, STEEP3 12-week testing); 6MWT, 6-minute walk test (6MWT1, Pre-CanWell testing, 6MWT2, 6-week testing, 6MWT3, 12-week testing); FACT - G, Functional Assessment of Cancer Therapy Scale – General (FACT - G1, Pre-CanWell testing, FACT - G2, 6-week testing; FACT - G3, 12-week testing); ESAS, Edmonton Symptom Assessment System (ESAS1, Pre-CanWell testing, ESAS2, 6-week testing, ESAS 3,12-week testing)
* *p* values were adjusted for Bonferroni correction of 3 multiple comparisons

Appendix 1: CanWell Description

To ensure participant safety and effective exercise programs, YMCA staff who work in the CanWell Program are required to attend specifically designed oncology training provided by the physiotherapist and nurse practitioner. The CanWell staff training is 12 hours long and covers several topics including: a review of cancer physiology, pathophysiology, a review of exercise in people with cancer, exercise prescription and testing, and exercise safety guidelines (outlined below). Other topics discussed include promoting exercise adherence as well as ensuring that research ethics guidelines are maintained. CanWell staff are also trained in how to provide emotional support for cancer survivors, as well as, how to maintain their own emotional health. Prior to the staff training, YMCA staff undergo a test evaluating their knowledge regarding cancer, cancer treatments, and their exercise and cancer knowledge. The test is repeated following the training sessions to confirm learning and identify further knowledge gaps that require mediation.

CanWell hospital staff provide on-going support for YMCA staff by formal and in-formal mentoring. This mentoring is achieved via hospital staff attending CanWell exercise sessions weekly (2-hours per week for the physiotherapist and another 2-hours for the nurse practitioner). Both mentors are also easily accessible for the YMCA staff via E-mail communication or a pager system.

Participant education sessions are led by a Physiotherapist, Nurse Practitioner, and other instructors include content on exercise safety, exercise progression, and the importance of maintaining an active life style. Additional education sessions include healthy diet, improving quality of sleep and cancer, lymphedema, and other topics identified by the participants. Education sessions are provided bi-monthly on a rotating basis and provide an opportunity for learning as well as psychosocial, and informal peer support. CanWell participants are encouraged to attend all the education sessions; however, these sessions are accessible to the surrounding community free of charge. The CanWell exercise and safety guidelines were designed by a Physical Therapist (OC) and a Nurse Practitioner (JPD) based on research and clinical experience. Following training, exercise program delivery is supervised by a Kinesiologist with assistance of YMCA trained Fitness Trainers.

Exercise safety considerations for CanWell.

A number of factors are considered when assessing a person with cancer for exercise, including:

- Cancer diagnosis, stage of cancer treatment, side-effects of treatment, and other co-morbidities. Examples of the thinking process are below.
- Participant co-morbidities are considered, given participants are often older, and have pre-existing conditions which may limit certain exercise interventions (e.g. cardiac conditions, osteoporosis, etc.).
- For people with advanced metastatic cancer the location of metastases and muscle forces on the bones where the metastases' are located must be considered.
- If metastases were located in the spinal column, participants are educated about the risk of vertebral fractures and instructed to avoid extreme flexion or rotation

exercises. There are also educated regarding the signs and symptoms of a potential spinal cord compression and how to act if one is suspected (details below).

- Participants with peripheral neuropathy in the legs are instructed to not use a treadmill. Those with peripheral neuropathy of the hands are cautioned about the use of heavy free weights or lifting objects over their heads.
- As this is a community based program, participants may not know their blood counts to follow previously published guidelines regarding exercise safety and low blood counts. Therefore participants are educated to identify signs and symptoms that may relate to a low hemoglobin and/or platelets level.
- All participants start the exercise programs slowly and progress based on their abilities and tolerance of exercise.
- Participants complete an “Exercise Safety Sheet” prior to each supervised exercise session (Appendix 2).

Appendix Table 1: Examples of person-specific exercise modifications

		Considerations	Exercise modifications	Comments
Diagnosis	Multiple myeloma	• Fragile bones with increased fracture risk	Low impact exercise. Avoid use of treadmill if participant is at risk for falls.	
	Breast, prostate and stage 1 cancers	• Low risk for injury (consider treatments and co-morbidities)	Non specific	
	Lung cancer	• Shortness of breath • Common late diagnosis with metastases (see advanced stage below)	Based on stage and shortness of breath, dizziness, and increased heart rate. Stop exercise if symptomatic.	
	Hematological cancers	• Low blood counts focusing on hemoglobin, white blood cell, and platelets.	Adjust exercise based on symptoms. Ensure clean equipment (before and after exercise)	
Cancer stage	• Risk for fracture for people with cancer that has spread to long bones. • Risk for spinal cord injury or compression fractures		Design exercise programs that do not stress affected bones. E.g. person with metastases in the femur may be at increased risk for fracture if running on a treadmill. However, walking on a treadmill that has good shock absorption may be appropriate.	It is important to remember muscles that cross two joints and may stress a bone more, e.g. biceps muscle and avoiding heavy weights lifting.

	Considerations	Exercise modifications
Treatment	• Radiation	Patients who have radiation therapy should not enter a public pool if there is visible skin damage. Radiation therapy may weaken connective tissue, clear guidelines are not available, and however, caution is recommended to avoid significant stress to areas within the field of radiation and for 6 weeks following to allow for tissue healing.
	• Chemotherapy	People who are receiving chemotherapy can, and should, exercise. Need to consider increased fatigue and to appreciate that the goal of exercise may be to maintain (or slow deterioration) muscle strength rather than muscle gain during this phase. People with a PICC line cannot swim in a pool, whereas people with a port-a-cath may swim.
	• Surgery	Following surgery allow sufficient time for wound healing. Generally range of motion should start close after surgery for affected areas (should clarify with physician philosophy).

		Considerations	Exercise modifications	Comments
Treatment side-effects	Fatigue	Consider differential diagnosis: cancer recurrence, blood work testing (e.g. liver problems related to disease or herbal medicines), other medical conditions that can cause fatigue.	Adjust exercise program to levels where the participant can complete their exercise program and their daily activities. Exercise intensities may need to be reduced and increased at a more gradual level	A participant that is unable to maintain exercise levels that they were previously able to complete requires further investigation. Other considerations may be exercising too hard, poorly controlled pain, depression, mood disturbances, and sleep disturbances. A referral to medical doctors may be needed.
	Nausea and vomiting		Defer exercise if nausea and vomiting is severe, person may be dehydrated, have electrolyte imbalance	
Cancer side-effects		• Gait disturbance, or alterations in balance related to hemiparesis	Avoid use of treadmill. Cardiovascular exercise in a seated position.	
Co-morbidities		• Osteoporosis.	Same as for multiple myeloma, or bone metastases. Low impact exercise. Avoid use of treadmill if participant is at risk for falls.	

Appendix 2: CanWell Exercise Program Safety

Pre-Exercise Safety Sheet

CanWell ID: ___________________________ Date: _______________________

Please complete the following safety questions prior to starting your exercise program. To ensure your safety, you are asked to complete this form at ***each visit***.

Did you injure yourself in the last 7 days while exercising? (Circle one)

- ❑ **No injury.**
- ❑ **Yes,** exercising at home.
- ❑ **Yes,** exercising at the YMCA.

❑ Do you have any new pains since the last visit?
❑ Do you feel as if you have a fever?
❑ Do you have any chest pain or tightness right now?
❑ Did you have any chest pain or tightness over the last 24 hours?
❑ Did you start on any new medications since the last visit? If yes which?
____

For your safety…
Please let us know if you have any chest pain, discomfort/pain, tightness, or any unusual symptoms IMMEDIATELY!

Starting Blood Pressure	Starting Heart Rate	Starting O_2 Saturation

Exercises will be stopped (by you or the exercise supervisor)[i] if you have:

- Chest pain
- Fall in systolic blood pressure >20 mm Hg from the highest value during the exercise
- High blood pressure (>250 mm HG systolic; >120 mm Hg diastolic)
- Severe desaturation: oxygen levels ≦80%
- Sudden pallor
- Loss of coordination
- Confusion
- Dizziness or faintness
- Signs of breathing difficulties
- Sudden onset of a sharp pain

[i] Adapted from the American Thoracic Society Statement on Cardiopulmonary Exercise Testing. Am J Respir Crit care Med 2003; 167:211-277.

Chapter 3: Identifying exercise adherence and barriers following participation in a community-based exercise and education program for cancer survivors.

Title: Identifying exercise adherence and barriers following participation in a community-based exercise and education program for cancer survivors.

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Abstract

Background

Cancer survivors participating in supervised exercise programs learn to exercise safely with oversight from care providers who monitor and facilitate their progress. This study investigated the long-term exercise participation levels and identified exercise barriers for graduates from a specialized exercise and education program.

Methods

Graduates from a 12-week supervised exercise program (www.canwellprogram.ca) participated in a, prospective, long-term evaluation. Measures included: six-minute walk test (6-MWT), STEEP treadmill test, Functional Assessment Cancer Therapy – General (FACT-G), Edmonton Symptom Assessment System (ESAS), Godin Leisure-Time Exercise Questionnaire, and exercise barriers survey. Analysis was performed using the paired *t*-test.

Results

Fifty-seven (55% of the living cohort) graduates (mean age=60; 74% females) participated in this study. Post program changes included statistically significant reductions in total minutes on the treadmill (t_{22}=-2.24, $p<0.05$; 95%CI=-1.53 to -0.06) and a trend towards improvements in 6-MWT distance. No significant changes were recorded in total FACT-G or ESAS score, however lower physical well-being (t_{36}=-2.15, $p<0.05$; 95%CI=-4.26 to -0.13) and higher social well-being (t_{36}=2.84, $p<0.01$; 95%CI=1.03 to 6.14) scores were reported. The most commonly reported exercise barriers included fatigue, cost, and return to work. While most participants (86%) believed they were able to exercise, only 60% reported being able to progress their exercise.

Conclusions

Although CanWell graduates have substantial support from exercise specialists and most have early success with exercise, environment-related factors diminish long-term independent adherence to exercise. Providing cancer survivors with the skills needed to monitor and progress their exercise routines, or access to "tune-ups" may increase exercise adherence and maximize benefits.

Keywords: Cancer, Oncology, Exercise, Community, evidence-based.

Background

Cancer and its treatments are associated with decreased physical function and adverse psychological and emotional effects (Binkley et al., 2012; Schmitz, Speck, Rye, DiSipio, & Hayes, 2012). Related symptoms often include fatigue, nausea, pain and decreased strength and endurance (Courneya, Blanchard, & Laing, 2001; Courneya & Friedenreich, 1999; Friendenreich & Courneya, 1996; Lynch, Schertzer, & Ryall, 2007). A growing body of research shows that exercise is safe and beneficial for cancer survivors (Courneya & Friedenreich, 2007). Benefits include improving physical function, mood, and quality of life while reducing fatigue (Courneya & Friedenreich, 1999; Courneya, Karvinen, et al., 2005; Dolan et al., 2010; Jones et al., 2009; McNeely et al., 2006). Exercise is also associated with improved survival, fewer new cancers, and earlier detection of some cancers (Barbaric, Brooks, Moore, & Cheifetz, 2010). In spite of the increasing evidence, survivors in general are not meeting the basic recommendations for physical activity (Courneya et al., 2012a, 2012b). Similarly, only 5% of survivors accumulate 150 minutes of moderate to vigorous exercise a week (Statistics Canada, 2011).

Cancer survivors face specific barriers to meeting exercise targets including; pain and symptoms related to cancer and its treatments, body image issues, lack of information about exercise and exercise safety, lack of supervised exercise programs (Blaney et al., 2010), and lack of priority (Rogers, Courneya, Shah, Dunnington, & Hopkins-Price, 2007). It is estimated that 10% of cancer survivors exercise at their pre-diagnosis level during treatment. An additional 20-30% resume their pre-diagnosis level of exercise following treatment (Courneya, Karvinen, & Vallance, 2007). Courneya et al (2005) (Courneya, Friedenreich, et al., 2005) identified 37 different exercise barriers for patients with colorectal cancer primarily including fatigue, lack of time, and non-specific cancer treatment side-effects. Women with breast cancer who are receiving chemotherapy also reported loss of interest, travel, and nausea/vomiting as exercise barriers (Courneya et al., 2008).

One of the most significant challenges to exercise is incorporating it into regular daily activities. Cancer survivors who participate in exercise and cancer research are attempting to overcome the barriers discussed above. To further reduce exercise barriers, researchers have investigated exercise facilitators that improve exercise adherence. Successful strategies included providing study participants with exercise prescriptions following completion of the research, improving perceived behavior control, and incorporating other behavior change counseling (Courneya et al., 2012b). Furthermore, it was found that survivors who participated in supervised exercise research reported overall better outcomes and more exercise minutes than survivors in control groups, lasting for at least six-months following the intervention (Courneya, Segal, et al., 2007; Courneya et al., 2012a). The long-lasting benefits of exercise are encouraging, however, participation in exercise research programs is often time limited (Courneya et al., 2012a), usually due to limited capacity of exercise facilities and available research funding. Furthermore, providing the tools for cancer survivors to exercise, such as exercise prescription and behavior counseling, is important, but without evidence-informed, community-based exercise programs and facilities, the potential for long-term high exercise adherence is possibly reduced. The CanWell exercise and education program for cancer survivors was developed to address this gap.

A full description of the CanWell program has been reported elsewhere[ii]. Briefly, it is a 12-week, community-based, evidence-informed, exercise and education program for cancer survivors located at a YMCA facility. It is led by a unique partnership between an acute care hospital, university, and a YMCA facility open to people with all types, or stage, of cancer. Program graduates can continue and exercise at the YMCA and have unlimited free access to CanWell-trained exercise and cancer experts. An important rationale for CanWell location and partnership is to ensure that exercise opportunities are available to cancer survivors close to their homes where they can exercise in a safe "normal" environment, the potential to exercise with family or friends, and have a visible link to the cancer center. While theoretically programs such as CanWell address several of the exercise barriers discussed above, it is imperative to evaluate their effects on long-term exercise adherence and identify potentially reversible exercise barriers.

To date, the majority of studies investigating exercise barriers for cancer survivors often included homogeneous populations (e.g. only women with breast cancer), have been university or hospital based, and access to the exercise resources were time limited. Our hypothesis was that the majority of CanWell participants would continue and exercise to maintain, or increase their physical abilities. This hypothesis was based on the fact that CanWell graduates have been educated on the benefits of exercise for people with cancer,

[ii] Cheifetz O, Park Dorsay J, Hladysh G, Woodhouse LJ, Serediuk F, MacDermid J (2013) CanWell: meeting the psychosocial and exercise needs of cancer survivors by translating evidence into practice. Accepted to Psycho-oncology.

have been instructed how to exercise safely based on their unique needs, and have access to an exercise facility where exercise and cancer experts are available for consultation on a long-term basis. Therefore, our research purpose was to identify what are the exercise levels, as well as, physical and health-related quality of life changes exhibited by cancer survivors who participated in a community-based exercise and education program (CanWell)? And, what where the exercise barriers reported by CanWell graduates who did not continue to exercise?

Materials and Methods

Participants,

Participants were recruited from the entire CanWell cohort who exercised between 2009 and June 2012. Inclusion criteria are; adults diagnosed with cancer (any type or stage) and at any phase of cancer treatment. Participants live in the community, ambulate independently, have no acute medical conditions (identified by ParMED-X), and no medical contraindications identified on pre-exercise safety screening. Excluded were those with unstable cardiac conditions. Prior to contacting CanWell graduates, hospital electronic charts were searched to identify those participants who have passed away. Recruited participants were invited for a one-hour face-to-face assessment session at the YMCA or were asked to complete the surveys over the phone if they were unable or unwilling, to attend to gym-based testing. Written informed consent was obtained from participants under the ethics approval of the Hamilton Health Science (HHS)/McMaster University Research Ethics Board.

The intervention

The CanWell program has been briefly described above with further information available at www.canwellprogram.ca. CanWell participants take part in 12-week, supervised, exercise program that includes individualized aerobic and strengthening exercise prescriptions. Aerobic exercise may include cycling, treadmill, or other exercises that lead to an increase in heart rate based on a calculated value (50-80% heart-rate maximum). Aerobic exercises are performed 2-5 times per week and range from 1-30 minutes (based on individualized abilities). Strength exercises target major muscle groups and utilized exercise machines, body weight, or free weights (based on participant interests and unique safety guidelines). Participants are encouraged to lift weights for 12-15 repetitions, 2-3 sets at a resistance that produces muscle fatigue. The education component includes formal classes discussing exercise safety, exercise and cancer research, nutrition, sleep and chemotherapy, and other topics.

Outcome Measures

Physical Performance Measures

Endurance testing was performed using the standardized exponential exercise protocol (STEEP) (Northridge et al., 1990). The STEEP can be performed on either a bicycle or treadmill and is useful for participants of varying capabilities (Northridge et al., 1990). The STEEP been used in healthy (Northridge et al., 1990) individuals, patients with congestive heart failure (Riley et al., 1992) and those with lung cancer to predict surgical outcomes (Win et al., 2005). It has demonstrated reliability coefficients ranging from 0.82-0.86 and high test-retest reliability (ICC=0.996) (De Backer et al., 2007).

The six-minute walk test (6-MWT) was chosen for the evaluation of overall physical function, as it is has been extensively studied and has been recommended for use in both research and the clinical settings (Solway, Brooks, Lacasse, & Thomas, 2001). The 6-MWT has excellent test-retest reliability (ICC 0.82-0.99) (Finch, Brooks, Stratford, & Mayo, 2002), and has been shown to be predictive of success for surgical oncology outcomes (Holden, Rice, Stelmach, & Meeker, 1992; Kadikar, Maurer, & Kesten, 1997; Szekely et al., 1997). The 6-MWT was administered according to a standardized protocol (ATS Committee on Proficiency Standards for Clinical Pulmonary Function Laboratories, 2002).

Self-Reported Quality of Life Measures

Health-related Quality of Life (HR-QoL) was measured using the Functional Assessment of Cancer Therapy Scale – General (FACT-G) (Cella et al., 1993). This scale has been rigorously investigated for use in assessing HR-QoL of people with different types of cancers and found to have a large effect size when used in both cross-sectional and longitudinal designs (Cheung, Goh, Thumboo, Khoo, & Wee, 2005). The FACT-G subdomains also yield scores for physical well-being (WB), functional WB, emotional WB, and social WB (Cella et al., 1993).

The Edmonton Symptom Assessment System (ESAS) was used to evaluate the burden of symptoms commonly associated with cancer including pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). The ESAS has been shown to be highly valid and reliable (ICC=0.65-0.83) (Watanabe, Nekolaichuk, & Beaumont, 2012), and has been extensively used throughout the cancer care continuum (Nekolaichuk, Watanabe, & Beaumont, 2008; Philip, Smith, Craft, & Lickiss, 1998; Richardson & Jones, 2009; Watanabe, Nekolaichuk, Beaumont, & Mawani, 2009). Currently, the ESAS is also used at Ontario Cancer Centers to monitor disease burden in people during or after cancer treatment.[iii]

Godin Leisure-Time Exercise Questionnaire

The Godin Leisure-Time Exercise Questionnaire was used to evaluate self-reported exercise participation in a 7-day period, prior to the evaluation date (Godin, Jobin, & Bouillon, 1986; Godin & Shephard, 1985). This questionnaire assesses the frequency of strenuous, moderate, or mild exercises performed for at least 15 minutes, during a typical week. This tool has been shown to be valid and reliable compared to other self-report measures (Gionet & Godin, 1989; Jacobs, Ainsworth, Hartman, & Leon, 1993) and has been used to evaluate people with cancer (Blanchard, Courneya, Rodgers, & Murnaghan, 2002).

Exercise Barriers Assessment

Questions evaluating exercise barriers were formulated based on concepts grounded in the Theory of Planned Behavior (TPB) (Ajzen, 1988, 1991). Briefly, the TPB proposes that a person's intention to change (Ajzen, 1988, 1991) (or in this case incorporate exercise to manage cancer treatment side-effects) is based on specific factors. It assumes that intention is formed on the basis of attitudes and beliefs in three areas: behavioral (whether the behavior will achieve the expected outcome; e.g. believe that

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[iii] http://www.cancercare.on.ca/cms/one.aspx?portalId=1377&pageId=57699 (accessed February 7, 2013)

exercise will improve strength, function, or HR-QoL), subjective norms (what others expect, e.g. family or health-care team expect people with cancer to exercise), and perceived behavioral control (i.e. whether the behavior is under their control, e.g. cancer survivors believe they can exercise) (Ajzen, 1991). It is suggested that by changing these factors there is a greater chance that a person will intend to do an action (Ajzen, 1988, 1991; Francis et al., 2004).

Statistical Analysis

Descriptive statistics were calculated for baseline demographics, physical characteristics, and all outcome measures utilized. Paired *t*-test was used to compare change in HR-QoL (ESAS, FACT-G totals scores, and subdomains where appropriate) and physical function over time (end of 12-week program vs. follow-up session) (Portney & Watkins, 2000). Binary logistic regression models were used to itentify factors contributing to completion of the 12-week exercise program, renewal of gym membership, and the continuation of exercise (Park, 2009). Results are presented as mean±(SD) with all tests set as 2-sided, and statistical significance set at $p<0.05$. The Statistical Package for the Social Science (SPSS) was used for analysis.[iv]

Results

There were 115 participants in the CanWell cohort eligible to participate in this study (Figure 1). Of the 57 participants consenting to the long-term follow-up evaluation 20% chose to perform a phone interview (Figure 1). Approximately 36% of the total CanWell group were lost to follow-up. There were no significant differences in

[iv] IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.

demographic information between participants lost to follow-up and those who participated.

The majority of follow-up participants were women with breast cancer (74% and 56% respectively, Table 1). Participants were evaluated on average 119 weeks following completion of CanWell (ranging from 44 to 175 weeks).

Results of the 6-MWT and treadmill tests are presented in Table 2. The increased distance ambulated during the 6-MWT (467 meters vs. 482 meters at follow-up) was not statistically significant, however, a significant reduction in time on the treadmill (8.1 minutes vs. 7.7 minutes at follow-up) was observed in the STEEP test (t_{22}=-2.24, p<0.05, 95%CI=-1.53 to -0.06). No significant changes were observed with FACT-G or ESAS total scores (Table 2). However, participants reported significant reductions in physical WB (t_{36}=-2.15, p<0.05, 95%CI=-4.26 to -0.13) from the end of the CanWell program. Conversely, significant improvements were reported in social WB (t_{36}=2.84, p<0.01, 95%CI=1.03 to 6.14) with improvements in functional WB approaching significance (p=0.06). No changes were reported in emotional WB.

The reported Godin Leisure-Time score averaged 29.3 (SD=28.06, ranging from 0 to 155), with 26% of participants *often* engaging in physical activity that works up a sweat. The majority of participants reported that they either sometimes, or never/rarely, participated in physical activities that produce a sweat (39% and 35%, respectively).

In terms of exercise participation and barriers (Table 3), the majority of CanWell graduates renewed their YMCA yearly memberships (67%) and 74% reported that they were able to complete the 12-week exercise program. The three most common barriers reported included cancer-related fatigue (12%), YMCA membership being too expensive (12%), and return to work (11%).

Considering exercise prescription parameters, exercise frequency was 2-3 times per week in 53%, and more than three times a week in 28%, of participants. Exercise types included a balance between aerobic and strength exercises (46%) and a subset of participants reported that they no longer required exercise supervision (47%).

The majority of graduates *expected* to continue and exercise in the next 12 months (83%; 9% not sure; 4% not intending) and 86% *wanted* to exercise (7% not sure; 45% not wanting). Additionally, while 72% intended to increase their exercise intensity, 16% were not sure and 7% did not intend to change exercise intensity.

Participants (86%) believed they could exercise (5% neutral; 5% not able to exercise) and 91% believed exercise would help them (5% did not think exercise could help). Most participants felt they could stay motivated (84%; 7% neutral; 3% not able) and that they are safe to exercise independently (79%; 5% neutral; 11% did not think they can exercise independently). However, only 60% thought they could progress their exercise program independently (16% neutral; 18% not able to progress exercise).

The logistic regression models that attempted to predict which participants reported they would or could continue exercise, and be able to exercise at levels similar to healthy controls (Godin Leisure Activity Score) found that none of the following factors were predictive: FACT-G (and subdomains), ESAS, 6-MWT, STEEP total minutes, BMI, age, and diagnosis.

Discussion

During the long-term follow-up of cancer survivors completing a supervised, community-based, exercise program 40% of the initial 115 CanWell participants continued to exercise. This participation rate is lower than that reported by Courneya et al (2012) in a six-month follow-up of cancer survivors with lymphoma (Courneya et al., 2012b) and may be explained by the inclusion of a mixed diagnosis group and older participants in the current study. The lower participation rate may also be related to the 36% of participants lost follow-up. Reasons for this loss may include changes in contact information not reported to the hospital, moving away from the HHS catchment area, and possible death not captured in the hospital electronic system.

Of note is that the majority of CanWell graduates reported that they continued to exercise following completion of the program and that almost half continued their exercise programs at the same facility as the initial exercise program, suggesting that structured programs and familiarity with the exercise facility are factors that facilitate exercise adherence. This is important as often cancer and exercise-related research is university or hospital based limiting on-going exercise participation in the same location as the initial study.

Participants in this study exhibited a reduction in endurance (STEEP) compared to their ability at the end of CanWell. These results are different than those reported by Courneya et al (2009) (Courneya et al., 2009) where study participant did not change in aerobic ability at six-month follow-up. Our results may be different due to including a mixed participant group, older participants, and a longer follow-up period. It is also possible that age-related decline, comorbid health conditions associated with age, or cancer-related issues have a greater impact on older patients observed over a longer follow-up period. The reduction in endurance may also be related in an overall increase in the disease burden (ESAS scores increasing, but not statistically significant).

However, it is also important to consider the possibility that participants in the current study did not change their exercise intensity between CanWell completion and follow-up. While exercise intensity was not directly evaluated, almost 20% did not think they could progress their exercise program without assistance. Furthermore, exercise participation captured by the Godin Questionnaire demonstrates that CanWell participants are not exercising at levels similar to healthy individuals (Godin & Shephard, 1985) but at reduced levels consistent with patients who have active myeloproliferative disorder (Mesa et al., 2007) or Parkinson's disease (Garber & Friedman, 2003). Conversely, CanWell graduates reported exercising at appropriate frequencies (2-3 times a week or more) and used both aerobic and strength exercise programs, meeting required exercise frequencies and modes to produce physical improvement. The reduced ability and lack of confidence about exercise progression, in the face of maintained commitment to exercise frequency, suggest that re-checks with a physical therapist to modify exercise prescription might be useful.

Participants in the current study did not report significant changes in overall HR-QoL or in their disease burden. However, considering the sub-domains for HR-QoL, significant reductions were reported in physical WB, consistent with reductions in participants' endurance observed on the treadmill test, while reporting significant improvements in social WB and borderline significant improvements in function. These results may be explained by either participants improving with their function and return to work (or other life activities) and do not have time to exercise regularly, or, participants having progression of their disease (increases in ESAS score approaching significance) affecting their endurance. The improved social WB score may relate to establishing support networks to helping cancer survivors manage their new realities. Regardless of the reason, it is important for care providers to understand that many cancer survivors may not improve with exercise due to disease progression or other exercise barriers, but that does not necessarily translate to negative effects on HR-QoL.

The top three exercise barriers reported by CanWell participants included fatigue, YMCA membership fees, and return to work. Fatigue is a common barrier to exercise reported by many cancer survivors regardless of the underlying disease (Coleman et al., 2011; Courneya et al., 2009; Haas, 2011; Weis, 2011). "Lack of time" for exercise was also a barrier consistently reported by many people relating to work and family demands (Courneya, Friedenreich, et al., 2005; Courneya et al., 2008; Rogers et al., 2007). However, one of the reasons the YMCA was chosen as the location for CanWell is its expanded hours allowing participants to find convenient hours to exercise. The results of this study may reflect that "lack of time" relates more to exercise being a lower priority. This emphasizes the need to educate cancer survivors on the benefits of exercise and help them identify strategies to prioritize exercise over other activities. The financial barrier was surprising, as a not-for-profit organization the YMCA offers generous financial assistance for those in need. A possible explanation for the financial barrier may be lack of knowledge of available resources, or perhaps, participants not wishing to discuss their financial challenges. This suggests a need for more “push-out” of information on the access to reduced fees, special arrangements for how these programs are financed or alterations in how people access fee reductions.

An important finding of this study is that over 40% of the participants did not feel they can progress their exercise programs independently. While CanWell graduates felt safe exercising, did not think they required special supervision, and maintained regular exercise program regimens, it was hypothesized that sufficient education is provided to participants regarding adjusting their exercise routine. In order for individuals to maintain, and increase, their fitness levels it is important to progress exercise programs as the body improves with its abilities. This study demonstrated that cancer survivors can gain the knowledge and confidence to exercise independently. However, it has also emphasized the importance of regular follow-up, or booster, sessions to ensure that exercise prescription guidelines are followed and that cancer survivors know to adjust their exercise programs based on their physical and medical abilities.

This study has several limitations that need to be considered when interpreting the results. The number of cancer survivors lost to follow-up from the start of CanWell to follow-up may have affected the results of the fitness testing. However, considering the number of participants who completed the supervised exercise program (65), after adjusting for death, the long-term follow-up rate is 87%, which is parallel to other published retention rates (Courneya, Friedenreich, et al., 2005). Potential contributions to reduction in CanWell participation during the program has been discussed in detail elsewhere, however, briefly included disease progress, injuries not related to exercise (e.g. falls), vacations, and return to work (Figure 1). These same factors may have contributed to post-program non-adherence and may explain the decline in some health indicators with longer follow-up. The small subgroups in cancer diagnostic groups other than breast cancer limited our ability to delve deeper assessing the contribution of cancer diagnosis on exercise behaviours or outcomes. The lack of a full medical examination at final follow-up limited our ability to determine the extent to which cancer reoccurrence/progression or other comorbid health problems may have affected behaviour or performance. Finally, since this work was quantitative, we were unable to fully explain the benefits, barriers or facilitators that contributed to the effects we observed. Future research should include sufficient numbers of patients with different types of cancer to analyze diagnostic subgroup effects, add a qualitative component to determine factors that affect intention and behaviour, and evaluate different variants in the approach that affect follow-up (i.e. tune-up visits) or access (variants in program fee structure or implementation).

In summary, we examined the physical fitness and exercise barriers of a mixed group of cancer survivors who previously exercised in the CanWell program. Overall, participants exhibited slight reductions in endurance, but were able to maintain physical function and HR-QoL. Furthermore, participants believed that they had the skills and knowledge to exercise safely independently in the community. However, opportunities to improve confidence, skills, and accessibility for exercise participation and progression were found. These findings can inform the development of exercise and education programs for cancer survivors.

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Conflict of Interest

None declared. The authors have full control of all primary data and agree to allow the journal to review data if requested.

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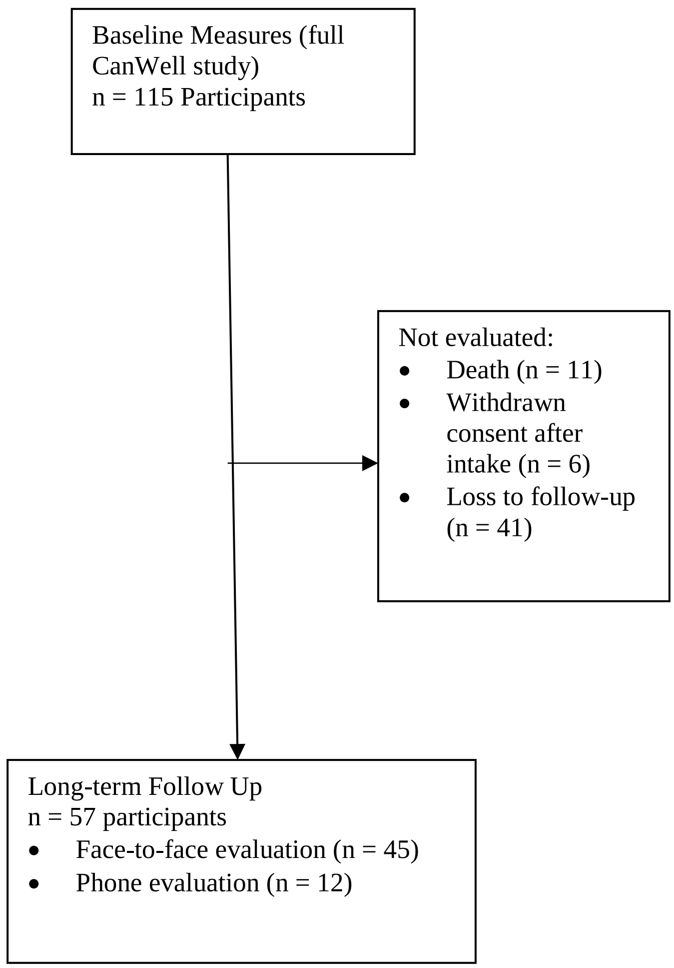

Figure 1 Program Participants Flow

Table 1 Participant characteristics at baseline

Characteristics	**CanWell Program** (n = 115)		**CanWell Follow Up** (n = 57)	
	Mean (SD)	**Min-Max**	**Mean (SD)**	**Min-Max**
Age (years)	54.9 (9.97)	32-78	59.6 (8.54)	43-80
Time from cancer diagnosis (months)	23.2 (25.64)	0-141	58.5 (32.37)	17-170
Mass (kg)	78.3 (16.94)	49-119	81.2 (17.6)	54.5-118
Height (cm)	168.8 (8.90)	152-193	168.8 (9.8)	142-188
BMI (kg/m^2)	27.43 (5.21)	18-42	28.5 (5.58)	19.7-43.3[††]
	Frequency	**% of Total**	**Frequency**	**% of Total**
Gender (female)	84	73	42	73.7
Cancer Diagnosis				
Breast	60	52.2	32	56.1
Lymphoma	9	7.8	5	8.8
Multiple Myeloma	8	7.0	4	7.0
Leukemia	5	4.3	1	1.8
Brain	5	4.3	1	1.8
Prostate	5	4.3	3	5.3
Pancreatic	4	3.5	1	1.8
Colon	4	3.5	3	5.3
Lung	3	2.6	1	1.8
Ovarian	2	1.7	1	1.8
Other*	10	8.7	5	8.8
Metastatic cancer**	7	6.1		
Cancer stage[†]				
1	12	10.4		
2	24	20.9		
3	19	16.5		
4	10	8.7		
unknown	50	43.5		

SD, standard deviation; BMI, body mass index
* Other cancers included anal, astrocytoma, bladder, cervical, kidney, melanoma, peritoneal, stomach, thymoma, uterine, and vulvar
** does not include systemic diseases such as lymphoma, leukemia, or multiple myeloma
[†] Includes participants who did not know their disease stage, see study limitation section
[††] Increase in BMI approaches statistical significance $p = 0.07$

Table 2: Physical Function and HR-QoL outcome measure results.

	End of CanWell		CanWell Follow Up	
	n	Mean (SD)	n	Mean (SD)
STEEP (minutes)	**23**	**8.1 (2.4)**	**33**	**7.7 (2.3)***
6-MWT (meters)	56	467 (93.7)	41	482 (97.3)
FACT - G	48	86 (15.3)	52	90 (16.2)
Physical WB	**57**	**22.7 (4.61)**	**52**	**21.8 (6.17) ***
Functional WB	**50**	**19.5 (5.92)**	**52**	**22.0 (5.19) *****
Emotional WB	50	19.5 (3.55)	52	19.1 (4.59)
Social WB	**56**	**23.6 (5.76)**	**52**	**27.6 (6.59) ***
ESAS	52	12 (11.8)	42	16 (14.5)

STEEP, standardized exponential exercise protocol; 6MWT, 6-minute walk test; FACT - G, Functional Assessment of Cancer Therapy Scale – General; WB, well-being; ESAS, Edmonton Symptom Assessment System

Significant changes from end of program to long term follow-up are bolded: $^{*}p<0.05$, $^{**}p = 0.062$

Table 3 Exercise Participation and Barriers reported by CanWell graduates at long term follow-up

Participation	Frequency	Percent
Renewed yearly YMCA membership	38	66.7
Completed full CanWell program	42	73.7
Continue to exercise following CanWell	47	82.5
General Barriers to Exercise		
Injury during CanWell	3	5.3
Returned to work	6	10.5
Family commitments	2	3.5
Exercise takes too long	2	3.5
Further cancer treatment	3	5.3
YMCA too far from home	3	5.3
Feel not safe at the YMCA (to exercise)	1	1.8
Worry about exercise related injury	1	1.8
Did not enjoy exercise	1	1.8
Difficult to motivate myself	4	7.0
YMCA membership too expensive	7	12.3
Cancer Specific Barriers to Exercise		
Fatigue affected ability to exercise	7	12.3
Pain affected ability to exercise	5	8.8
Cancer recurrence affected ability to exercise	2	3.5
Ongoing cancer treatment affected ability to exercise	4	7.0
Location of exercise following CanWell		
At home	12	21.1
Same YMCA as CanWell	25	43.9
Other community gym	4	7.0
Other YMCA facility	1	1.8
Other	8	14.0
Do not exercise	5	8.8
No answer	2	3.5
Frequency of Exercise		
Once a week	1	1.8
2-3 times a week	29	52.5
Twice a week	10	17.5
More than three times a week	16	28.1
Do not exercise	8	14.0
No answer	2	3.5
Mode of Exercise		
Equal aerobic and strength exercise	26	45.6

Mostly aerobic exercise	11	19.3
Mostly strength exercise	2	3.5
Mostly pool exercise	2	3.5
Other	7	12.3
Not applicable	6	10.5
No answer	3	5.3
Exercise supervision needs		
Comfortable to exercise with no supervision	27	47.4
Occasional supervision of fitness trainer specifically trained to work with cancer survivors	6	10.5
Occasional supervision of fitness trainer with *no* cancer related training	11	19.3
Regular supervision of fitness trainer specifically trained to work with cancer survivors	5	8.8
Regular supervision of fitness trainer with *no* cancer related training	2	3.5
No answer	6	10.5

Chapter 4: Rasch Analysis of The Edmonton Symptom Assessment System (ESAS) and Research implications

Title: Rasch Analysis of The Edmonton Symptom Assessment System (ESAS) and Research implications

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Abstract

Background

Reliable and valid assessment of the disease burden across all forms of cancer is critical to the evaluation of treatment effectiveness and patient progress. The Edmonton Symptom Assessment System (ESAS) is used for routine evaluation of persons attending for cancer care. This study employed Rasch analysis to explore the measurement properties of the ESAS and determined the impact of utilizing Rasch-proposed interval-level ESAS scoring versus traditional scoring when evaluating the effects of an exercise program for cancer survivors.

Methods

Data from 26,645 ESAS questionnaires completed at the Juravinski Cancer Center were analyzed using Rasch analyses based on the - Andrich Rating Scale model for polytomous data. ESAS fit to the Rasch model was investigated including evaluating differential item functioning (DIF) of gender, age, and disease group. The research implication was investigated by comparing the results from an observational research study previous analysed using a traditional approach with that of the Rasch-proposed interval-level ESAS scoring.

Results

The Rasch reliability index was 0.73, falling short of the desired 0.80-0.90 level. However, the ESAS was found to fit the Rasch model including the criteria for unidimensional data. The analysis suggested that the current ESAS scoring system of 0-

10 may be collapsed to a six point scale. Employing the Rasch proposed interval-level scoring yielded different results than those calculated by using summarized ordinal-level ESAS scores. DIF was not found between gender, age, or diagnosis groups.

Conclusions

The ESAS is a moderately reliable, unidimensional measure of cancer disease burden and can provide interval-level scaling with Rasch based scoring. Further, this study indicates such scoring may result in substantive changes in conclusions in comparison to the traditional scoring metric.

Keywords: Edmonton Symptom Assessment System, ESAS, Rasch analysis, Cancer

Background

Cancer and its treatments (including surgery, chemotherapy, radiation, and hormone therapy) are associated with decreased physical function and adverse psychological and emotional effects. Physical symptoms commonly include fatigue, nausea, pain, and decreased strength and endurance (Courneya, Blanchard, & Laing, 2001; Courneya & Friedenreich, 1999; Friendenreich & Courneya, 1996; Lynch, Schertzer, & Ryall, 2007). The importance of appreciating the consequences of cancer-related side effects is magnified as the number of people living with cancer continues to increase (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). Evaluating the impact of cancer-related (or treatment-related) side-effects on patients has evolved beyond physiologic evaluations (for example, changes in hemoglobin levels) to a more holistic view considering the constellation of symptoms exhibited by patients (e.g. pain, nausea, and anxiety) (Chen et al., 2012).

The Edmonton Symptom Assessment System (ESAS) was developed to assess a variety of symptoms often reported by patients in the palliative care setting, regardless of their specific diagnosis (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). It is comprised of 10 questions evaluating symptoms commonly associated with cancer including pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath, and an “other” condition identified as important by the patient (Bruera et al., 1991). Each item is scored on a rating scale ranging from zero to 10 (maximum score of 100 if including all the ESAS items), with higher scores indicating higher disease burden. The ESAS does not claim to measure health status or quality of life, but rather focuses on bothersome symptoms that burden cancer survivors and are likely to interfere with quality of life (Bruera et al., 1991). Clinicians are able to address patient-specific symptoms identified on the ESAS and record change-over-time by graphing symptom scores. Conversely, researchers have used the ESAS total scores (symptom distress score) to evaluate the effects of interventions, such as exercise (Cheifetz et al., 2013), or a combination of symptom management strategies on overall disease burden (Modonesi et al., 2005).

The ESAS has been studied extensively throughout the cancer care continuum, in a variety of cancer diagnostic groups, and its validity and reliability have been studied in different settings and with different patient populations (Nekolaichuk, Watanabe, & Beaumont, 2008; Philip, Smith, Craft, & Lickiss, 1998; Richardson & Jones, 2009; Watanabe, Nekolaichuk, Beaumont, & Mawani, 2009). The ESAS has also been incorporated as a "Standard of Care Assessment" by Ontario Cancer Centers which suggests that it should be used routinely in practice and research.[v] Chang et al. (Chang, Hwang, & Feuerman, 2000) conducted a validation study relating the ESAS to the Memorial Symptom Assessment Scale (MSAS) and the Functional Assessment Cancer Therapy (FACT) surveys. In their sample of 233 cancer survivors, they reported the ESAS had an overall Cronbach's alpha of 0.79 with one-day, test-retest reliability (Spearman correlation) ranging from 0.39-0.86, depending on the symptom measured (Chang et al., 2000). However, in a 15-year retrospective review of ESAS validation studies, Nekolaichuk et al. (Nekolaichuk et al., 2008) found 13 publications specifically

[v] http://www.cancercare.on.ca/cms/one.aspx?portalId=1377&pageId=57699 (accessed February 7, 2013)

evaluating various versions of the ESAS and concluded that while this tool has been extensively adopted in clinical use, psychometric validation is limited in scope and that further studies are required to address this gap.

To date, the majority of the literature validating the ESAS, or using the scale as an outcome measure, utilize statistical methods such as regression, correlations, and traditional descriptive statistics such as means, standard deviations, and frequencies (Bruera et al., 1991; Chang et al., 2000; Chen et al., 2012; Davison, Jhangri, & Johnson, 2006b). These statistical methods are grounded in Classical Test Theory (CTT) (Streiner D.L. & Norman G.R., 2008) and are based on associated theoretical assumptions such as: a) the estimates of reliability and validity only apply to the population tested, and b) a greater number of questions, or items, reduces the amount of variability directly attributable to random error. In contrast, Rasch analysis is a statistical method in the tradition of Item Response Theory (IRT); assumptions therefore include a) the easier the item on a scale, the more likely it is that respondents will obtain a positive score on that item, b) respondents with more ability are more likely to obtain a higher score on any given item, and c) the measurements are not dependent on the study population if the model can be applied (i.e. items on the scale are locally-independent: that is, one data point has no influence on the value of another)(Streiner, 2010). Further, Rasch analysis is based on mathematical modeling that supports the utilization of ordinal scaling (such as the scaling employed by the ESAS) for interval-level calculations such as overall score summation if the scale is found to fit the Rasch model (Streiner, 2010). Pallant and Tennant (2007) published an introduction to the Rasch model including a review of some of the mathematical formulation of the Rasch model (Pallant & Tennant, 2007). Tennant and Conaghan (2007) also summarized the Rasch measurement model and discuss why and when Rasch should be used (Tennant & Conaghan, 2007). A basic introduction to Rasch Analysis is provided by Bond and Fox (2007) (Bond & Fox, 2007) and a description of the use of Rasch to produce scale free measurement of functional ability has been published by Velozo et. al. (1999) (Velozo, Kielhofner, & Lai, 1999). Rasch analysis has also been used in the development and evaluation of physical abilities questionnaires (Batcho, Tennant, & Thonnard, 2012; Davis et al., 2008).

To date, we are unaware of any published examinations of the measurement properties of the ESAS based on Rasch analysis. This is a critical gap since most studies which have been published using the ESAS have used parametric statistics whose assumptions would be violated if the scale is ordinal. The purposes of the current study are 1) to estimate the measurement properties of the ESAS utilizing Rasch analysis and 2) to determine whether a Rasch-driven scoring metric provides different results than the current scoring metric when evaluating effects of an exercise program for people with cancer.

Methods

Participants

Edmonton Symptom Assessment System scores were collected electronically from patients attending (standard program of care) appointments at the Juravinski Cancer Center, Hamilton, Ontario, Canada. Electronic kiosks are located at the entrance to the cancer center, where all patients sign in and score the ESAS based on their symptoms at time of completion. The ESAS scores are then forwarded to the patients' medical team for review at their appointment; needs identified by the results guide the care provided. Following permission from the joint Ethics Board of Hamilton Health Sciences/McMaster University all completed ESAS questionnaires filled between November 1, 2010 and October 31, 2012 were retrospectively retrieved and included in the current study. Patients completing the ESAS may be visiting the cancer center at any stage of their cancer journey, including initial assessment pre (or post) cancer diagnosis, chemotherapy or radiation therapy treatments, and short- or long-term medical follow-up visits. All completed ESAS forms were included in the analysis. Each patient in the sample included has only one ESAS as part of the current analysis.

Rasch Analysis

Rasch analysis was designed *a priori* and included the following components: the Andrich Rating Scale model was used as ESAS scoring is polytomous. Fit of items and persons to the Rasch model were evaluated using InFit and OutFit values of 0.7 and 1.4 (Linacre, 2013). The assumptions of local independence and unidimensionality, evaluation of differential item functioning (DIF), and the person separation reliability were analyzed following the guidelines provided by Linacre (2013) (Linacre, 2013). To evaluate the current measurement properties of the ESAS, item deletion or rescoring was not performed. Response reordering was not performed in the current study (Linacre, 2010),however, item misfit was evaluated (Linacre, 2013).

Following the Rasch analysis, ESAS scores reported by cancer survivors participating in a community-based exercise program (CanWell program) (Cheifetz et al.,

2013) were converted to the standardized scores proposed by the Rasch analysis results, and reanalyzed.

Statistical Analysis

All the ESAS scores were exported from the electronic charts to an Excel database and subsequently imported into The Statistical Package for the Social Science (SPSS)[vi] for analysis of demographic information including date of birth, diagnosis type, visit date, and gender. Rasch analysis was completed using Winsteps® Rasch Measurement software, version 3.80.1.[vii] To explore if the conclusion regarding the effects of exercise on cancer disease burden in CanWell participants a repeated-measures analysis of traditional (ordinal-level scoring), and Rasch proposed (interval-level scoring), ESAS scores was performed using SPSS. Statistical analyses were two-sided, with significance set at $p<0.05$.

Results

A total of 26,645 completed ESAS forms were collected during the time period outlined above. Patient that were identified as "non-cancer" (n=13,178) are those people who are waiting pathological confirmation of their cancer diagnosis. Further, 1.7% of the patients did not report their cancer diagnosis when completing the ESAS (n=443). The majority of patients who completed the ESAS were women with breast cancer (12.1%) followed by those diagnosed with genitourinary cancers, including prostate cancer (10.2%). Further demographic information is presented in Table 1. Regardless of the

[vi] IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.
[vii] Linacre, J. M. (2013). Winsteps® Rasch measurement computer program. Beaverton, Oregon: Winsteps.com

symptom measured, the most common ESAS response in the current sample is zero (Table 2).

Rasch summary statistics are presented in Table 3. Extreme scores defined by the Rasch software were omitted by the software as they do not provide additional information about the relative difficulty of the ESAS categories and reduce reliability scores (Linacre, 2013). The mean score on the scale as a whole is (18.7/90), which indicates that the average response on each ESAS item is roughly 2/10, demonstrating that patients with cancer in this sample generally score at the low end of the response range (0-10, with 10 representing worse symptoms) on each item. A general pattern of responses at the lower end of the continuum is further supported by the negative client mean for the measure in its entirety (-0.81). Considering the separation statistic (ranging from 1.53 to 1.66) and the patient reliability (0.73) together may indicate that the ESAS is not sufficiently sensitive to distinguish between patients who score high or low. Ideally, person separation values would be >2 and reliability would be at least 0.80 and, better yet, would be 0.90 or greater (Linacre, 2013). This is in contrast to the CTT-base calculation of Cronbach's alpha on patients' raw scores, which yielded a reliability coefficient of 0.88. When including the extreme scores, separation and reliability values were further reduced.

Considering item fit criteria, or the ability of each individual item to measure a unique level of cancer symptoms, it is expected that outfit mean square (MS) range between 0.7 and 1.4 (Smith & Hudgens, 2004) with values ranging from 0.5 to 1.7 considered appropriate for clinical observations and values ranging from 0.5 to 1.5 being productive for Rasch measurement (Wright & Linacre, 1994). For the current study, all items but "well-being," (item eight MS=0.65) have acceptable item fit within the Rasch model, indicating that we are able to predict with certain accuracy how any given client will respond to a given item. Further evidence that the items are consistently discriminative are the calculated point-measures correlations ranging from 0.4 to 0.74 (Linacre, 2008).

An important condition for a measure to fit the Rasch model is that the tool in question is unidimensional (Linacre, 2013), or measures one theoretical construct. Unidimensionality is substantiated within the Rasch model if the unexplained variance in the first contrast is less than four-times the total unexplained variance (Linacre, 2013). In the current analysis, the unexplained variance in the first contrast was 8.6%, while the total unexplained variance observed was 45.5%. Additionally, the Eigenvalue of the first construct was calculated to be 1.6 (should be <3 to support unidimensionality (Linacre, 2013)). These results support the contention that the ESAS does measure one overall construct, disease burden.

Item Maps are used to indicate the degree of difficulty of each individual item relative to both the scale and the construct of interest. The ESAS Item Map is presented in Figure 1. The Rasch measure is shown on the far left of the figure, ranging from -3 to 2 (negative values indicate either patients of lesser "ability" or items that are "easier" for the patient to endorse at high levels, and the reverse for positive values). Patients are shown immediately to the left of the vertical line, while the ESAS items are on the right of the vertical line. The letter "M" in the figure indicates the mean for patients and items, "S" is one standard deviation from the mean and "T" indicates two standard deviations from the mean. The figure demonstrates that the patients in our sample are less "able" than the items are "difficult" (person mean is roughly -1, while the item mean is centered on zero). The importance of this will be discussed later in this paper.

Another key component of Rasch analysis involves the evaluation of the actual measurement or scoring used. While the ESAS scores each item from 0-10, offering the respondent 11 score options from which to select. Figure 2 demonstrates that patients are not utilizing or discriminating well among response options 2-7 (indicated by clustering of the patients' responses).

Differential item functioning (DIF) was evaluated looking at patients age groups, gender, and diagnostic groups (as outlined in Table 1). DIF is considered to be a factor when a DIF size of ≥0.43 logits is calculated (Linacre, 2013). In the current study gender DIF ranged from -0.16 to 0.11. All DIF logits calculated for the diagnosis groups and age groups were also <0.43 (data not presented).

To evaluate the research implications of developing Rasch-proposed ESAS scoring (Appendix 1) the results of ESAS scores reported by CanWell participants (Cheifetz et al., 2013) were converted to the interval-level scores and a repeated-measures analysis was performed. Contrary to the initial results where participants reported statistically significant reductions in overall disease burden ($F_{(2, 102)} = 3.37$, $p < 0.05$, power = 0.6), reanalysis failed to show significant statistical changes ($F_{(2, 102)} = 1.6$, $p = 0.21$).

Discussion

This study established that the Edmonton Symptom Assessment System (ESAS) fits with the requirements of the Rasch model in that it measures a single construct (disease burden) and that ESAS scores can be converted to interval-level scoring metric. This study adds to the previous studies that have demonstrated that the ESAS has moderate measurement reliability and provides important new information about the structure and scoring of the ESAS.

Several studies have investigated the reliability and validity of the ESAS using a variety of statistical methods (Davison et al., 2006b; Nekolaichuk et al., 2008). In two studies (Davison, Jhangri, & Johnson, 2006a; Davison et al., 2006b) including patients with kidney disease and those on hemodialysis, the reliability of the ESAS was reported to be moderate-high (ICC=0.70, p<0.01). However, in 15-year narrative review of ESAS validation studies, Nekolaichuk et al. (2008) concluded that there is lack of psychometric evidence for this instrument, possibly related to the various ESAS formats studied in the validity studies (Nekolaichuk et al., 2008), and that more validations studies are needed. Richardson and Jones (2009) (Richardson & Jones, 2009) conducted a narrative review of the reliability and validity of the ESAS. The authors found 33 studies that evaluated reliability and/or validity of the ESAS in patients with cancer and concluded that it is a reliable tool (correlation coefficients ranging from 0.56 to 0.74) with restricted validity (Richardson & Jones, 2009). Neither review located a study evaluating the ESAS using Rasch analysis.

In the current study the results of the Rasch analysis supported the use of the ESAS as a global measure for disease burden. Although the ESAS has items that may be considered as primarily evaluating physical health (pain, fatigue, nausea, drowsy, appetite, and shortness-of-breath) and emotional health (depression, anxiety, well-being), our analysis demonstrated that in patients with cancer, the ESAS total score can assess one factor, overall symptom disease burden. That is, the ESAS may be considered unidimensional. Although the symptoms measure by the ESAS are diverse, they are common complaints attributed to both the disease and treatment process and are often used independently to direct patient care (e.g. high scores on the pain item may trigger a referral to the pain management team). A possible question arises: should the ESAS be used by evaluating each item independently or using the total score? The answer depends on the setting where the ESAS is used. In the clinical setting using independent ESAS items and graphing their individual change over time will provide the clinician more important information than the total score. Conversely, when evaluating the overall effects of an intervention, for example exercise, a total ESAS score may be more relevant. While our study has demonstrated that the ESAS is unidimensional, it is important to consider the constructs being evaluated and the purpose of the measurement tool (Bond & Fox, 2007; Linacre, 2013).

We calculated Cronbach's alpha of the patients' raw scores to be 0.88, which is similar to results reported in other studies (Chang et al., 2000; Richardson & Jones, 2009). However, the observed patient reliability of 0.73 calculated using Rasch analysis in this study indicates some error in how Rasch assign person ability (Linacre, 2013). A possible reason for variations in ESAS reliability is that there are only nine items on the overall scale, and that studies samples differ, creating some instability in the findings.

While increasing the number of items could increase reliability, it would also potentially increase response burden. This change would be in conflict with the intended purpose of the ESAS to provide an easy tool for patients to complete (Bruera et al., 1991). Richardson and Jones (2009) suggested adding 2-3 more items evaluating other symptoms to the ESAS to potentially increase the tool's reliability and provide additional important information for the health-care team (Richardson & Jones, 2009). Such items could be generated from participative research to strengthen the content validity. However, such additions should include well written questions that do not detract from the ESAS overall fit with the Rasch model ensuring the tool continues to be unidimensional in evaluating disease burden. The addition of new questions at the higher levels of the ESAS may increase the spread of the patients who respond to the ESAS, further improving its reliability.

In the review by Richardson and Jones, it was discussed that some patients interpreted the ESAS 11-point scale as having less categories (Richardson & Jones, 2009). Patients in the current study had similar difficulties. As demonstrated in Figure 2, the response options 2-7 are clustered together for most items, indicating that they are being responded to similarly. This suggests that the 10-response points on the scale are too many, and that patients are not easily able to discriminate between these options. Future iterations of Rasch analysis on the ESAS may want to consider collapsing these response items and assess if there is a change in fit to the model and tool reliability.

Rasch analysis allows for the examination of bias from individual factors such as age, gender, and as well as exploration of the effects of a specific cancer diagnosis (e.g.

breast vs. prostate) on ESAS scores. While it is reasonable to assume that people with different cancers may interpret the ESAS differently, our study did not identify DIF between diagnosis groups, gender, or age group. As the data for the current study was collected in an ambulatory cancer center setting, it is unknown if patients in a palliative setting would have a different distribution of ESAS scores. Future research may include data from the palliative setting in combination with our data and examine if DIF is present between the two clinical settings. This analysis would contribute important information to understanding how ESAS scores may be interpreted by different patient groups (Wright & Stonne, 1979). This analysis would also support generalizability of results, as a major advantage of the Rasch tradition is that the items and person measures are not sample dependent if the data can be shown to fit the Rasch model after adjusting for differential item functioning (Smith & Hudgens, 2004).

The research implications of the current study are highlighted by using data from the CanWell study. Rasch-proposed interval-level ESAS scores (Appendix 1) were used to review the results found in the CanWell study where the effects of a community-based, supervised, exercise program for people with cancer were evaluated (Cheifetz et al., 2013). In that study, the authors reported statistically significant reductions in overall ESAS scores following completion of the 12-week exercise program (Cheifetz et al., 2013). However, using Rasch-produced interval-level scoring for the ESAS, a revised analysis found no statistically significant changes in ESAS scores. While the overall conclusion of that study did not change, that exercise does not have a negative effect on people with cancer, the conclusion that exercise reduced overall disease burden in that patient sample may need to be modified. Other researchers are encouraged to use the Rasch-proposed, interval-level, ESAS scores when evaluating intervention effects on overall cancer-disease burden.

Limitations

It is important to acknowledge that while this study demonstrated that the ESAS as a whole fits the Rasch model, some issues remain, such as the lower patient reliability. Newer versions of the ESAS have added short explanations under items such as wellbeing (Wellbeing = how you feel overall), to help improve reliability and validity. Data collected in this study pre-dates these changes. It is important that research and clinical settings use the newest versions of the ESAS to allow for ongoing evaluation and improvements. Future research should include Rasch analysis of data collected with the revised version of the ESAS currently employed in routine care.

When collating the data for the current study patients' cancer stage was not available, limiting the ability of readers to compare their patients to those in this study. It is possible that patients in a palliative setting may respond differently than the patients in the current study. However, considering that one of the major advantages of Rasch analysis is that items and person measures are sample independent within the same population, both ambulatory and palliative patients would be able to be positioned on an "ESAS ruler" and identified using DIF analysis.

Conclusions

This study has demonstrated that the Edmonton Symptom Assessment System (ESAS) does fit with the Rasch model and can be converted to an interval-level scale.

This study has also supported the notion that the ESAS can be summed up to produce an overall disease burden score. However, future research is needed to evaluate if cancer survivors in different clinical settings interpret ESAS scores differently. Additionally, when interpreting ESAS scores in research, it is important to consider converting patient-reported ordinal results to interval-level scores prior to conducting parametric statistical testing.

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Conflict of Interest

None declared. The authors have full control of all primary data and agree to allow the journal to review data if requested.

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Table 1: Participant Demographics

	Mean(SD)
ESAS score	16(15.64) ranging from 0-88
Gender (female)*	14,054(52.7)
Age	64.6(14.4) ranging from 17-111
Age Group (years) *	
<24	296(1.1)
25-34	727(2.7)
35-44	1,523(5.7)
45-54	3,800(14.3)
55-64	6,195(23.3)
65-74	7,171(26.9)
75-84	5,533(20.8)
>85	1,400(5.3)
Cancer Type*	
Breast	3,232(12.1)
Genitourinary	2,712(10.2)
Haematological	1,828(6.9)
Gastrointestinal	1,323(5)
Gynecological	1,119(4.2)
Skin	833(3.1)
Lung	614(2.3)
Head and Neck	427(1.6)
Other cancers	334(1.3)
Sarcoma	265(1)
CNS	213(0.8)
Primary unknown	175(0.7)
Non-cancer**	13,127(49.3)

SD, standard deviation; ESAS, Edmonton Symptom Assessment System; CNS, central nervous system

[*] Frequency (%)

[**]Non-cancer indicates patients waiting for pathology confirmation of their diagnosis

Table 2: ESAS Response frequencies

	Pain	**Tired**	**Nauseated**	**Depression**	**Anxious**	**Drowsy**	**Appetite**	**Wellbeing**	**Dyspnea**
n	26,537	26,587	26,558	26,582	26,520	26,528	26,554	26,489	26,579
Median	0	2	0	0	1	0	1	2	0
Mode	0	0	0	0	0	0	0	0	0
0*	55.9	31.9	80.8	62.3	48.1	57.1	49.4	32.3	58.4
1*	9.5	9.4	6.2	8.2	10.5	9.1	10.2	13.3	9.8
2*	7.5	10.8	3.8	7.2	9.7	7.8	8.0	11.7	7.2
3*	6.9	10.5	2.5	6.1	8.3	6.6	6.6	9.9	5.8
4*	4.6	7.2	1.6	3.6	5.0	4.1	5.1	7.1	4.0
5*	5.0	9.7	1.7	4.9	6.7	5.2	8.4	11.7	4.8
6*	3.1	5.5	0.9	2.1	3.1	2.8	3.1	3.9	2.7
7*	2.8	5.7	0.8	2.0	2.9	2.8	3.1	4.1	2.6
8*	2.3	5.1	0.6	1.7	2.7	2.3	2.6	3.0	2.2
9*	1.0	2.0	0.3	0.8	1.1	1.0	1.3	1.2	1.1
10*	0.9	1.9	0.3	0.8	1.3	0.8	1.9	1.3	1.0

* Percent of total n (26,645)

Table 3: Rasch person summary statistics excluding extreme scores (n=22,871)

	Total Score	Count	Measure	Model Error	Infit MNSQ	Infit ZSTD	Outfit MNSQ	Outfit ZSTD
Mean	18.7	9	-0.81	0.25	0.97	0	0.98	0.1
SD	15.3		0.58	0.16	0.65	1.1	0.72	1.1
Max	88.0	9	2.16	0.85	5.85	5.0	9.90	6.8
Min	1.0	2	-2.26	0.14	0.00	-4.1	0.00	-3.9

Real RMSE	0.32	True SD	0.48	Separation	1.53	Patient Reliability	0.70
Model RMSE	0.30	True SD	0.49	Separation	1.66	Patient Reliability	0.73

Standard Error of Patients Mean = 0.00

MNSQ, mean squares; SD, standard deviation; ZSTD, z-standardized; RMSE, root mean square error

Table 4: ESAS means utilizing current and rescored data

	Mean	SD	Re-scored mean	Re-scored SD
Pre CanWell	17.9	13.68	-0.9354	0.71318
6-Week measure	15.4	13.36	-1.0542	0.73996
End CanWell	13.9*	11.83	-1.1056	0.68142

SD, standard deviation

* Statistically significant reduction over the 12-weeks of CanWell exercise program

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                .### S|
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Figure 1: ESAS Item map demonstrating that the majority of patients reported low scores on the measure (left side of the vertical line). Also seen is clustering of the ESAS items around zero logits (right side of the vertical line).

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-3       -2        -1         0         1         2         3
|---------+---------+---------+---------+---------+---------|  NUM   ITEM
0                  0   :   1 :2:3:45:6:7: 8 : 9    :    10 10    3  NAUSEATE
|                                                           |
|                                                           |
0              0   :  1 :2:3:4:56:7 :8 :  9   :    10      10    4  DEPRESSION
0             0   :  1 : 2:34:5:6:7:8 :  9    :    10      10    9  DYSPNEA
0             0   :  1 :2:3:4:56:7 :8 :  9   :    10       10    6  DROWSY
0             0   :  1 :2:3:4:56:7 :8 :  9   :    10       10    1  PAIN
0            0  :   1 :2:3:45:6:7: 8 :  9   :    10        10    5  ANXIOUS
0           0   :   1 :2:3:45:6:7: 8 : 9    :    10        10    7  APPETITE
|                                                           |
0          0   :  1 :2:3:4:56:7 :8 :  9   :    10          10    8  WELLBEING
0         0   :  1 :2:3:45:6:7 :8 :  9   :    10           10    2  TIRED
|---------+---------+---------+---------+---------+---------|  NUM   ITEM
-3       -2        -1         0         1         2         3

3           1   1  1 2121111
7      8    1 9 0985700185339753211
6      2    5 1129376493482297492306632
111    172119724987574971368158754410238623151 3 1  3       1  PERSON
        S         M         S         T
0 10       20   30 40 60 80 90   99                            PERCENTILE
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Figure 2: Keyform graph presenting clustering of ESAS responses between answer 2-7.

Appendix A

Table of raw scores to interval scale conversion (calibrated to 0-90 scoring)

SCORE	MEASURE	S.E.	SCORE	MEASURE	S.E.	SCORE	MEASURE	S.E.
0	2.91	20.55	31	37.54	1.73	62	45.56	1.96
1	14.56	10.23	32	37.78	1.72	63	45.89	1.98
2	20.16	6.70	33	38.03	1.72	64	46.22	2.01
3	23.05	5.22	34	38.27	1.71	65	46.56	2.04
4	24.95	4.38	35	38.52	1.71	66	46.91	2.07
5	26.34	3.84	36	38.76	1.70	67	47.28	2.11
6	27.45	3.46	37	39.00	1.70	68	47.65	2.15
7	28.36	3.17	38	39.24	1.70	69	48.04	2.19
8	29.13	2.95	39	39.48	1.70	70	48.45	2.24
9	29.81	2.77	40	39.72	1.70	71	48.88	2.29
10	30.42	2.63	41	39.96	1.70	72	49.32	2.34
11	30.96	2.51	42	40.20	1.70	73	49.79	2.40
12	31.46	2.40	43	40.44	1.71	74	50.28	2.47
13	31.93	2.32	44	40.68	1.71	75	50.80	2.55
14	32.36	2.24	45	40.93	1.71	76	51.36	2.63
15	32.76	2.18	46	41.17	1.72	77	51.96	2.73
16	33.15	2.12	47	41.42	1.73	78	52.60	2.83
17	33.51	2.07	48	41.67	1.74	79	53.30	2.96
18	33.86	2.02	49	41.92	1.75	80	54.05	3.10
19	34.19	1.98	50	42.18	1.76	81	54.90	3.27
20	34.51	1.95	51	42.43	1.77	82	55.85	3.48
21	34.82	1.91	52	42.69	1.78	83	56.93	3.73
22	35.12	1.89	53	42.96	1.79	84	58.18	4.04
23	35.41	1.86	54	43.23	1.80	85	59.68	4.46
24	35.70	1.84	55	43.50	1.82	86	61.54	5.03
25	35.97	1.82	56	43.78	1.83	87	63.99	5.89
26	36.25	1.80	57	44.06	1.85	88	67.57	7.37
27	36.51	1.78	58	44.35	1.87	89	74.09	10.85
28	36.77	1.77	59	44.64	1.89	90	86.64	20.98
29	37.03	1.75	60	44.94	1.91			
30	37.29	1.74	61	45.25	1.93			

Chapter 5. Discussion

It is estimated that approximately two out of every five Canadians will develop cancer at some point throughout their life (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). As previously discussed, while the incidence of cancer increases significant improvements are also seen in cancer survival. The five-year relative survival from cancer has improved to 63% (2006-2008) from 56% (1992-1994), and is expected to continue and improve (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). The increased incidence and the improved survival rates have led to more people living with cancer (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013) and potentially affected by the disease and its sequelae. This thesis provided a description of a community-based, supervised, exercise program for people with cancer aimed at managing side-effects associated with cancer and its treatments: the CanWell program.

The CanWell program that was studied and described in Chapters 2 and 3 of this thesis was established following a survey of cancer survivors at the Juravinski Cancer Center in 2007 (Cheifetz & Park Dorsay, 2007). The majority of the survey respondents stated that they would like to participate in an exercise program designed for cancer survivors, associated with a hospital, but located in the community (Cheifetz & Park Dorsay, 2007). The CanWell program was designed to meet this need. Based on a partnership between Hamilton Health Sciences (HHS), McMaster University, and the YMCA of Hamilton/Burlington/Brantford a Physiotherapist and Nurse Practitioner from HHS created the CanWell research program and implemented it at the YMCA. In the first study (Chapter 2) the effectiveness of the 12-week exercise program was established using physical and health-related quality of life (HR-QoL) measures including the 6-minute walk test, STEEP treadmill test, as well as, Functional Assessment of Cancer Therapy – General (FACT-Q) and Edmonton Symptom Assessment System (ESAS) questionnaires. Subsequently, a long-term follow-up study (Chapter 3) was completed to evaluate the fitness level of cancer survivors who participated in the CanWell program and identify exercise facilitators, or barriers, to continuation of the exercise routines. To ensure consistency in the type of data collected, the same outcome measures used in the first study were also used in the follow-up study, with an addition of an exercise barriers questionnaire. While the psychometric properties of the outcome measures used in the two studies outlined above were based on the Classical Test Theory (CTT) techniques, the third study (Chapter 4) focused on the examining the ESAS employing a Rasch analysis, which is grounded in the Item Response Theory (IRT) (da Rocha, Chachamovich, de Almeida Fleck, & Tennant, 2013). This study affirmed the psychometric properties of the ESAS and has identified important considerations regarding using the ESASs' scores in clinical practice and research, that will be discussed later in this chapter.

In the following sections of the thesis, the scientific contributions of each of the three included studies will be reviewed with additional discussion regarding their clinical implications. Additionally, the strengths and weaknesses of this work will be presented to help direct future research.

Scientific Implications and Contributions of Individual Manuscripts

CanWell: Meeting the psychosocial and exercise needs of cancer survivors by translating evidence into practice (Chapter 2)

Concerns regarding a gap between research findings and clinical implementations are long standing with significant efforts being put into "closing the gap" (Teachman et al., 2012). The CanWell program described in the first paper demonstrates a successful model for bridging the gap between exercise and cancer research and meeting the patients' clinical needs in the community.

The exercise program implemented was created using available research supporting incorporation of exercise both during (Courneya, Sellar, et al., 2012) and after (Courneya et al., 2003) cancer treatment. As a research implementation study, the CanWell program included cancer survivors with a variety of diagnoses and mixed cancer stage. While the results of this study demonstrated beneficial effects of a combination of aerobic and strength exercise for people with cancer, the confirmation that this program was safe (indicated by no exercise-related injuries during participation in CanWell), effective (indicated by the positive outcomes found), and sustainable (indicated by continuation of the program without on-going research funding). While other community-based exercise programs do exist (Rajotte et al., 2012), the unique partnership between the YMCA, HHS, and McMaster University possibly provides further credibility to the program and contributes to the creation of two important "bridges". The first bridge uses evidence-based information collected and evaluated at an academic setting for creating a clinical program, narrowing the gap between research and practice. The second bridge, narrows the gap between the hospital setting and patient integration into the community, where hospital-based care providers are closely monitoring the exercise program at the YMCA, and interacting with cancer survivors there.

Although the CanWell research project is evidence-based, further research is needed to continuously evaluate its effect on specific cancer diagnosis groups. Additionally, while it is known the exercise is beneficial for people with cancer and should include both aerobic and strength routines, the best exercise dosages, or prescription parameters, are yet to be found.

Identifying exercise adherence and barriers following participation in a community-based exercise and education program for cancer survivors.

Exercise barriers for people with cancer have been investigated in previous studies primarily focusing on challenges to initiate, or maintain, increased physical activities (Blaney et al., 2010; Courneya et al., 2005). Common barriers to exercise include a lack of supervised exercise programs (Blaney et al., 2010) and patients not considering exercise as a priority (Rogers, Courneya, Shah, Dunnington, & Hopkins-Price, 2007). As previously discussed throughout this dissertation, there is a relatively large pool of evidence supporting the incorporation of exercise program at all stages of the cancer care continuum. The second paper included in this thesis (Chapter 3) is important in that the exercise barriers of cancer survivors who have participated in, and have access to, the CanWell program were investigated. Cancer survivors who participated in CanWell have been exposed to the evidence supporting exercise as a treatment for cancer-related side-effects, as well as the evidence demonstrating improvements survival for cancer survivors who exercise (Ibrahim & Al-Homaidh, 2011) leading to the notion that exercise should be a priority and should be integrated into normal daily activities. Furthermore, CanWell participants have on-going access to cancer exercise specialists at the YMCA who can provide support and assistance even after completing the 12-week supervised exercise program.

Another important finding in the exercise barriers study was that while CanWell graduates were provided exercise prescriptions during the program, and were instructed on how to progress their exercise, exercise progression did not take place regularly following program completion. This highlighted the importance of providing on-going access to cancer exercise specialists who can help adjust exercise programs so that they remain effective and the possible incorporation of pre-scheduled "booster sessions" where cancer survivors can review their exercise sessions. The strategy of providing cancer survivors with exercise prescriptions upon completion of exercise studies has been previously presented by Courneya et al. (Courneya, Stevinson, et al., 2012) and has been shown to be effective to improve exercise adherence. Combining these prescriptions with long-term booster session should further help with maximizing exercise participation. Important exercise facilitators highlighted in the long-term follow-up study included the extended hours available at the YMCA gym facility which enables cancer survivors to exercise around work or medical appointment hours and on-going access to hospital-based health care providers who help participants' answer medical questions without the need to go to the cancer center. The health-care providers were also able to identify those

CanWell graduates that required referrals to their medical oncologists to investigate symptoms associated with cancer recurrence (or progression).

Rasch analysis of the Edmonton Symptom Assessment System (ESAS) and its research implications.

The effects of exercise on cancer survivors have been investigated utilizing a variety of outcome measures, including the Edmonton Symptom Assessment System (ESAS). While the ESAS was initially developed to evaluate overall symptom burden of patients in the palliative care setting (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991), it has since been utilized extensively in people with cancer throughout the cancer care continuum both in clinical and research environments (Nekolaichuk, Watanabe, & Beaumont, 2008; Richardson & Jones, 2009). Although the reliability and validity of the ESAS have been established in many studies, all of those studies have utilized statistical analyses based on the Classical Test Theory (CTT). The importance of the third manuscript in this dissertation is the exploration, and confirmation, of the ESAS's psychometric properties using Rasch analysis which is associated with the Item Response Theory (IRT).

An in-depth comparison between the CTT and IRT (and the Rasch model) was beyond the scope of the manuscript presented in Chapter 4. However, it is important to acknowledge that there is on-going controversy between different authors as to the superiority of one theory versus the other. For example, Fan (1998) compared the relationships between CTT and IRT item and person statistics to try and identify quantifiable differences (Fan, 1998). Following his analysis, Fan concluded that neither theoretical framework was superior to the other, and that his statistical findings were generally similar, regardless of which analysis was used (Fan, 1998). Conversely, Tesio (2003) reviewed the advantages of Rasch analysis in rehabilitation research (Tesio, 2003). Tesio concluded that utilizing Rasch analysis provided researchers the ability to create assessment tools with “unprecedented metric validity (including internal consistency and reliability” (Tesio 2003, page 105), a sentiment supported by Linacre and others (Linacre, 1996). While the study presented in Chapter 4 does not aim to resolve the CTT and IRT discussion, it does support that the ESAS is a reliable measurement tool (regardless of statistical theoretical background used).

Another important contribution of the ESAS manuscript relates to the scoring of the measure. Scoring of the ESAS is completed on a Likert scale that ranges from 0-10 (Richardson & Jones, 2009) with the scores of each item measured summed to produce an overall disease burden score. While summing ESAS scores is common in both the clinical and research settings, it assumes that the scores have interval-level measurement properties, which they do not (Streiner D.L. & Norman G.R., 2008). Following confirmation that the ESAS fits with the Rasch model, the Rasch software was able to propose a revised scoring scheme for the ESAS, which has interval-level characteristics (Linacre, 2013; Streiner D.L. & Norman G.R., 2008). The proposed scores (Chapter 4, Appendix 1) were used to re-analyze the effects of the CanWell program on cancer disease burden reported in Chapter 2. As previously discussed, the re-analysis yielded different results, changing statistically significant improvements observed with exercise to no significant change. This highlights that treating ordinal-level data as interval-level data may lead to erroneous conclusions. It would be interesting for researchers that have previously published ESAS results re-analyze their data using the Rasch-proposed interval-level scoring.

Implications and Contributions of the Overall Thesis

The overall focus of this thesis work was to describe a program that meets the physical and emotional needs of cancer survivors. The evidence presented in Chapter 1 summarized the adverse effects of cancer and its treatments. The benefits of exercise for cancer survivors were also summarized in Chapter 1, however the pathways required aligning exercise as a standard of care for cancer survivors do not exist. Furthermore, gaps continue to exist when considering the relationship between chemotherapy and exercise prescriptions. For example, performance status measures are often used to determine if cancer patients will receive chemotherapy, or not (Gridelli et al., 2004). However, those patients who require chemotherapy are not regularly referred to exercise program so that they can increase, or maintain, their physical status. Through the research behind this thesis, the Cancer Center staff have been exposed to the benefits of exercise for cancer survivors. Patients have learnt about the benefits of cancer through presentations and public media reporting on the CanWell program (Teotonio, 2012). Furthermore, the CanWell program described in previous chapters has won the Cancer Care Ontario 2010 Innovation Award[viii] as an example model for delivery of exercise for people with cancer.

[viii] Announcement available at http://www.hamiltonhealthsciences.ca/workfiles/Express/CQCO%20Awards.pdf

While not directly evaluated through this thesis work, the theoretical framework underpinning the CanWell program is that of self-efficacy (Bandura, 1986, 1989). Developing, and implementing, the CanWell program allowed hospital-based health care providers to share their knowledge and expertise with YMCA Fitness staff, hence helping them learn how to work with people with cancer and *building their confidence* in doing so. Similarly, by providing an exercise program specifically designed for people with cancer allowed cancer survivors to learn about exercise and *build their confidence* in their ability to exercise safely, regardless of the diagnosis and potential treatments. Future research may focus on using reliable and valid measures of self-efficacy to assess the proposed confidence changes, both in the Fitness trainers and in the exercise program participants.

Limitations

Limitations for each of the studies reported earlier are listed in their respective chapters. However, several limitations to the thesis as a whole should be considered. One of the main limitations of the CanWell research project is that it was not designed either as a randomized controlled trial or a cohort controlled trial. The optimal method to evaluate the effects of a treatment is to have some type of a control group (Portney & Watkins, 2000). During the development of the CanWell program the researchers considered the long-term goals of the program, meeting the physical needs of people with cancer, and decided that all those who are referred to the program should have access to the supervised exercise program. Future research can investigate whether providing access to the YMCA exercise facility and CanWell-trained fitness trainers, as well as, access to hospital-based care professionals without a structured exercise program would result in similar physical improvements.

A second limitation concerning the research design was that those who supervised the exercise programs were the same staff who administered the outcome assessments. Having un-blinded assessors may has the potential to introduce bias in the findings (Portney & Watkins, 2000). To reduce the potential for assessor bias, standardized instructions were used for the outcomes measured. Future work may consider recruiting outcome assessors not associated with the CanWell program.

Another important limitation concerns that the majority of CanWell participants, in both the first and second studies, are women with breast cancer, limiting generalizability of the results. Additionally, the primary referral source for the CanWell program is the Juravinski Cancer Center (JCC) in Hamilton, Ontario. Although many people with cancer are seen annually at the JCC (approximately 7,500 new referrals and 93,000 annual patient visits[ix]), only approximately 250 patients have been referred to the program since its inception in 2009. This suggests a knowledge translation gap regarding the effectiveness of the program within the local cancer center referral sources. Different strategies have been used to close this gap including presentations at clinical regional rounds, newsletter articles, e-mails to JCC staff, use of prescription pads, and personal communications. Future research investigating methods to bridge the gaps existing in the referral sources would be important to ensure that community-based exercise program meet the needs of those who require them.

[ix] Information available at http://jcc.hhsc.ca/body.cfm?id=307, accessed July 9, 2013

Future Directions

Several future research recommendations were presented in each of the included manuscripts and the discussion above. Following is a summary of some of the research ideas presented.

As mentioned in the Limitations section above, identifying a comparator, or control, group for the CanWell research program will allow a more rigorous evaluation of the effects of the exercise program in the YMCA setting. Since the overall benefits of exercise for people with cancer have been established, the control group may include a cohort of people referred to exercise programs but not provided with exercise supervision. Alternatively, the control group may be cancer survivors who receive exercise counseling only, with no actual referral. However, due to the strong evidence supporting cancer survivors' participation in exercise programs, the traditional control group of "standard care", i.e. no exercise referral or counselling, would not be appropriate.

Considering the gaps in referral patterns from the JCC to the CanWell program, future research should include evaluation of exercise referral gaps (e.g. what factors would increase the number of cancer survivors' referrals to exercise programs throughout the cancer care continuum?). This research can investigate barriers to incorporating exercise for patients who are admitted to hospital (i.e. how to exercise while being an in-patient?), patients who are discharged home (i.e. are cancer survivors discharged from hospital counselled about the benefits of exercise, and are they referred to exercise programs?), to those patients who are seen at ambulatory clinics at the cancer center (i.e. do cancer survivors receive exercise counselling during clinic appointments? What would be the facilitators to promote exercise counselling in the clinics? And, is there a change in referral patterns before and after an intervention aimed at increasing referral rates?).

Another important study can look at the most efficient process to expand CanWell to other YMCA facilities. A knowledge translation research project would be beneficial to help identify barriers to grow programs that are based on partnerships between different organizations. Identifying cost effective methods to utilize hospital-based staff to support community-based program, such as CanWell, may help identify strategies to expand similar programs in a time efficient manner.

Conclusions

This dissertation described the development of a community-based, supervised, exercise program for people with cancer (the CanWell program). Exercise programs for people with cancer primarily exist as research projects in hospitals or university settings. Conversely, CanWell is an exercise program where hospital-based staff see cancer survivors in the community. A partnership with a university provides on-going research collaboration and access to evidence-based information, thus ensuring the program is current in its approach to the exercise programs. The studies in this thesis provided support for the incorporation of exercise for cancer survivors, and contributed information to reducing barriers to maintain long-term exercise adherence. Lastly, this thesis contributed to the literature supporting the utilization of the Edmonton Symptom Assessment System to assess cancer disease burden, with an alternate scoring structure that allows parametric analysis of the reported scores.

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