

The Perceived Barriers to Exercise and Physical Activity for Individuals with Metastatic Cancer Undergoing Chemotherapy: A Qualitative Exploration

by

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The above committee determined that the thesis is acceptable in form and content and that a satisfactory knowledge of the field covered by the thesis was demonstrated by the candidate during an oral examination. A signed copy of the Certificate of Approval is available from the School of Graduate and Postdoctoral Studies.

Abstract

Over the recent years Exercise and Physical Activity (PA) have demonstrated Quality of Life (QoL) benefits for individuals with metastatic cancer. What is less known are the formal barriers that inhibit participation within this population. This study was a qualitative exploration that investigated the barriers to exercise and PA for individuals with metastatic cancer who were undergoing chemotherapy. The Health Belief Model (HBM) and its constructs (perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy) informed this research investigation. The researcher identified 12 subthemes that related to the HBM. Risk of infection in public spaces, fear of falling and age were unique findings. The HBM also proved to be a useful theoretical framework in understanding the barriers to exercise and PA for individuals with metastatic cancer, and should be considered in future research. A larger sample size is also necessary for future research.

Keywords: Cancer; metastatic cancer; exercise; physical activity; barriers

Author's Declaration

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Statement of Contributions

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication. I have used standard referencing practices to acknowledge ideas, research techniques, or other materials that belong to others. Furthermore, I hereby certify that I am the sole source of the creative works and/or inventive knowledge described in this thesis.

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Pursuing this research path emerged in 2008 after my wife, Nalisha Asgarali, was cured of stage 3 ovarian cancer after intense chemotherapy and surgery. It was a very difficult time in our lives, however since then I've had a strong desire to contribute to the cancer community in a positive way. The best means by which to acknowledge anyone's struggle is to enable their voice in the pursuit of meaningful change. This was the goal of this research and I will continue to strive to help the cancer community, both through my clinical and academic work.

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Chapter 1: Introduction

Introduction

Cancer is responsible for nearly 30% of deaths in Canada, and nearly half of all Canadians will develop the disease within their lifetime (Canadian Cancer Society's Advisory Committee, 2014). With the growing number of cancer cases, treatment strategies should focus on improving prognosis, while simultaneously preserving Quality of Life (QoL) (Mishra et al., 2012). According to the National Cancer Institute (2013) QoL refers to one's overall enjoyment of life as well as an individual's sense of well-being and ability to carry out various activities. Unfortunately, traditional anti-cancer treatments such as chemotherapy adversely affect QoL, thereby necessitating complimentary strategies to mitigate the negative side effects of cancer and cancer treatment. For the cancer patient, the debilitating effects of chemotherapy include, but are not limited to, Cancer Related Fatigue (CRF), which is "a distressing, persistent sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activities and usual functioning" (National Comprehensive Cancer Network, 2003, p. 308), poor fitness (Courneya et al., 2007) or adverse psychological outcomes such as depression, frustration and decreased motivation (Curt et al., 2000).

While the data is limited, cancer research focusing on exercise and Physical Activity (PA) has been seen as a possible solution to improving QoL during cancer treatment. Traditionally the research was primarily isolated to cancer survivors. However, studies have investigated the impact of exercise and PA on patients receiving cancer treatment (Courneya, 2003; Courneya, Keats & Turner, 2000; Oldervoll et al., 2005; Porock et al., 2000). The research indicates that multimodal exercise (aerobic, strength and flexibility training) can be successful in alleviating

the negative side effects of cancer and cancer treatment, thereby improving CRF (Dimeo et al., 1999), physical fitness (Barton, 2013; Dimeo et al., 1997), psychological outcomes (Dimeo et al., 1999) as well as overall QoL (Courneya, 2003; Courneya et al., 2000).

Background

Although the exercise, PA and cancer research are beginning to focus on cancer patients receiving chemotherapy, there is a lack of research directed toward patients with higher risk or advanced cancers such as metastatic disease (Beaton et al., 2009). Metastatic cancer is the process by which the cancer cells have moved beyond their point of origin into areas such as the lymphatic system or distal organs (National Cancer Institute, 2013). Metastatic cancer is more likely to be fatal because it has spread to different parts of the body which further complicates treatment as the cancer is no longer centralized (National Foundation for Cancer Research, 2014). Of all newly diagnosed cancer cases, approximately 30% have metastasized (Goodman et al., 2002). Cancer patients receiving chemotherapy for metastatic disease will likely suffer similar impairments to QoL as patients with different forms of cancer. However, this is often more discouraging as the cancer has metastasized, and performing longitudinal research within this population poses a challenge due to high attrition and mortality rates (Oldervoll et al., 2005).

Research question

Being that exercise and PA can mitigate the negative side effects of cancer and chemotherapy, barriers to exercise and PA need to be better understood. Furthermore, this remains less conclusive in individuals with metastatic cancer (Beaton et al., 2009). In an effort to expand this area of understanding, this proposed research study seeks to answer the following question:

What are the perceived barriers to exercise and physical activity for individuals with metastatic cancer who are undergoing chemotherapy?

More particularly, this study focuses on the perceived motivational, physical and psychosocial factors involved in (de)motivating exercise participation and PA for individuals with metastatic cancer who are undergoing chemotherapy.

Reflective experience

As an Exercise Physiologist, I've had the fortune of working with individuals with metastatic cancer who were undergoing chemotherapy in an out-patient setting by delivering a structured exercise program focused on improving strength and aerobic endurance. While the exercise acceptance rates were quite high (approximately 70%), I've always sought to understand the barriers to participation for these individuals. Based on my experience, typical barriers would often entail transportation limitations, negative side effects of chemotherapy as well as conflicting medical appointments. Considering such barriers, it is important for health care professionals to administer programs that are accessible and mindful of these barriers. This research is intended to add to the existing body of evidence and expand the overall understanding of exercise and PA for individuals with metastatic cancer. This research is intended to contribute to the current knowledge translation initiatives by organizations such as Cancer Care Ontario (CCO) that further enhance the understanding of exercise and PA for individuals with metastatic cancer.

Theoretical framework: The Health Belief Model

The researcher considered five potential theoretical frameworks for this research; The Health Belief Model (HBM; Rosenstock, 1974), the Theory of Planned Behavior (TPB; Ajzen, 1991), the Social Cognitive Theory (SCT; Bandura, 1977), the Transtheoretical Model of behavior change (Prochaska & Diclemente, 1983), and the Health Action Process Approach (Schwarzer, 2008). The HBM is a psychological model that attempts to explain and predict health behaviors by focusing on individual attitudes and beliefs, and was therefore chosen as the theoretical framework for this research. While initially used as a framework to promote tuberculosis screening in the 1950's by social psychologists, the HBM has evolved into a health research framework that aims to understand and predict health behavior change (Rosenstock, 1990). The basic tenet of the HBM is that individuals will take action to ward off or control negative health conditions if they regard themselves susceptible to a certain condition (Kazdin, 2000). The HBM relies primarily on six basic constructs to predict behavior: perceived susceptibility, perceived severity, perceived benefits and perceived barriers. Cues to action and self-efficacy were added in later years. An individual's perception of these constructs will determine their likelihood of engaging in the health related behavior.

Although this framework was initially used to evaluate public health initiatives, health science researchers have successfully expanded the scope of the HBM to further understand behaviour in those with other chronic health conditions such as diabetes, coronary heart disease, and metastatic cancer (Koch, 2002; Mirotznik et al., 1995; Sheill et al., 2017). In understanding the barriers and determinants, care providers can better cater exercise programs that are appealing to the intended population. To the researchers' knowledge, this is amongst the first

studies to utilize the HBM in understanding the barriers to exercise and PA for individuals with metastatic cancer undergoing chemotherapy. For the purpose of this research the negative health outcome is a compromised QoL and exercise and PA is the intervention that can mitigate the negative side effects of chemotherapy.

Current developments

Cancer and exercise has been an emerging field of research over the past two decades, however on June 30, 2015 Cancer Care Ontario (CCO) formalized their stance on cancer and exercise by launching a guideline with recommendations for individuals living with cancer (Segal et al., 2015). The guideline investigated the evidence relating to the benefits of exercise and cancer, and recommended the following:

1. People living with cancer can safely engage in moderate amounts of exercise while on active treatment or post completion of treatment.
2. Moderate amounts of exercise are recommended to improve the QoL, as well as muscular and aerobic fitness.
3. Clinicians should advise their patients to engage in exercise consistent with the recommendations outlined by the Canadian Society of Exercise Physiology (CSEP) and the American College of Sports Medicine (ACSM). The recommended duration, frequency, and/or intensity are the following:
 - a. 150 minutes of moderate-intensity aerobic exercise spread over three to five days and resistance training at least two days per week;
 - b. Resistance training sessions should involve major muscle groups two to three days per week (eight to ten muscle groups, eight to ten repetitions, two sets); and
 - c. Each session should include a warm up and cool down.

4. Conduct a pre-exercise assessment for all people living with cancer before starting a formal exercise program to evaluate for any effects of disease, treatments and/or comorbidities.
5. It is recommended, where possible, that people living with cancer exercise in a group or supervised setting as it may provide a superior benefit/outcomes in QoL and muscular and aerobic fitness.
6. It is recommended, where possible, that people living with cancer perform exercise at a moderate intensity (three to six times the baseline resting state) on an ongoing basis as part of their lifestyle so that improvements in QoL and muscular and aerobic fitness can be maintained for the long term.

These recommendations serve as a good starting point for exercise and PA programming for all individuals affected by cancer irrespective of where they lie on the continuum, however patient perceptions toward exercise and PA necessitate a deeper understanding especially in light of metastatic cancer.

Chapter 2: Literature review

Introduction

The purpose of this literature review was to better understand the lived experience of individuals with metastatic cancer, consider potential barriers to exercise and PA, critique the current research and identify potential research gaps. This literature review incorporated both peer-reviewed and grey literature articles. Grey literature was included to gain a comprehensive understanding of this research study matter. As this field of research is in its preliminary stages, some of the studies are small in nature, lack longitudinal follow up and suffer from poor methodological quality. This chapter begins by defining the search process and lists key words used in the search and is organized into understanding metastatic cancer and its accompanying symptoms; exercise and PA; psychosocial and physical benefits; barriers to exercise and PA; the HBM and its relevance to this research study; and lastly identifying the potential gaps within the literature.

Search process

The research articles were primarily found using PubMed, ProQuest and MEDLINE via Ovid online search engines. Original keywords used to search in the database were: “neoplasm”; “cancer”; “palliative”; “metastatic cancer”; “advanced cancer”; “exercise”; “physical activity”; “benefits”; “barriers”; or a combination of these words were searched by using Boolean operators (And/Or). A variety of research study types were used such as clinical trials, prospective studies, observational studies, and qualitative research to gain relevant information relating to exercise, PA and metastatic cancer. Relevant association statements/websites were used (Canadian Cancer Society, Canadian Society of Exercise Physiology, Scarborough and

Rouge Hospital) to provide information on definitions, current policy and exercise programming related to individuals with metastatic cancer. Publications over 15 years old were excluded unless they were useful in defining terms, concepts, or presented meaningful background information. Therefore, the publication dates ranged from 1958-2017. Many of the older articles were primarily used in relation to theoretical frameworks. The research articles were also limited to English language.

Literature review

This literature review provides an analysis of the current state of knowledge for exercise and PA in individuals with metastatic cancer. It is organized into the following sections:

1. Understanding metastatic cancer and its accompanying symptoms
2. Exercise and PA
3. Biological mechanisms related to exercise, PA and metastatic cancer
4. The benefits of exercise and PA
5. The barriers to exercise and PA
6. Theoretical framework
7. The Health Belief Model

Understanding metastatic cancer and its accompanying symptoms

Metastatic cancer is the process by which the primary cancer spreads to other parts of the body, namely the lungs, lymph nodes, brain, liver and/or bones (Holmes & Fouts, 1970). The original cancer is referred to as the “primary tumour” and the cancer that has spread beyond its

point of origin is referred to as “metastatic”. When cancer cells spread, or metastasize, the cancer cells have the same characteristics as the cells of the primary tumour site. There are three primary ways that metastatic cancer spreads: 1. direct extension by which the primary tumour grows into surrounding structures around it, 2. cells travel to another part of the body through the lymphatic system or, 3. cancer cells break away from the primary tumour site and travel through the bloodstream to another cancer site (Canadian Cancer Society, 2017). Individuals who are diagnosed with metastatic cancer typically have a poorer prognosis as more than one system within the human body has been affected by the cancer. Individuals with metastatic cancer are usually treated with chemotherapy or radiation, with a treatment goal to prolong survival and preserve QoL.

Common symptoms of metastatic cancer

There are many side effects that occur as a result of metastatic cancer such as cachexia, anorexia, dyspnea, delirium, fatigue, nausea, vomiting, and constipation (Lagman, Davis, LeGrand, & Walsh, 2005). These symptoms can often occur concurrently as the cancer progresses and vary in intensity from mild to severe (Tsai, Wu, Chiu & Chen, 2010). These symptoms severely hamper an individual’s sense of QoL and well-being, and unfortunately have become an accepted part of the journey for individuals with metastatic cancer (Slevin et al., 1990). The symptoms are described in greater detail below.

Cachexia

Cachexia, also known as muscle wasting, is a systemic inflammatory response that is caused by host-generated cytokines; tumor-derived cytokines; or specific (unique) cachexins that

detrimentally alter carbohydrate, lipid, and protein metabolism (Tisdale, 2001). Cachexia is more common in children and the elderly and becomes more evident with cancer progression; cachexia is present in 50% of patients who have active cancer and 80% of patients at the time of death (Inui, 2002). Cachexia reduces performance status and determines QoL to a greater extent than pain in metastatic cancer (Goldberg & Loprinzi, 1999). The detrimental effects associated with the ill effects of cachexia are responsible for 20% of cancer deaths (Inui, 2002).

Anorexia

Anorexia, or weight loss, occurs despite an increased need for calories. Cancer disengages the normal balance between one's appetite signals and energy expenditures (Davis, Dreicer, Walsh, Lagman, & LeGrand, 2004). Anorexia, as measured by dietary intake, does not correlate well with the degree of weight loss. Weight loss can be precipitous, despite a normal appetite (Bosaeus, Daneryd, Svanberg, & Lundholm, 2001). Anorexia in cancer may be a general loss of appetite, early satiety, altered food preferences, or a combination of these. There is a distinct difference in the proposed pathophysiology between cachexia and anorexia such that cachexia and anorexia should not be considered synonymous although they overlap in frequency. Both anorexia and cachexia are a major cause of morbidity and mortality in metastatic cancer (Lagman et al., 2005).

Dyspnea

Dyspnea, a subjective sense of difficulty breathing, remains a common concern for those with metastatic cancer. Dyspnea is typically treated with opioids, corticosteroids, bronchodilators, anxiolytics or oxygen (Lagman et al., 2005). Dyspnea is subjective and has

multi-dimensional physical, emotional, and social components. There are no tests (e.g. oximetry, pulmonary function test, chest radiograph, arterial blood gas) that correlate with the presence or severity of dyspnea within these patients. It is whatever the patient says it is. A patient who has a normal respiratory rate, normal blood gas, and a normal chest radiograph may be dyspneic. Studies of the correlates of dyspnea found that weakness of the respiratory muscles plays a significant role (Bruera, Schmitz, Pither, Neumann, & Hanson, 2000). In the setting of metastases, complications related to dyspnea can be related to chemotherapy, co-morbid conditions (i.e. heart failure, heart disease) or the cancer itself (Lagman et al., 2005).

Delirium

Delirium, also known as acute confusional state, is a common and complex side effect. In a prospective assessment of 113 patients investigating the occurrence, causes, and outcome of delirium in patients with metastatic cancer, 42% of patients were delirious on admission, 45% developed it during the admission, and 88% were delirious at death (Lawlor et al., 2000). Delirium is frequently unrecognized and undertreated as it can be confounded with other similar mental health issues such as short term memory loss or anxiety. Delirium can create significant distress for patients, family members as well as the medical team who provide bedside care (Breitbart, Gibson & Tremblay, 2002). Delirium can be difficult to diagnose as it can be mistaken for anxiety or depression. The most common causes of delirium are related to medications, infections, and central nervous system malignancy; and most medications that are prescribed frequently for symptom management have delirium as a potential toxicity (Lawlor et al., 2000).

Cancer Related Fatigue

Cancer Related Fatigue (CRF) is a subjective symptom that is often referred to as feeling tired, weary, or having a lack of energy and is among the most common symptoms related to metastatic cancer. It is reported by 60% to 90% of patients (Cella, Davis, Breitbart, & Curt, 2001). The Fatigue Practice Guidelines Panel defines CRF “as an unusual, persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning” (Mock, Piper, Sabbatini, & Escalante, 2000. p. 151). Although the metabolic process for what causes CRF is unknown, it is clear that CRF is caused by multiple factors including: chemotherapy/radiation treatment, co-morbidities, cachexia, anemia, sleep disorders, anxiety/depression, pain, or medications (Lagman et al., 2005).

Nausea and Vomiting

Nausea and vomiting commonly occur in patients who have metastatic cancer. Approximately 60% to 70% will experience nausea and 30% will experience vomiting in the last weeks of life (Fainsinger, Miller, Bruera, Hanson, & MacEachern, 1991). Nausea is a subjective, unpleasant sensation of wanting to vomit whereas vomiting is the forceful expulsion of gastric contents (Rhodes & McDaniel, 2001). Most research is focused on chemotherapy-induced nausea and vomiting and there is a scarcity of data on nausea and vomiting from other causes. As nausea and vomiting also relate to the cancer itself, it is thought to be a result of metabolic abnormalities, brain metastases, bowel obstruction, constipation, or medications (Lagman et al., 2005).

Constipation

Constipation is reported by approximately 40% of patients with metastatic cancer (Curtis, Krech, & Walsh, 1991). Constipation is particularly prevalent in individuals who are treated with opioids (Levy, 2003). Other causes of constipation may be related to neurologic abnormalities (spinal cord lesions, autonomic neuropathy), metabolic disorders (hypokalemia, hypercalcemia, uremia, diabetes mellitus) or structural abnormalities (fibrosis, obstruction) (Lagman et al., 2005).

Symptom Clusters

Symptoms often do not occur in isolation. When symptoms occur simultaneously it is referred to as 'symptom clusters'. Although there is no definitional consensus, symptom clusters occur when cancer patients experience two or more interrelated, concurrent symptoms, that are relatively independent of other symptoms (Dodd, Miaskowski, & Paul, 2001; Kim et al., 2009). Symptom clusters occur in light of cancer and the associated treatments such as chemotherapy, radiation therapy, surgery, hormone therapy, immune therapy or a combination. Mustian et al. (2016) state:

These therapies may cause an array of physical and psychological symptoms that hinder a cancer patient's ability to comply with treatment protocols, perform activities of daily living, and maintain a conventional standard of living...the clustering effect of these symptoms is not simply additive, but can be multiplicative in terms of the negative consequences they portend, significantly impairing a patient's ability to complete treatment and a survivor's ability to thrive post-treatment. (p. 384)

This section highlighted the common symptoms experienced by individuals with metastatic cancer. Although symptoms may vary, the aforementioned symptoms are a common occurrence and represent a severe degradation of their QoL. Unfortunately, there is no solution to alleviating these adverse symptoms as cancer and the toxicity of chemotherapy takes a drastic toll on the human body. Being that metastatic cancer has a poor prognosis and therapy is typically palliative driven, maintaining a reasonable QoL is an important standard to strive for.

Exercise and Physical Activity (PA)

Exercise and PA are often used interchangeably in the literature, and can often be misconstrued for one another. Although Exercise is a subset of PA, there are distinct differences in their meaning. PA is defined as “Any bodily movement produced by skeletal muscles that result in energy expenditure” whereas “Exercise is planned, structured, and repetitive, and has a final or an intermediate objective in the improvement or maintenance of physical fitness” (Caspersen, Powell, & Christenson, 1985, p. 126). Examples of PA include carrying groceries, going to the mall or cleaning one’s home. Examples of exercise include walking at a sustained speed over a prolonged period of time with a particular goal in mind, such as achieving a particular heart rate range or intensity threshold.

Traditionally exercise and PA were not part of the continuum of care for individuals with metastatic cancer who were undergoing chemotherapy, however recent literature has demonstrated exercise and PA as safe, and that patients with metastatic cancer may benefit by partaking in exercise and PA during active treatment with improvements in QoL, psychosocial

well-being and physical fitness (Adamsen et al., 2009; Chiarotto, Akbarali, Bellotti & Dranitsaris, 2017; Courneya & Friedenreich, 2010; Lowe, Watanabe, Baracos, & Courneya, 2009B; Segal et al., 2015; Zopf et al., 2017). Also, exercise has been shown to ameliorate some of the negative side effects of metastatic cancer such as muscle mass degradation or symptom clusters (Blauwhoff-Buskermolen et al., 2016; Gerritsen & Vincent, 2016; Mustian et al., 2016) and are being endorsed by some of the major exercise physiology associations such as the American College of Sports Medicine (ACSM), the Canadian Society of Exercise Physiology (CSEP) as well as Cancer Care Ontario (CCO) (ACSM, 2016; CSEP, 2014; Segal et al., 2015).

Biological Mechanisms related to Exercise, PA and Metastatic cancer

Although the exercise, PA and metastatic cancer research is primarily concerned with improving the QoL and well-being of patients, there is growing body of evidence demonstrating that exercise may be an adjunct anti-cancer treatment alongside conventional cancer therapy (i.e. chemotherapy and radiation). In healthy individuals, exercise is known to positively influence immune, metabolic, neuroendocrine, musculoskeletal, genetic and epigenetic function. Because of this inherent ability, exercise may be a promising tool to treat metastatic cancer, and improve symptoms as well as symptom clusters (Mustian et al., 2016). Koelwyn, Wennerberg, Demaria and Jones (2015) examined the role of cancer, immunity and cancer cell proliferation. They posit that because some pharmacological agents are aimed at manipulating the immune system to decrease tumorigenesis among some cancer patients, there may be an inherent effect on the modulation of the immune system thereby improving anti-tumour immunity and decreasing inflammation, which may in turn decrease cancer cell proliferation. Also, Chiarotto et al. (2017) sought to determine if exercise can be used as an anti-cancer treatment strategy as opposed to a

symptom management strategy for individuals with metastatic cancer undergoing chemotherapy. They examined the Wnt signaling pathway (a signal transduction pathway of the cell) and its effect on Beta Catenin. Beta Catenin is a protein marker that is implicated in colorectal carcinogenesis and other metabolic diseases, and can be used as a possible biomarker to determine mortality (Morikawa et al., 2011). Chiarotto et al. (2017) found that the presence of Beta Catenin was less in the exercise group versus non exercise group and postulated that exercise can have possible benefits that can alter one's overall prognosis.

Understanding the biological mechanisms of exercise, PA and metastatic cancer hold much promise, however many of these studies are prospective and hypothesis generating and require further investigation. Small sample sizes and lack of follow up (primarily due to poor prognosis) are a common downfall of this type of scientific research. It is important to understand that the variable and dynamic influence of cancer on the human body/bodies create a circumstance that is difficult to replicate in another setting, and therefore complicate the understanding of the biological implications of exercise, PA and metastatic cancer. Patient symptoms also play a key role in one's ability to partake in exercise programs, which further confounds the precision that is necessary to examine biological mechanisms within the human body especially in light of metastatic cancer. However, while the biological aspects of exercise and metastatic cancer hold some promise, maintaining QoL is important to individuals with metastatic cancer, and exercise and PA may have an important role to play.

The benefits of exercise and PA

“What every physician wants for every one of his patients old or young, is not just the absence of death but life with a vibrant quality that we associate with a vigorous youth. This is nothing less than a humanistic biology that is concerned, not with material mechanisms alone, but with the wholeness of human life, with the spiritual quality of life that is unique to man. Just what constitutes this quality of life for a particular patient and the therapeutic pathway to it often is extremely difficult to judge and must lie with the consciousness of the physician.”

- Elkington, 1966. p. 714

As mentioned earlier, the benefits of exercise and PA are still in the early stages of being regarded as a staple therapy that all patients should undertake, as study quality and lack of general expertise/availability become an issue. That being said, preliminary findings are positive and hypothesis generating which lead many exercise science professionals to believe in the benefit of exercise and PA.

Lowe, Watanabe & Courneya (2009A) performed a systematic review of all of the available published studies examining the feasibility of PA as a supportive care intervention in patients living with metastatic cancer aged 18 years or older. Six studies were identified involving a total of 84 participants from five countries (Australia, Austria, Germany, Norway and the United States), published over a seven-year period (2000-2006). Of the six studies, three were case reports, two were single group uncontrolled trials, and one was a randomized control trial. Half of the studies examined were ‘aerobic only’ exercise interventions, whereas the other half were both aerobic and resistance training interventions. The primary objective of these studies was not to establish efficacy, but rather to determine if patients living with metastatic cancer were interested, and able to safely tolerate exercise and PA due to their condition. The researchers determined that majority of participants were able to tolerate the exercise and PA

interventions. Of the six studies, half reported an increase in QoL scores, and one study reported a slower decline in total well-being among the exercise group. Two of the studies reported an increase in patient reported physical function post exercise, and one study didn't show any significant differences. In regards to fatigue, one study demonstrated a significant decrease and another reported a borderline significant decrease. Three of the studies used objective measures (6-minute walk test and timed sit-to-stand before and after exercise intervention) to assess physical fitness, with all three yielding improvements in work capacity and physical fitness. Only one study objectively measured dyspnea, and was able to find a significant improvement before and after the exercise intervention. The researchers mentioned that the overall methodologic quality of the six studies were low and go onto say:

As is often the case with pioneering studies in a new field, emphasis is placed on pilot and feasibility issues such as recruitment, adherence, and retention; categories such as selection bias, allocation bias, blinding, and confounding, may not apply to the qualitative comparison of feasibility studies. (Lowe et al., 2009A, p.31)

The researchers point out that more feasibility studies are required to advance this field of research, and there is a need to determine which subgroup of patients living with metastatic cancer benefit the most. Also, there needs to be a determination of the participant characteristics of those who chose to participate versus those who chose not to participate. In another study by Oldervoll et al. (2005) it was determined that a high proportion of patients living with metastatic cancer were willing to participate in a structured exercise program (63%) and despite a high attrition rate due to symptoms, 53% were able to complete the 6-week exercise program. But like

Lowe et al. (2009A), there were no consistent attributes of participants versus non-participants. Also, of the studies that reported objective measures such as QoL, fatigue or physical functioning (Lowe et al., 2009A), they differed in their use of measurement tools and reporting methods, many of which have not been validated or tested among individuals with metastatic cancer. Lowe et al. (2009A) conclude that:

Few studies have examined PA in palliative cancer patients, and the current state of evidence is largely limited to case reports and uncontrolled trials. Nevertheless, these preliminary studies provide some evidence that at least some palliative cancer patients are willing and able to tolerate PA interventions, with some patients demonstrating improvement in some supportive care outcomes post intervention. The potential role for PA as a supportive care intervention is promising, and further feasibility studies are needed to substantiate preliminary findings and further advance this emerging area of research. (p.33)

These researchers also mention that exercise interests and preferences were never accounted for in the analysis and this team went onto to look into this in their 2010 study.

Lowe, Watanabe, Baracos and Courneya (2010) administered a cross sectional survey among 50 patients living with metastatic cancer in an outpatient setting. They found that an overwhelming 92% of participants reported that they would be interested in participating in a PA program at the time of survey administration. Fifty-four percent of participants reported that they would prefer to exercise on their own, such as a home based program, and 64% preferred

walking as their primary modality. This was also supported by Tsianakas et al. (2017), who also reported that patients living with metastatic cancer have an affinity for walking. The overarching theme of this study (Lowe et al., 2010) is that individuals with metastatic cancer are willing to engage in exercise and PA given the opportunity, as they also have their own reasons for participation.

Gulde, Oldervoll & Martin (2011) examined patients living with metastatic cancer experience of PA. This was a multi-center trial involving 11 participants. The participants were involved in a one-on-one exercise program with a physiotherapist at the time of the interview. Participants were asked to undergo a semi-structured interview that focused on understanding their experience, with or without the physiotherapist. Via thematic analysis, four predominant themes emerged: 1. the exercise program contributed to *routines of everyday life* which resulted in a feeling of meaning in their day to day transactions, 2. the participants reported *less fatigue* and had greater ability to perform their activities of daily living, 3. the participants appreciated the *professional guidance* and encouragement by their physiotherapist and lastly, 4. the exercise program gave them *hope* and they had thoughts that “PA could prolong their lives or obstruct the spread of their disease, or at least offer them a better QoL in their remaining time” (Gulde et al., 2011, p. 300). This is one of the few studies that address the patient experience through qualitative methods and semi-structured interviews that are not entirely reliant on questionnaires. These findings are insightful to those working with individuals with metastatic cancer and represent a willingness for patients to participate in exercise and PA that is driven by their own motivations and perceived value.

Lowe et al. (2009B) examined the associations between PA and QoL in those with metastatic cancer who were receiving palliative care, with a clinician-estimated life expectancy of 3-12 months. This study included 50 participants who completed a cross-sectional survey by means of a face-to-face interview assessing self-reported QoL (McGill Quality of Life Questionnaire [MQOL]), self-reported physical function (Late-Life Function and Disability Instrument), symptoms (Edmonton Symptom Assessment System), and physical activity behavior according to their daily PA levels. They found that individuals who reported more than 30 minutes of PA per day over a one-week period reported positive QoL associations versus those who did not achieve 30 minutes. They even found stronger, positive associations among those who reported greater than 60 minutes of PA. Being that there is a tendency for participants to over report their perceived PA levels, there was still a positive association between PA and QoL. However, as pointed out by Pinquart et al. (2006), poor levels of QoL are often attributed to psychological well-being as opposed to functional status. Pre-existing psychological status will play a role in one's perception of QoL, which makes it difficult to solely attribute QoL changes to PA, or exercise for that matter. Also, due to the observational nature of this study, one cannot infer a cause-effect relationship.

In a multicenter trial in Sweden, Oldervoll et al. (2011) conducted a randomized control trial in individuals with metastatic cancer. This study was primarily concerned with the effects of exercise on fatigue and physical fitness. Of the 231 patients with a life expectancy of <2 years, 121 were randomized to the exercise group and 110 were randomized to the non-exercise group. The exercise group met twice/week for 60 minutes under the supervision of a physiotherapist for eight weeks. The program was tailored to improve aerobic, strength, balance and flexibility

capacity. Assessments were performed before and after the intervention. Fatigue was measured by utilizing the widely used Fatigue Questionnaire (Butt et al., 2013). Physical fitness was measured through the shuttle walk test and hand grip strength tests, both of which are valid testing modalities (Bohannon, 1998; Wise & Brown, 2005). Thirty-six percent of the exercise group and 23% of the usual care group were lost to follow up primarily due to disease progression. The remainder of participants completed the intervention. The analysis did not show any significant differences in feelings of fatigue. This is likely because fatigue is a complex phenomenon and is further exacerbated by several biological and psychological factors that are largely due to disease progression and anti-cancer treatment i.e. chemotherapy (Stone & Minton, 2008). Currently, it is not known if exercise has the ability to fully counteract the side effects of disease progression and chemotherapy, and if so, which patients benefit the most and what type of exercise is most beneficial. In a Cochrane review, Cramp & Daniel (2008) demonstrated that the strongest effect of exercise on CRF was seen in patients who were off chemotherapy treatment. However, Oldervoll et al. (2011) found statistically significant improvements in physical fitness. The researchers also concluded that although fatigue did not improve, the improvements in physical fitness can justify exercise as being beneficial for individuals with metastatic cancer.

Gerritsen and Vincent (2016) performed a meta-analysis by which they sought to examine the effectiveness of exercise in improving the QoL for patients with cancer (irrespective of stage and type), during and after medical treatment. They examined the results of 16 randomized control trials, by which the exercise interventions varied widely in content, frequency, duration and intensity. It was found that QoL improved significantly in the exercise

groups versus the non-exercise groups ($p < 0.001$) based on data from all 16 studies. Also, two studies reported significant improvements in peak oxygen consumption, four studies reported significant improvements in physical functioning and four studies reported significant improvements in fatigue. They concluded that exercise has a direct positive impact on QoL in patients with cancer, during and following medical intervention. This is juxtaposed by a randomized control trial of 269 cancer patients undergoing chemotherapy who were involved in a multimodal high intensity exercise intervention (Adamsen et al., 2009). Participants of this study met five times/week and were involved in high/low intensity, relaxation and flexibility training. This group found no improvements in QoL, however there were improvements in fatigue, vitality, aerobic capacity, muscular strength and emotional well-being. Like Gerrtisen and Vincent (2016), this research was not limited to individuals with metastatic cancer, however all participants were receiving chemotherapy at the time of the exercise intervention.

Lastly, Yee et al. (2014) undertook a multi-center trial looking at the prevalence of PA in women with metastatic breast cancer compared to healthy controls. A total of 142 women (71 metastatic breast cancer and 71 healthy controls) participated in the study. The participants were age matched and joined their respective arm. The research team measured PA levels (Godin Leisure-Time Exercise Questionnaire and electronic device monitoring), performed fitness assessments (Modified Canadian Aerobic Fitness Test, handgrip strength, back-leg dynamometer) as well as QoL (European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire, Functional Assessment of Chronic Illness Therapy: Fatigue). There was no exercise intervention. It was found that women living in the community with metastatic breast cancer had lower aerobic fitness, reduced muscular strength, and less PA

compared to their healthy counterparts. They also reported poorer functioning and higher symptom burden. This demonstrates an ongoing need to encourage individuals with metastatic cancer to engage in exercise and PA, and necessitates an investigation into the barriers that prevent one from engaging in exercise and PA.

The barriers to exercise and PA

While it has been demonstrated that exercise and PA can be beneficial for individuals with metastatic cancer who are undergoing chemotherapy, what is less known are the formal barriers that inhibit participation. This section seeks to explore some of the barriers faced by individuals with metastatic cancer in their pursuit of adding exercise and PA to their lives. This section categorizes the perceived barriers into four broad categories: physiological factors, psychological factors, social factors, and environmental factors.

Physiological factors

Physiological factors relate to elements of the cancer that physically limit one from participating in exercise and PA. These would include factors such as the side effects of the illness, side effects of cancer treatment, CRF, pain, or other co-morbidities that would limit participation.

In their qualitative study looking at the barriers to, and facilitators of PA in patients receiving chemotherapy for lung cancer, Mas, Quantin and Ninot (2015) found that side effects of the disease and treatments were barriers to PA for all five participants in their study. The most common side effects mentioned by their participants were CRF, pain, vomiting, bronchial infections, and neuropathy. Common side effects of cancer treatment such as CRF as a deterrent

are also supported by Smaradottir, Smith, Borgert, and Oettel (2017) in their qualitative study investigating the perceptions of exercise and PA during cancer treatment for individuals with metastatic and non-metastatic cancer. Other pre-existing diseases or co-morbidities that patients had before their cancer were not necessarily barriers to exercise or PA, however limited their duration, intensity and frequency of exercise (Mas et al., 2015). In a cross-sectional, survey based study that adopted the theory of planned behavior (TPB) to understand patient experiences, Kartolo, Cheng and Petrella (2016) looked at the motivation and preferences of exercise programs in patients with inoperable metastatic lung cancer. The TPB helped shape their 67-item questionnaire, and was one of the few studies that utilized a major health behaviour theoretical framework in understanding the barriers to exercise and PA for individuals with metastatic cancer. Of the 60 participants involved in the study, 18% of the respondents reported that ‘feeling unwell’ was a potential barrier to not participating in an exercise program. Interestingly, 63% of respondents reported that they had the motivation to exercise with a preference for light intensity exercise such as walking. Lastly Sheill, Guinan, Neill, Hevey, and Hussey (2017) undertook a qualitative exploratory analysis of the barriers to PA involving 20 individuals with colorectal metastatic cancer. This study utilized the health belief model in the development of their questionnaire, and was also one of the few studies (along with Kartolo et al., 2016) that utilized a major health behaviour theoretical framework in understanding the barriers to exercise and PA for individuals with metastatic cancer. Sheill et al. (2017) found that symptom burden was a significant barrier to PA as patients attributed their ill physical feelings toward cancer treatment as well as the cancer itself.

Symptom and disease burden play a role in one's willingness and ability to participate in exercise and PA (Cheville, Dose, Basford & Rhudy, 2012). Patients living with metastatic cancer face a dichotomy by which their symptoms vary on a day to day basis, as some days are better than others, and the perception of their willingness to participate in exercise and PA can also change. Research concerning perceived barriers need to consider this reality. As alluded to by Kartolo et al., (2016), individuals with metastatic cancer may feel unwell to participate in exercise and PA due to their symptom burden, however are willing to participate depending on the intensity of the exercise program.

Psychological factors

Psychological factors are based on one's psychological feelings that either promote or dissuade from participation in exercise and PA.

Mas et al. (2015) found that all of their participants avoided PA because they were fearful that during participation they would experience an adverse physical effect such as gastric upset or fatigue. Understanding this fear is important because "symptoms (or fear of triggering symptoms) may result in an unnecessarily accelerated pattern of decreased activity, deconditioning, morbidity, and disability" (Cheville et al., 2012. p. 91).

It is also important to mention that the benefits of exercise and PA are not immediate, and because of their poor diagnosis and inability to take on medium-term projects, medium to long term adherence to regular exercise would be difficult. Some individuals can also develop

kinesiophobia which is when they lose confidence in their physical abilities and develop a fear of moving (Mas et al., 2015).

Psychological fears, whether real or perceived, can limit one's motivation to participate in exercise and PA. The disease burden is immense, and can have psychological implications that may necessitate alternative supportive care, such as psychosocial therapy (Goedendorp, Gielissen, Verhagen, & Bleijenberg, 2009), that have the potential to address this issue.

Self-efficacy is also an important psychological factor as it relates to an individual's beliefs about their abilities to produce actions/effects (Bandura, 1994). Ungar, Wiskemann and Sieverding (2016) examined the role of self-efficacy in promoting PA among cancer patients undergoing chemotherapy. The group included individuals with metastatic and non-metastatic cancer. This was an interventional study by which participants were assigned to either an exercise group or a stress management group. The primary outcomes were related to one's level of self-efficacy and PA enjoyment, measured via the SQUASH assessment (Short Questionnaire to Assess Health Enhancing Physical Activity), and its relationship to the respective intervention. The authors demonstrated that PA enjoyment and self-efficacy were positively associated with participation in an exercise program. Positive associations with exercise and PA are often confirmed by personal experience with exercise and PA. If a patient can establish a positive link with usual and past activities, they will likely engage in exercise and PA as a supportive care measure (Cheville et al., 2012). If an individual is compromised in their perceived physical ability to participate in exercise and PA, their level of self-efficacy may serve as a deterrent.

Social factors

A diagnosis of metastatic cancer can have a dramatic impact on one's life, including their social well-being, and can influence their interactions with the world around them. It can also bring on a sense of introversion and individuals may withdraw from regular activities and social gatherings, only preferring to stay home and remain isolated from wider society (Mas et al., 2015). While this is not an ideal approach to coping with illness, it is important to understand the psychological burden placed on these individuals. A cancer diagnosis not only affects the person but it also affects those close to them. Rhudy, Dose, Basford, Griffin and Cheville (2015) examined the attitudes of 20 caregivers in promoting exercise among patients with late-stage lung cancer. They found that caregivers viewed exercise as important, however felt limited in their ability to promote exercise to their loved ones as this was better suited to be endorsed by a health care practitioner. Some felt the conversation relating to exercise was "off limits" because its promotion could be perceived as a criticism towards the patient. The social reality of the patient to caregiver relationship is very delicate due to the sensitive nature of the diagnosis and may be a limiting factor in exercise participation. This study is important because it one of the few studies that focuses on the lived realities of patients and their caregivers, and aids in understanding the patient experience.

Environmental factors

The immediate environment of the patient is a determinant of participation. For instance, Kartolo et al. (2016) found that 27% of their respondents felt that distant location would be a barrier and 18% felt that bad weather would be a factor in participation. Environmental factors also relate to the facility and the health care team who are treating them. Many times exercise

programs and professionals are not readily available and therefore become a barrier, while having professional guidance along with an Oncologist referral would motivate patients to participate in exercise and PA (Cheville et al., 2012). Smaradottir et al. (2017) undertook a study by which 20 patients and nine health care providers participated in a focus group, and ten patients were individually interviewed. The objective of the study was to determine the role of exercise in cancer care and address the potential barriers. This group was comprised of individuals with metastatic and non-metastatic cancer. The most prominent barrier to exercise was fatigue (50%), followed by other barriers such as the symptoms (dyspnea, pain, and impaired mobility). Also, the side effects of treatment such as nausea, vomiting, diarrhea, neuropathic pain, emotional state and lack of motivation served as a deterrent toward exercise. That being said, the majority of participants and health care providers acknowledged that exercise is important during cancer treatment (95%) and the primary barrier from a health care provider standpoint was due to their own time constraints, lack of available expertise in exercise programming, and no referral pathway to an exercise program.

Literature gaps

After a review of the literature, it is surprising that more research has not been done in understanding the barriers to exercise and PA for individuals with metastatic cancer. Cancer is the leading cause of death in Canada and therefore warrants more attention to aspects of care that contribute to enhanced QoL, especially for those coping with metastatic cancer. Based on the results of this literature review, the researcher has identified the following three gaps:

- 1. The need for interview-based, qualitative research to capture the patient experience**
- 2. The need for an enhanced understanding of the barriers to exercise and PA that exist for individuals with metastatic cancer**
- 3. An opportunity to utilize one of the major health behaviour theoretical frameworks in addressing this area of research**

According to the results of this literature review there have only been six studies (Cheville et al., 2012; Gulde et al., 2011; Mas et al., 2015; Rhudy et al., 2015; Sheill et al., 2017; Smaradottir et al., 2017) that have addressed the patient experience by using interview-based, qualitative methods to gain insight into the patient experience. Research has primarily relied on questionnaires such as the McGill Quality of Life Questionnaire, Late-Life Function and Disability Instrument, Edmonton Symptom Assessment System, Godin Leisure-Time Exercise Questionnaire, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire, or the Functional Assessment for Chronic Illness Therapy series, among others. While these questionnaires serve their purpose and reach a large number of patients within a short period time, they lack the ability to provide insight into the lived experience of the patient as symptoms and feelings vary on a day to day basis. Patient perceptions may differ from the results of their survey. For example, in the study by Chiarotto et al. (2017) the researchers reported no changes in QoL based on the Functional Assessment for Chronic Illness Therapy questionnaires, however the patients perceived an improved QoL solely because they were exercising among others in the same position as themselves. In an era where funding sources and health care systems value the patient experience, it is ever more important to create research that

amplifies the patient voice and takes the time to understand their experience. Understanding the patient experience is paramount in providing services that are important to these individuals.

Over the recent years, the research has focused on the potential benefits of exercise and PA for individuals with metastatic cancer. Being that the benefits of exercise and PA seem promising, clinicians and academics alike need to consider the best strategies to promote exercise and PA. The research regarding barriers is sparse and requires more investigation. The reasons for non-participation seem obvious, however additional patient insight may allow for better patient centered care outcomes and creative ideas in making exercise and PA accessible, such as home programming for example (Kartolo et al., 2016; Smaradottir et al., 2017).

Upon examining the literature related to barriers to exercise and PA for patients with metastatic cancer, irrespective of methodology, the researcher only found nine studies (Cheville et al., 2012; Gulde et al., 2011; Kartolo et al., 2016; Lowe et al., 2010; Mas et al., 2015; Oldervoll et al., 2005; Rhudy et al., 2015; Sheill et al., 2017; Smaradottir et al., 2017). All were relatively small sample sizes, and were not exclusively representative of patients with metastatic cancer. Of the nine studies, only six (as mentioned earlier) incorporated a qualitative, interview-based approach with participant numbers ranging from 5 to 29.

Lastly, according to the researcher's knowledge, only two studies have utilized one of the major health behavior theoretical frameworks in trying to understand the barriers to exercise and PA for individuals with metastatic cancer. Kartolo et al. (2016) incorporated the Theory of Planned Behaviour (TPB) in their study investigating motivation and preferences of exercise

programs in patients with inoperable metastatic lung cancer. Their study utilized a 67-item questionnaire based on the tenets of the TPB in trying to understand the barriers to exercise and PA for individuals with metastatic lung cancer. In addition, Sheill et al. (2017) utilized the Health Belief Model (HBM) in the development of their interview questionnaire and relied on content analysis in the coding of their data. Studies in this research area typically rely on thematic, exploratory or content analysis (Cheville et al., 2012; Gulde et al., 2011; Mas et al., 2015; Rhudy et al., 2015; Sheill et al., 2017; Smaradottir et al., 2017).

Theoretical Framework

Very little of the research within this field has pursued a theoretical framework in trying to understand the barriers to exercise and PA for individuals with metastatic cancer. For instance, the Health Belief Model (HBM; Rosenstock, 1974), the Theory of Planned Behavior (TPB; Ajzen, 1991) the Social Cognitive Theory (SCT; Bandura, 1977), the Transtheoretical Model of behaviour change (Prochaska & Diclemente, 1983) or the Health Action Process Approach (Schwarzer, 2008) try to explain why people do (not) engage in a health behaviours such as PA within healthy populations, however have seldom been used to understand the barriers to exercise and PA in metastatic cancer. For the purpose of this study the researcher considered five major health behaviour theoretical frameworks; 1. Health Belief Model, 2. Theory of Planned Behavior, 3. Social Cognitive Theory, 4. Transtheoretical Model of behaviour change and, 5. Health Action Process Approach. This section begins with a description of each theoretical framework and key considerations for the purposes of this research investigation (Table 2.1). Thereafter, the section moves into the justification for the use of the HBM as well as an analysis of the HBM.

Table 2.1 – Defining and considering the major health behaviour theoretical frameworks

Table 2.1	
Health Behaviour Theoretical Framework	Definitions and considerations
Health Belief Model (HBM)	<p>Definition “The HBM is premised on the notion that one’s <i>expectations/beliefs</i> and their determination of the inherent <i>value</i> of an action will either promote, or detract, from the performance of that action. The HBM assumes that individuals will (1) <i>value</i> avoiding illnesses/getting well and (2) <i>expect</i> that a specific health action may prevent (or ameliorate) illness. The expectancy is further delineated in terms of the individual’s estimates of personal susceptibility to and perceived severity of an illness, and of the likelihood of being able to reduce that threat through personal action.” (Champion & Skinner, 2008, p.46).</p> <p>General considerations (LaMorte, 2016A)</p> <ul style="list-style-type: none"> • The HBM considers that two primary factors drive health related behaviour change. They are: 1) the desire to avoid illness, or get well if already ill and 2) believing that a specific health action will prevent, cure, or ameliorate illness. • HBM is based upon six specific constructs that determine adoption of a specific health related behaviour: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. • In preventive health behaviours, early studies showed that perceived susceptibility, benefits, and barriers were consistently associated with the desired health outcome <p>Implications for this research</p> <ul style="list-style-type: none"> • Although the HBM has been used primarily within healthy populations, there is a provision within this framework that considers individuals with illness (as it has been used for individuals with hypertension, diabetes, end stage renal disease, and metastatic cancer). Its ability to adapt, and consider a healthy behaviour that can ameliorate the common symptoms experienced by individuals on chemotherapy enhance its relevance within this research. • The HBM considers the common barriers (to a high level of accuracy) that are experienced by individuals seeking behaviour change. Understanding perceived barriers are at the crux of this research investigation.

<p>Theory of Planned Behavior (TPB)</p>	<p>Definition “The theory of planned behavior posits that intentions to perform behaviors of different kinds can be predicted with high accuracy from attitudes toward the behavior, subjective norms, and perceived behavioral control; and these intentions, together with perceptions of behavioral control, account for considerable variance in actual behavior” (Ajzen, 1991 p. 179)</p> <p>General considerations (LaMorte, 2016B)</p> <ul style="list-style-type: none"> • The TPB has been used successfully to predict and explain a wide range of health behaviors and intentions including smoking, drinking, health services utilization, breastfeeding, and substance use. • The TPB states that behavioural achievement depends on both motivation (intention) and ability (behavioural control). • TPB assumes that behavior is the result of a linear decision-making process, and does not consider that it can change over time. <p>Implications for this research</p> <ul style="list-style-type: none"> • While the TPB is a widely used framework in healthy populations, it assumes that individuals have the physical ability to partake in behaviour change. • The TPB does not consider that patient symptoms may vary on a day to basis. • The TPB considers attitudes toward the behavior, subjective norms, and perceived behavioral control, all of which may contribute positively to the objectives of this research.
<p>Social Cognitive Theory (SCT)</p>	<p>Definition “Posits that learning occurs in a social context with a dynamic and reciprocal interaction of the person, environment, and behavior. The unique feature of the SCT is the emphasis on social influence and its emphasis on external and internal social reinforcement. SCT considers the unique way in which individuals acquire and maintain behavior, while also considering the social environment in which individuals perform the behavior. The theory takes into account a person's past experiences, which factor into whether behavioral action will occur. These past experiences influences reinforcements, expectations, and expectancies, all of which shape whether a person will engage in a specific behavior and the reasons why a person engages in that behavior” (LaMorte. 2016C)</p> <p>General considerations (LaMorte, 2016C)</p> <ul style="list-style-type: none"> • The goal of the SCT is to explain how people regulate their behavior through control and reinforcement to achieve goal-directed behavior that can be maintained over time. • The theory heavily focuses on processes of learning and in doing so disregards biological and hormonal predispositions that may influence behaviours, regardless of past experience and

	<p>expectations.</p> <ul style="list-style-type: none"> • The theory does not focus on emotion or motivation, other than through reference to past experience. There is minimal attention on these factors. <p>Implications for this research</p> <ul style="list-style-type: none"> • It is highly unlikely that the SCT will serve as a suitable framework for this research as it does not consider biological or hormonal predispositions that may influence behaviour. • Lack of focus on emotion and motivation may also hamper its utility.
<p>Transtheoretical Model of behaviour change (TTM)</p>	<p>Definition The Transtheoretical Model of behavior change (TTM) determines that change is an intentional process that unfolds over time and involves progression through a series of six defined stages: Pre-contemplation, contemplation, preparation, action, maintenance, termination (Prochaska, DiClemente & Norcross, 1992)</p> <p>General considerations (LaMorte, 2016D)</p> <ul style="list-style-type: none"> • Different intervention strategies are most effective at moving the person to the next stage of change and subsequently through the model to maintenance. • The theory ignores the social context in which change occurs, such as socioeconomic status, income or health status. • The TTM provides suggested strategies for public health interventions to address people at various stages of the decision-making process. <p>Implications for this research</p> <ul style="list-style-type: none"> • The TTM is a process that evolves over time to elicit behaviour change. Being that the prognosis is poor for patients living with metastatic cancer, it may be unreasonable to assert that these individuals have the necessary time to consider the six stages of behaviour change. • The TTM may not be suitable as the focus of this research is not to enable individuals to partake in exercise and PA, but rather to understand the common barriers that exist for these individuals with metastatic cancer.
<p>Health Action Process Approach (HAPA)</p>	<p>Definition “Suggests a distinction between 1. a preintentional motivation process that leads to a behavioral intention and 2. a postintentional volition process that facilitates the adoption and maintenance of health behaviors” (Schwarzer & Luszczynska, 2008. p. 141)</p> <p>Considerations (Schwarzer, 2016)</p> <ul style="list-style-type: none"> • Primarily based on two processes: goal setting and goal pursuit.

	<ul style="list-style-type: none"> • Risk perception, outcome expectancies, self-efficacy, intention, planning, and action control constitute the building blocks for the HAPA. <p>Implications for this research</p> <ul style="list-style-type: none"> • The HAPA can possibly be a viable framework for this research due to its emphasis on risk perception, outcome expectancies, self-efficacy, intention, planning, and action control. That being said, there is no explicit caveat that addresses the barriers to participation in exercise and PA.
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Rationale for the utilization of a theoretical framework

According to the researcher’s knowledge, only the HBM and TPB have been utilized in understanding this topic. It is important to note that the aim of this research was not to test the strength of any particular framework, but rather incorporate the framework as a guide and means by which to synthesize and analyze the results in a meaningful way. Through this analysis, the researcher considered several aspects of each theoretical framework in relation to this research investigation. Due to their inapplicability, the TTM and SCT were eliminated from consideration. Thereafter the researcher was left to consider the HBM, TPB or HAPA. All of these frameworks could have potentially been utilized within the context of this research due to their overall emphasis on intention, self-efficacy and behavioural control. However, the objective of this research was to determine the barriers that exist for individuals with metastatic cancer to engage in exercise and PA. The HBM was the only framework that considered ameliorating illness as a driver of health behaviour change, and was used in other illness related populations studies such as those with metastatic cancer, hypertension, diabetes and end stage renal disease. It also considered perceived barriers within its primary constructs. According to Carpenter (2010) and Janz and Becker (1984), the “perceived barriers” is a consistently reliable construct

of the HBM, and simultaneously is at the center of this research investigation. Therefore, the HBM was chosen as the theoretical framework for this research investigation.

The Health Belief Model

The HBM was initially developed in the 1950's by the United States Public Health Service to explain the widespread failure of individuals to participate in programs that prevent and detect disease (Rosenstock, 1974). Later, the model was used to study individuals' responses to physical symptoms (Kirscht, 1974) and their behaviours in response to a diagnosed illness and adherence to medical regimens (Becker, 1974). With its basis in psychological theory, the HBM has become a predominant, and one of the most notable of the theoretical frameworks that seek to understand health-related behavior.

The HBM is premised on the notion that one's *expectations/beliefs* and their determination of the inherent *value* of an action will either promote, or detract, from the performance of that action. The HBM assumes that individuals will “(1) *value* avoiding illnesses/getting well and (2) *expect* that a specific health action may prevent (or ameliorate) illness. The expectancy is further delineated in terms of the individual's estimates of personal susceptibility to and perceived severity of an illness, and of the likelihood of being able to reduce that threat through personal action.” (Champion & Skinner, 2008, p.46).

The HBM has six primary constructs that predict why individuals will take action to prevent, or control illness conditions. These include: *Perceived susceptibility*, *perceived severity*, *perceived benefits*, *perceived barriers*, *cues to action*, and most recently, *self-efficacy*. These constructs are further explained in Table 2.2. Initially, Hochbaum (1958) studied perceptions

about whether individuals believed they were susceptible to contracting tuberculosis along with their beliefs about the personal benefits of early detection. Of those who exhibited positive beliefs about their susceptibility to tuberculosis and expressed personal benefit in early detection, 82% had at least one voluntary chest x-ray for tuberculosis. In contrast, in those exhibiting neither of those beliefs, only 21% obtained voluntary chest x-rays for tuberculosis. If individuals regard themselves susceptible to a physical condition/illness with potentially serious consequences while believing that a course of action is available that would reduce their susceptibility or severity of a condition, and believe that the benefits of the action outweigh the barriers, they are more likely to engage in that health-related behavior (Champion & Skinner, 2008).

Table 2.2 – *Key concepts and definitions of the Health Belief Model* (Champion & Skinner, 2008, p. 48)

Table 2.2		
Concept	Definition	Application
Perceived Susceptibility	Belief about the chances of experiencing a risk or getting a condition or disease	Define population(s) at risk, risk levels Personalize risk based on a person's characteristics or behaviour Make perceived susceptibility more consistent with individual's actual risk
Perceived Severity	Belief about how serious a condition and its sequelae are	Specify consequences and risk of conditions
Perceived Benefits	Belief in efficacy of the advised action to reduce risk or seriousness of impact	Define action to take: how, where, when; clarify the positive effects to be expected

Perceived Barriers	Belief about the tangible and psychological costs of the advised action	Identify and reduce perceived barriers through reassurance, correction of misinformation, incentives, assistance
Cues to action	Strategies to activate “readiness”	Provide how-to information, promote awareness, use appropriate reminder systems
Self-efficacy	Confidence in one’s ability to take action	Provide training and guidance in performing recommended action Use progressive goal setting Demonstrate desired behaviors

Limitations of the HBM

The HBM is one of the most widely used theoretical models that seek to promote, predict and understand health behavior change across populations. Systematic reviews indicate that the HBM is effective in predicting a wide range of health related behaviours, most notably as it relates to benefits and barriers (Carpenter, 2010). According the Barley and Lawson (2016), interventions informed by the HBM can increase adherence to a wide range of health related behaviours such as taking medications, adhering to diets and other lifestyle changes. This being said, there are some considerations that one must have when using the HBM to understand perceptions towards health behavior.

Modifying factors

Champion and Skinner (2008) highlight the modifying factors that influence the six primary constructs of the HBM. The modifying factors include: *age, gender, ethnicity,*

personality, socioeconomics and knowledge. It is important to understand that the modifying factors may influence an individuals' response to any of the primary constructs of the HBM, and may unwittingly create a bias or perpetuate a false perception of the issue at hand. Modifying factors become increasingly important in the delivery of public health initiatives/research and require an understanding of its applicability to one demographic over another.

HBM Constructs

Within the HBM itself, there remains debate as to which constructs are more predictive of health behavior change than others. For example, if individuals score high on perceived severity versus perceived benefits, are they still likely to engage in the health behavior change? Or if they score favourably on four of the six constructs, will they engage in a health behavior change? This was most notably analyzed in two separate review papers. Janz and Becker (1984) critically analyzed 46 HBM-related investigations since its inception. Twenty-four studies examined preventative health behaviours, nineteen explored sick role behaviours, and three addressed HBM use in clinics. Their findings support the empirical use of the HBM, with findings supporting its use in retrospective and prospective research. They found that "*perceived barriers*" was the strongest construct of the HBM. They also found support for "*perceived susceptibility*", "*perceived severity*" and "*perceived benefits*" in their analysis of the HBM and recommended its use for further research.

Carpenter (2010) performed a meta-analysis of 18 studies (2,702 subjects) to determine if the HBM could predict whether measures of the HBM could longitudinally predict behavior. It was found that "*perceived benefits*" and "*perceived barriers*" were consistently the strongest

predictors of behavior change. Carpenter (2010) concluded that this meta-analysis requires further research due to the small number of studies and the need to test some more complex versions of the HBM that may offer greater predictive power. The researcher also recommends that the model should abandon its traditional construct and focus on the mediation and moderation of the current construct.

It is clear that some of the constructs of the HBM have greater predictive power than others, and that the interpretation of the HBM cannot be performed in a silo, and is better understood along with the modifying factors.

Disease specific

According to the researchers' knowledge, there has been only one other research study that has utilized the HBM to explore the barriers to exercise and PA for individuals with metastatic cancer (Sheill et al., 2017). The HBM has explored other disease states such as hypertension, diabetes and end stage renal disease which lends itself to the possibility of being used in understanding cancer populations.

Conclusion

This review considered the day to day lived experience of individuals with metastatic cancer and shed light on the significant symptom burden. It then attempted to understand the viability of using exercise to either help combat cancer or aid in ameliorating the symptoms associated with cancer and cancer treatment, most notably chemotherapy. Thereafter, this review examined the potential benefits of exercise and PA along with the accompanying barriers, literature gaps, and an exploration of a theoretical framework. This review concluded with a

description and analysis of the HBM and its significance within the context of this research investigation. It is clear that exercise and PA have the potential to become a supportive care measure and it is necessary to further investigate this topic. Being that there are relatively few research studies (compared to exercise for cancer survivors) within this discipline, there is room for all researchers to contribute to this growing field.

Within Ontario, Canada, the value of understanding the patient experience is fundamental to the health care system and has become a primary outcome in service delivery throughout all health care bodies funded by the Ministry of Health and Long Term Care (MOHLTC) and the Local Health Integration Network (LHIN). The patient experience shapes the care received and there is a continued need to incorporate the patient voice in decisions related to patient care.

Chapter 3: Methodology

Introduction

This study examined the barriers to exercise and PA for individuals with metastatic cancer. It took place in the oncology department of the Scarborough and Rouge Hospital (SRH) - Centenary site, located in Scarborough, Ontario, Canada. Semi-structured interviews were used to identify the perceived barriers to exercise and PA. Semi-structured interviews let for the natural flow of ideas and allow the participant to expand on areas which they feel are important to understand their experience (Britten, 1995). As Chapter 2 discussed, the HBM was used to understand perceptions of the existing barriers to exercise and PA rather than predict or promote behaviour change. The participant responses were initially organized according to the constructs of the HBM and thematically analyzed thereafter. This chapter is organized according to the following:

- Ethical considerations & research approval
- Recruitment strategy
- Research considerations
- Data collection
- Consent and confidentiality
- Interview process
- Data analysis
- Achieving trustworthiness

Ethical considerations & research approval

Research ethics approval was granted from the University of Ontario Institute of Technology (UOIT) on November 22, 2016 (File #14092) (Appendix A) and from SRH on November 1, 2017 (File CAR-16-006) (Appendix B).

Recruitment strategy

Participants were recruited from the Oncology program at SRH - Centenary site. The Centenary site oncology program sees approximately 20 to 25 patients living with metastatic cancer per year. This study was conducted over a three-month time period (February 2018 to April 2018). The selection criteria was based upon purposive sampling to reflect similar features and characteristics within the participant group (Bowling & Ebrahim, 2005) as all participants had metastatic cancer and were undergoing chemotherapy treatment. Eligibility criteria included: 1. diagnosis of metastatic cancer (non-site specific), 2. ability to participate in the interview as determined by the physician, 3. being 18 years of age or older, and 4. the ability to understand and speak English, and to provide written informed consent. There were no formal exclusion criteria. Participants were invited to speak with the researcher regarding this voluntary investigation during one of their regularly scheduled medical appointments as the Oncologist had a pre-determined script (Appendix C). If the individual consented to the Oncologist their name was forwarded to the researcher. The researcher then contacted the individual to explain the purpose of the research study and offer reassurance that non-participation would not affect their usual medical care (Appendix D). If the individual consented to participate in the study, an interview time would be scheduled during one of their regular oncology appointments to ensure ease of access for the participant. Interviews were conducted in a private patient room in the

oncology clinic. Eight candidates were referred to this study, and all eight completed an interview with the researcher. The intention of the researcher was to terminate recruitment once data saturation was achieved. Data saturation is defined as “the point at which no new information or themes are observed in the data” (Guest, Bunce & Johnson, 2006, p.59). That being said, the researcher was compelled to terminate recruitment after the eighth interview primarily because all eligible patients had participated in the study.

Research considerations

Reflexivity

As a qualitative study, additional care should be taken to diminish the extent to which the researcher’s expectations might unintentionally influence the interview and data analysis processes. First, as an Exercise Physiologist the researcher had to consider his predilections toward exercise/PA and take steps to mitigate these biases. For instance, throughout the interview process the researcher did not discuss the benefits of exercise and PA for individuals with cancer and not express their role in exercise programming for individuals with cancer. Furthermore, none of the participants were under the personal care or supervision of the researcher. Second, the researcher is a health care professional within SRH and had to ensure that their role within the organization did not influence the interview process in any way. This is a process called reflexivity. Reflexivity is considered “the critical gaze turned towards the self, thus examining the personal position, identity, and self of the researcher as an ongoing process” (Hand, 2003, p.18). Whiting (2008) states that the three components of reflexivity are: “1. demonstrating an awareness of how biases may emerge, 2. thoughtfulness about, and attempts to minimize the impact of the researcher on data collected, and 3. attempts to address bias through

systematic and comprehensive analysis, and reflectiveness on the research methods, the decisions made, and the consequent limitations of the study” (Whiting, 2008, p.36).

The researcher also had to ensure an equitable recruitment process by which all potential candidates were offered an opportunity to participate in the study, and not only individuals who may have been perceived as an ideal candidate based upon their views of exercise and PA. This was discussed with the Oncologist prior to commencing the research study. Lastly, in order to ensure that an equitable and trustworthy relationship was established between the researcher and participants, the researcher avoided the use of medical terminology and relied on language that participants were familiar with and understood.

Credibility

Research credibility is important as it is one of the most significant factors in achieving quality research, and that the correct adaptation of research methods to a particular subject will enhance credibility (Shenton, 2004). The researcher felt that a qualitative, interview-based approach would capture the essence of the research question in a meaningful way. This not only allowed for the natural flow of ideas, but also captured the individual phenomena of participants. Capturing this phenomenon will enhance the understanding of the clinical and academic communities, of which this research is intended for.

Data collection

All interviews were scheduled according to the participant availability and took place during one of their regularly scheduled appointments. This was done to decrease travel times and

increase convenience for participants. All of the interviews took place in a private room in the oncology department at SRH – Centenary site. The private room ensured full disclosure as well as comfort in responding to the interview questions.

Consent and confidentiality

All study participants provided informed consent by reading or being read the Consent form (Appendix E), initialing each page, printing their name, signing and dating the document. The researcher answered all questions related to the consent form and interview at this time. The researcher explained that participation was completely voluntary and that they can choose to withdraw from the study at any time and refuse to answer any question they see fit without negative consequences, all without providing a reason. The participants were made aware that the interview would be audio-recorded. The audio-recording device was small and discreet in an effort to make the participant feel comfortable throughout the interview. Confidentiality was upheld by not identifying participants by their actual name during the data collection phase of the research, securing the data once obtained, and destroying all audio-recordings as of August 1, 2018.

Once consent was obtained, the participants were asked to complete a socio-demographic questionnaire (Appendix F) that sought demographic information such as: gender, age, education, employment, income, marital status, and date of diagnosis. Upon completion of the socio-demographic questionnaire, the researcher sought formal permission to turn on the recording device and commence the interview.

Interview process

The researcher did not reference the participant's name during the interview and the initials of their name were used during transcription and coding. In an effort to ensure inclusivity, participant spouses or family members were also allowed in the room while the interview was being conducted, however were asked not to participate nor influence the interview in any way. They were assured that their questions could be answered once the interview had concluded. That being said, the mere presence of a family member could have an unintended consequence and inadvertently influence the participant answers. However, being in a patient and family centered care facility, the researcher felt appropriate to allow family members to be present during the interview. Once the interview formally began, participants were asked questions from the interview guide document (Appendix G). There were 23 possible questions that were adapted from the constructs of the HBM. Typically, only six to eight questions (of the 23) were asked during each interview as majority of the responses addressed nearly all 23 questions. All participants completed the full interview and no one requested for their information to be retracted from the study. The average duration of each interview was approximately 10 to 15 minutes. Once completed, the researcher verbally thanked each participant for their involvement in the research. The recordings were uploaded onto a password protected computer and deleted immediately off of the recording device after file transfer to computer. All recordings were permanently deleted from the password protected computer as of August 1st, 2018 following transcription.

Data analysis

Transcription

All interviews and transcriptions were performed by the researcher. The advantages of transcribing and performing all interviews is that it builds theoretical sensitivity which is “The ability to generate concepts from data and to relate them according to normal models of theory in general, and theory development in sociology in particular, is the essence of theoretical sensitivity. Generating a theory from data means that most hypotheses and concepts not only come from the data, but are systematically worked out in relation to the data during the course of the research.” (Glaser & Holton, 2004. p. 11). Transcribing also brings the researcher closer to the data and provides an opportunity to critique and improve the research process (Hesse-Biber, 2010). The researcher conducted and transcribed all interviews in an effort to familiarize themselves with the data and ensure accuracy (Bowling & Ebrahim, 2005), and all interviews were replayed twice for quality assurance purposes.

Analytical process

Once interviews were transcribed they underwent template analysis (Brooks, McCluskey, Turley, & King, 2015) according to the six constructs of the HBM. Template analysis is “a form of thematic analysis which emphasizes the use of hierarchical coding but balances a relatively high degree of structure in the process of analyzing textual data with the flexibility to adapt it to the needs of a particular study. Central to the technique is the development of a coding template, usually on the basis of a subset of data, which is then applied to further data, revised and refined.” (Brooks et al., 2015. p. 203). Within template analysis it is permissible to utilize an existing theoretical framework to establish common themes, and code the data as it relates to

those predetermined themes (Brooks et al., 2015). This will be discussed in greater detail in the results section of this research paper.

Achieving trustworthiness

In an effort to ensure validity and reliability in qualitative research Lincoln and Guba (1985) developed criteria of trustworthiness. These criteria are important in establishing research legitimacy that can be understood and appreciated by researchers, practitioners, policy makers and the general public (Nowell, Norris, White, & Moules, 2017). The trustworthiness criteria, according to Lincoln and Guba (1985) include: *credibility, transferability, dependability and confirmability*. Below describes each criteria as they were all considered by the researcher throughout this investigation.

Credibility (as it relates to achieving trustworthiness) refers to how well the researcher is able to represent the views of the participants (Tobin & Begley, 2004). This requires “prolonged engagement, persistent observation, data collection triangulation, and researcher triangulation.” (Nowell et al., 2017. p. 3). The researcher was mindful of achieving credibility as per his experience with cancer patients, and spending time in the oncology department. The researcher also became familiar with the qualitative and quantitative research related to this research topic through the literature review process. Research supervisors were also sources of guidance throughout the data collection process.

Transferability in qualitative research refers to the generalizability of the research investigation on a case by case basis (Tobin & Begley, 2004). Providing thick descriptions of the inquiry are necessary as this can enhance the breadth by which the research findings can be

utilized and applied (Lincoln & Guba, 1985). The intention of this research is to enhance the overall of understanding of the common barriers to exercise and PA for clinicians and academics working with this patient population, and has the ability to be operationalized on a day to day basis. Transferability proved to be a limitation of this study and will be discussed further in the Chapter 5.

Dependability refers to the research process and ensures that the investigation is “logical, traceable, and clearly documented” (Nowell et al., 2017. p. 3). Readers can judge the dependability of the research by examining the research process (Lincoln & Guba, 1985). The researcher attempted to take reasonable measures (primarily through the guidance of research supervisors) to confirm dependable results through the research process, patient selection, interview process, participant confidentiality, maintaining participant autonomy as well as establishing a directed research question.

Confirmability is concerned with establishing that “the researcher’s interpretations and findings are clearly derived from the data, requiring the researcher to demonstrate how conclusions and interpretations have been reached” (Nowell et al., 2017. p. 3). Confirmability can be established if credibility, transferability and dependability have been achieved (Guba & Lincoln, 1989). It is important for the researcher to clarify the reasons for theoretical, methodological, and analytic choices throughout the research study (Koch, 1994). The researcher aims for confirmable results as the aforementioned tenets of trustworthiness were considered throughout the research process.

Chapter 4: Results

Introduction

This chapter summarizes the participant interviews. It begins with an overview of the sociodemographic characteristics of the participant group. The chapter then moves into understanding the analytical process and concludes with a thematic description of the twelve key subthemes derived from the participant interviews.

Socio-demographic characteristics of participants

A total of eight individuals participated in this research study. Socio-demographic information was collected through a questionnaire based approach prior to commencing each interview. The sociodemographic makeup of the participant group was primarily female, Caucasian, and socioeconomically diverse. A legend is provided in Appendix H that summarizes the age and gender. Detailed descriptions of the study sample can be found below in table 4.1.

Table 4.1	
Participant socio-demographic characteristics	
Gender	6 females 2 males
Age range	27-83
Race/ethnicity	5 Caucasian 2 South Asian (or South Asian descent) 1 Afro-Canadian (or Afro-Caribbean)
Marital Status	6 married 1 separated 1 never married
Employment status	5 retired 3 not employed

Annual household income	1 \$100,000 to \$150,000 1 \$75,000 to \$99,999 2 \$50,000 to \$74,999 2 \$40,000 to \$49,999 1 \$30,000 to \$39,999 1 \$20,000 to \$29,999
Level of Education	1 completed some university 1 completed college 2 completed some college 3 completed high school 1 completed trade/technical/vocational training

Analytical process

As mentioned in Chapter 3, once interviews were transcribed they underwent template analysis which is a form of thematic analysis that utilizes a coding template, or a pre-existing framework (such as the HBM) to interpret the data (Brooks et al., 2015). Once all interviews were organized according to the categories of the HBM, they were sub-categorized, analyzed, and thematically organized into common subthemes that emerged from the participant interviews. As per the participant responses, three of the six constructs emerged from the data set; *perceived barriers*, *perceived benefits*, and *cues to action*. Early into the interview process the researcher noticed common subthemes that primarily related to perceived barriers, perceived benefits, and cues to action. There were limited responses related to perceived susceptibility, perceived severity, and self-efficacy, and these constructs were therefore not elaborated into a formal theme.

After the initial analysis occurred, the researcher identified a total of 12 subthemes; 6 perceived barriers, 3 perceived benefits and 3 cues to action. The researcher was cognizant to remain neutral in the research process as the objective of this research was to gain insight into the perceived barriers for these individuals and bring forward the participant voice.

Summary of key subthemes related to HBM constructs

This section will focus on the key constructs and subthemes derived from the participant interviews according to three constructs of the HBM (perceived barriers, perceived benefits and cues to action). See Table 4.2 for a summary with quotes. This section then delves into a detailed description of the identified constructs and subthemes.

HBM Construct	Emerging Subthemes	Illustrative quotes
Perceived Barriers	Treatment related side effects	“I was engaged in PA until each consecutive chemo made me so tired that I didn’t do much apart from walking up and down the stairs several times a day and around the house and with occasional bending a stretching”
	Risk of infection in public spaces	“We were thinking of going up to the mall and walking at the mall first thing in the morning. But then, I don’t want to catch anything. The flu is rampant this year and I really don't want to get sick, I can't afford to get sick”
	Co-Morbidities/Limiting conditions	“I know the benefits (of exercise), especially because of my heart (history of two stents). That is a big motivator too. Now that I am dealing with the cancer I don’t want something to happen that I will have to have something done to my heart. So I look at it as, this is not only good for the cancer, but it is good for the heart”
	Fear of Falling	“I went downhill. passed out several times backwards. I was just standing there and all of a sudden I went flat down so it used to make me nervous about going out because there was no warning sign. It just happened”
	Weather as a deterrent	“I wish that the weather could have been a little milder to get some fresh air because I know being in the house is stifling. When I’m deep in my chemo I don’t feel like doing anything. The fact that I am shut in is very, very hard”

	Age as a barrier	“If I was a little younger then maybe I would have had more incentive. Nowadays I keep thinking I’ve had a great life. I’m now entitled to stay on my rocking chair”
Perceived Benefits	Beliefs about exercise	“I think exercise can help because you need stimulation and I think that’s part of the battle with the treatments is to have something else to put your mind and your thoughts rather than concentrating on the downside. I think it’s great if you can stay up, and exercise will help you stay up”
	Exercise as a coping strategy	“And I feel that the more that I do walk hopefully the shortness of breath will ease off and may improve”
	Belief in the value of exercise, and participating according to how one is feeling	“You know I’ve had 83 treatments now so I am used to the cycles and I know what to expect and I don’t plan on chemo weeks”
Cues to Action	Physical environment	“Some days I’ll walk on the Ajax Waterfront and is perfect for it (walking) because there are all sorts of benches. You can walk along and stop and rest, and go along and just enjoy”
	Family and friends	“my husband’s been very good about bugging me for trying to go out and go for a little walk everyday but I can’t walk long distances because I do get short of breath”
	Physician encouragement	“When I was diagnosed I lost about 20 lbs. and I was really weak so I started to walk as the Doctor (unnamed) had encouraged me to go out and walk”

Perceived Barriers

“The diagnosis of cancer really bothered me. Because when you hear that it is metastatic, that means you are always going to have it. It’s in your body. That was really emotionally disturbing. So I didn’t focus on exercise a lot” - DH

This section identifies the common barriers to exercise and PA among participants which include:

1. Treatment related side effects

2. Risk of infection in public spaces
3. Co-Morbidities/Limiting conditions
4. Fear of falling
5. Weather as a deterrent
6. Age as a barrier

Treatment related side effects

Chemotherapy treatment is one of the predominant barriers to exercise and PA for individuals with metastatic cancer. The chemotherapy treatments can be very taxing on the body and limit one's ability. The general symptoms are inclusive of fatigue and general tiredness. Especially in light of surgery, the cancer experience can be very tiresome. NM had brain surgery to remove a tumour with subsequent radiation and chemotherapy. She describes the following:

I think it's a combination of everything. Because after my brain surgery I wasn't eating. Like everything I eat I'll bring back up so I was weak. Because I had to go to the emergency one time to get IV to get my energy back. After the brain surgery I wasn't eating at all. Everything I eat I'll bring back up. The only thing that will settle is soup and sometimes I still bring up back the broth. So with not eating you're gonna get weak too right.

When asked about how she currently feels, NM says, "Right now I'm tired. So I guess just tired". NM began discussing her ability to participate in exercise and PA and goes onto say, "I just physically can't right now. I get tired too easily. I tried doing it. Yesterday was so nice and I tried going for a walk, and I walked from my house to four houses and I had to come back because I was tired already...My legs started to feel weak".

AR was previously an active person however now says, “I was engaged in PA until each consecutive chemo made me so tired that I didn’t do much apart from walking up and down the stairs several times a day and around the house and the occasional bending a stretching”. When AR was asked how long it would take for her to become physically active after a session of chemotherapy, she responded by saying, “it would take me at least 4 days to come out of this so maybe by the middle of next week”. When SA was asked if she’d be more active if she wasn’t on chemotherapy, she responded by saying “I’d be more active yes. I know the girls were coming over when I first started chemo and wanted me to come out to walk, but I wasn’t up to it”. This generalized tiredness or lack of energy is a common feeling. JB had moved to a rural community between Fenelon Falls and Bobcaygeon, Ontario and had hoped to enjoy life outside of the city. He described his experience after starting chemotherapy as the following: “The problem is that as soon as we moved out there I started getting sick. So the energy level dropped and we are right on the water. We had a boat and we never really used the boat because I was too tired. You know. No desire to do anything”.

The extent of side effects may also depend on how long one has been on chemotherapy treatment as is with the case of PC who mentioned, “I’ve only finished the second cycle. This drug is two weeks on and one week off so I’ll be starting the third cycle this coming Saturday but so far I have not had any unpleasant side effects. There’s been no nausea, no diarrhea, none of the blistering they said to watch out for, the string on the hands and feet. The Doctor (unnamed) said that may start with a third cycle. Sometimes the symptoms take a couple of cycles to kick in but we’ll see. But so far so good”.

Risk of infection in public spaces

One of the primary side effects of chemotherapy is compromised immunity due to the decreased production of white blood cells in the bone marrow. This is a real consideration for individuals who are on chemotherapy as contracting an infection may lead to unnecessary hospitalizations and illness that can further diminish their physical condition. CP and SA had a similar experience. When CP was asked about walking at a local community track she said, “I stay away from there mainly because I don’t want to catch anything. I don’t want to get the flu, I don’t want to get any colds. I haven’t had a cold in a couple of years. Not during this whole session did I have a cold. So I take care of myself”. This was clearly a priority for CP as she went onto say, “We were thinking of going up to the mall and walking at the mall first thing in the morning. But then, I don’t want to catch anything. The flu is rampant this year and I really don’t want to get sick, I can’t afford to get sick”. SA did not enjoy many forms of exercise and PA however she really enjoyed swimming. Once she was diagnosed with cancer and was on chemotherapy treatment she mentioned that she was going to go swimming and experienced the following: “The only thing I really liked was swimming. I’m not a great swimmer but I like being in the water. But when chemo came along they (the Doctor) said to stay away from it because of the risk of contamination.”

Co-Morbidities/Limiting conditions

Although exercise and PA are generally understood to be beneficial for individuals with cancer, some individuals also have other conditions such as surgeries, acute/chronic illnesses or musculoskeletal conditions that limit their ability to participate. Their conditions may, or may not be associated with their cancer.

NM describes the experience since her brain surgery by saying, “Since the brain surgery in December and starting chemotherapy in February, that kind of slowed me down. Before the brain surgery in December I was just on medication right. So I would take my pills every day and go about my everyday life. But now I have to restart everything...From the recovery to the brain surgery and they finding a spot on my liver, like I think there wasn’t enough time for my body to recover from the surgery to start chemotherapy, so I guess that’s why I’m so tired”.

JB contracted pneumonia since commencing chemotherapy and explains the following: “It’s been complicated since my pneumonia. I’ve had two bouts of pneumonia since my last chemo session. So after the first session in January, I was starting to gain weight and eat again and started to feel good about everything and then after the second one I got pneumonia twice and ended up going to the emergency in Lindsay and getting treated. Whatever progress I had made from the first one I had lost”. PC had experienced a cancer that had metastasized to her lungs and felt that her shortness of breath was due to the cancer itself. Regarding shortness of breath, PC says, “Some days I get short of breath or sometimes I find I have a little episode in the morning when I get up and I get really short of breath and that’s sort of the main issue that I have at the moment other than the fact that I have cancer. You know so I’ll be puttering in the kitchen and I feel that I really have to sit down because I’m really short of breath. But then it goes away and doesn’t last very long”. Some individuals also suffer from muscle degradation as a result of the chemotherapy. JB says the following, “Well I don’t have too much muscle anymore and the joints are a little tight...since the diagnosis”.

Some individuals also suffer chronic conditions alongside cancer. Regarding exercise limitations, DH says that, “I have a touch of vertigo. I had a fall in my basement. So I try not to go on the treadmill”. DH also has to stay physically fit as she has a heart condition. She attended cardiac rehab a few years back and doesn’t want to risk another cardiac event, and wants her heart to remain strong throughout her cancer journey. DH goes onto say, “I know the benefits (of exercise), especially because of my heart (history of two stents). That is a big motivator too. Now that I am dealing with the cancer I don’t want something to happen that I will have to have something done to my heart. So I look at it as, this is not only good for the cancer, but it is good for the heart”.

Fear of falling

Some of the participants felt that the fear of falling inhibited them from participating in exercise and PA. Falling is one of the major reasons for re-hospitalization and can lead to poorer health outcomes. This is especially important for individuals with cancer as an unnecessary hospitalization can impair their chemotherapy regimen and overall prognosis. Some of the reasons for the fear were cancer related and non-cancer related. SA relayed a story of her experiencing a fall since commencing chemotherapy. She says, “I went downhill. Passed out several times backwards. I was just standing there and all of a sudden I went flat down so it used to make me nervous about going out because there was no warning sign. It just happened...It hurt. I was nervous to drive, so I drove very little. Like you know, I would go to my local grocery store and back again. I wasn’t interested in tripping around. No malls, I didn’t want anything to do with that”. Outside of the interview, SA alluded to the fact that her falling was attributed to her chemotherapy. She mentioned that the chemotherapy played a “trick” on her brain that increased the risk of falling. Co-morbidities also play a role in the fear of falling. DH

describes this risk in relation to her diagnosis, “Because of the vertigo, I don’t want to risk going outside alone. If I get a walking companion, then maybe I will”.

AR was deterred by the fear of falling outdoors as she describes the following: “this winter has been tough for me. The coldest in about 40 years because we haven’t experienced. So I feel disinclined to come out. And put as a reason for that, that I don’t want to slip, and I don’t want to fall. I don’t want to take any chances on the ice. The children are always telling us. They are always telling us don’t risk anything, don’t go in crowds, don’t go out too much. Let us know if you need anything”. JB felt similarly and said, “We keep saying (JB and his spouse) that when we get a half decent weather day we will get out and walk. But right now in the winter is not really a good time for walking. You know. It’s very slippery, the roads are not maintained all that well”. CP actually had a fall experience and does not want to risk another fall. She goes onto say, “I’m really tired. I went out one day and tried to mail a letter and I fell on the road so I am weary of going out and walking this time of year, especially this bad year. This bad winter we’ve had. So I’ve had no exercise”. The fear of falling is a reality for all individuals living with illness and is a barrier to participation.

Weather as a deterrent

To complement the previous section, weather (specifically temperature) played a role in ones’ desirability and willingness to participate in exercise and PA. The participants felt that exercise and PA were good for them, however the weather was a significant deterrent. AR says the following: “I wish that the weather could have been a little milder to get some fresh air because I know being in the house is stifling. When I’m deep in my chemo I don’t feel like doing

anything. The fact that I am shut in is very, very hard”. CP says, “If it was nice outside I would walk. I feel that exercise is needed you know, so you still have the strength to do things”. PC also goes onto say, “well it's exercise, and any kind of exercise is good for you. And yeah during the winter, living out in the country we don't get a great deal”.

Age as a barrier

The intersection of age and illness also comes into play. Some individuals feel that it is not only the cancer experience that is preventing them from exercising, however age may also be a factor in their ability and willingness to participate in exercise and PA. PC says that, “some of the other meds had bizarre side effects. One of the medications made my nails get very soft and would split and one of the medications made my knees ache and my knees get stiff. Now that's possibly age related as well”. Beyond the physical limitations associated with aging, motivation also seems to wane amongst some of the participants as they got older. SA says, “I also have low, low drive. Of course, and I'm not getting any younger either... You don't seem to be able to motivate yourself the same”. AR also describes something similar by saying, “I think I was concerned with my age or something, and maybe laziness. I love sitting and watching television and I love reading and playing bridge. Show me a pack of cards and I am there”. She goes onto say, “If I was a little younger then maybe I would have had more incentive. Nowadays I keep thinking I've had a great life. I'm now entitled to stay on my rocking chair”.

Perceived Benefits

“After I started the chemo it was taking over me and I wouldn’t have any energy to do anything. You can become a couch potato and sit down and feel sorry for yourself and I was feeling blah. I then told my son that I have to start exercising and he said that you will feel a lot better” – DH

“I think exercise can help because you need stimulation and I think that’s part of the battle with the treatments is to have something else to put your mind and your thoughts to rather than concentrating on the downside” - SA

This section identifies the perceived benefits of exercise and PA amongst participants which include:

1. Beliefs about exercise
2. Exercise as a coping strategy
3. Belief in the value of exercise, and willingness to participate according to how one is feeling

Beliefs about exercise

All of the participants innately felt that exercise was beneficial and had a positive opinion of the value of exercise. SA says, “I think exercise can help because you need stimulation and I think that’s part of the battle with the treatments is to have something else to put your mind and your thoughts to rather than concentrating on the downside. I think it’s great if you can stay up, and exercise will help you stay up”. CP felt the same way by saying, “If the weather was nice outside I would go for a walk. I feel that exercise is needed so that you have strength to do things”.

Exercise as a coping strategy

Some of the participants also viewed exercise as a coping mechanism by which they would feel better if they engaged in exercise and PA. DH says, “The chemo is really tiring and

that's when I found that exercise was going to help. As I got back into exercise I found that I had more energy and that I was sleeping better at night...It was like a light bulb went off, because I had no energy, I should be exercising to get some energy...some days you have to push yourself. If you don't push yourself, you won't do it". PC felt that more exercise may improve her shortness of breath by saying, "And I feel that the more that I do walk hopefully the shortness of breath will ease off and may improve".

Although DH and PC felt that exercise had physical benefit, JF also felt that exercise also helped him psychologically cope with his cancer diagnosis as he mentions, "Well I know it's good for me and beyond the physical there's the time I'm spending by myself and to be alone with my thoughts and just get lost in them without walking into too many people". When asked why he started exercising he says, "Part of it just became, like a, like I said it was more than just the walking. It was a time for me to be by myself, you know, figure out how to manage this in the best way I could. And just enjoying being out in the fresh air, going outside and you never know what you are going to see. So I just kind of enjoyed that part of it.

Belief in the value of exercise, and willingness to participate according to how one is feeling

Some participants were currently active as they believed in the inherent benefits of exercise and PA. They seemed to understand how their bodies felt in relationship to the chemotherapy treatments. There also seems to be a cyclical nature to how one feels that determines their physical ability to participate in exercise and PA. DH explains, "The first few weeks you don't really feel fatigued. It's very cyclical. Like tonight I will want to sleep. Tomorrow I am okay. As I get into Friday I will start to feel tired. I will try to exercise on

Thursday and Friday. Then Saturday and Sunday I will have low energy and not be able to exercise until Monday. Then Tuesday I am feeling good and then Wednesday I am back here". When asked about what she does for exercise, DH says "I do a warm up and then I walk around my basement rather than walking outside...I do that anywhere between 25 and 35 minutes". JF also describes something similar: "You know I've had 83 treatments now so I am used to the cycles and I know what to expect and I don't plan on chemo weeks. I try to plan on lower commitment weeks and I'm not going to commit to doing a lot of stuff that week" and "Typically I'll walk alone. I prefer that. I don't know why. My wife will come with me sometimes which is always great". NM was also very conscious about understanding her limitations and listening to her body. She says, "I just listen to my body because I know my body. So whenever I want to go outside I go outside, whenever I want to take a nap, I take a nap".

For these individuals, exercise was perceived as important and beneficial. However, in order to participate, they had to consider how they were feeling in relation to their cancer and cancer treatments. Their perceived benefit was manifested in their willingness to participate in spite of their cancer treatments.

Cues to Action

"When I was diagnosed I lost about 20 lbs. and I was really weak so I started to walk as the Doctor (unnamed) had encouraged me to go out and walk" - CP

This section identifies the cues to action among participants which include:

1. Physical environment
2. Family and friends
3. Physician encouragement

Physical environment

JF describes his motivations of walking, and how his walking route enables him to perform activity according to his own pace. He describes the following: “Some days I’ll walk on the Ajax Waterfront and is perfect for it (walking) because there are all sorts of benches. You can walk along and stop and rest and go along and just enjoy... The lake draws you. There’s a draw to the lake. And it’s not only the lake. Where I live, I live right beside a park and I have an easement across the end of my driveway for access to the park. But from the park to the lake, because of how they laid out Ajax, you only have to cross lake driveway and I’m at the lakefront park. But if you cross over into Pickering, into the Duffins Marsh area you know, there’s swans, there’s goose, there’s duck, there’s deer, there’s all kinds of stuff out there. You never know what you are going to see”.

Family and friends

SA used to walk with a group of friends prior to starting chemotherapy treatment, however when treatment began she didn’t feel to walk with them anymore. She says, “I know the girls were coming over when I first started chemo and wanted me to come out to walk, but I wasn’t up to it”. This could have been a cue to action however SA was not well enough to join her friends. Conversely, PC was encouraged by her to spouse to walk. She says the following: “my husband's been very good about bugging me for trying to go out and go for a little walk everyday but I can't walk long distances because I do get short of breath... Now he doesn't nag. He asks “do you want to go for a walk?”, “no, but yes, let's go”.

Physician encouragement

Physicians also play an encouraging role in participating in exercise and PA. CP says, “When I was diagnosed I lost about 20 lbs. and I was really weak so I started to walk as the Doctor (unnamed) had encouraged me to go out and walk. This was the end of September to early October. I could only make it to the end of the street which was only six houses and then I had to come back again. And then I went a little further and back again. Eventually I was going around the block circle for about six blocks. We went every day until winter arrived”. CP had made significant physical improvements and felt a lot better due to the encouragement of her physician.

Chapter 5: Discussion and Conclusion

This study investigated the barriers to exercise and physical activity (PA) faced by individuals with metastatic cancer who were undergoing chemotherapy. Semi-structured interviews helped uncover several barriers. In examining the barriers to exercise and PA, the researcher used the health belief model (HBM) to structure the investigation. This is among the first studies to employ the HBM in this capacity within this patient population (along with Sheill et al., 2017). Through the use of the HBM the researcher discovered that there were several barriers to exercise and PA. Beyond the barriers, the researcher also discovered that participants perceived a benefit of exercise and PA, and recognized cues to action during chemotherapy treatment that influenced their attitudes and activity levels. The participant's perceived barriers, perceived benefits and cues to action are diverse and underscore the need to incorporate the patient's perspective when designing and developing research, clinical services or policy related to enhancing the QoL for those with metastatic cancer undergoing chemotherapy.

The first major construct of the HBM identified was perceived barriers. For respondents, perceived barriers included *treatment related side effects, risk of infection in public spaces, co-morbidities/limiting conditions, fear of falling, weather as a deterrent, and age*. These findings are consistent with some of the previous literature (Mas et al., 2015; Sheill et al., 2017) however offer some unique findings in the risk of infection in public spaces, fear of falling and age as a deterrent. Previous research has primarily focused on the barriers related to the side effects of chemotherapy treatment and this is one of the few studies that has gone beyond the typical barriers. Acknowledging the risk of infection is important due to one's compromised immunity, which can result in an unnecessary hospitalization and can hamper the overall course of

treatment. Being restricted within public spaces can severely limit one's ability to exercise indoors such as at malls or gyms, especially during the winter months in Canada. Health care professionals should consider home exercise programs to eliminate the need to be in public spaces. The fear of falling presents a similar issue in that a fracture can also lead to a hospitalization that can delay one's treatment regimen and increase the risk of a hospital-acquired infection, thereby compromising any progress that one has achieved. Beyond the physical reality of the risk of infection and the fear of falling, there is also a motivational barrier that is interconnected with age. As some of the participants (such as SA and AR) got older they did not have the same vigour and motivation to participate in exercise and PA compared to when they were younger. It was almost as if there was more incentive when they were younger and had more physical energy, and there was no urgency to hassle themselves with exercising in their current condition. Recognizing these barriers is important for all health care professionals working with those with metastatic cancer in this capacity. It allows one to administer exercise programs that are suitable and safe, while being empathetic towards their needs and concerns.

The second major construct identified was perceived benefits. The perceived benefits included *beliefs about exercise, exercise as a coping strategy, as well as a belief in the value of exercise and willingness to participate according to how one is feeling*. Understanding the perceived benefits is an important finding as it gives insight into the motivations that encourage positive exercise and PA habits. All of the participants innately felt that exercise and PA was good for them, however their ability to participate was primarily limited by their physical condition. For some of the participants, exercise energized them, made them feel better, and gave them something to focus on outside of their cancer. These individuals were able to engage

in exercise and PA in spite of their cancer related symptoms. They would plan their exercise days according to their chemotherapy treatment schedule, knowing their bad days and making the best of their good days. According to Lowe et al. (2010), 92% of their participants with metastatic cancer reported that they would be willing to participate in PA. Among the participants of this study, willingness to continue to exercise during their cancer treatment can be perceived as a manifestation of their seeming benefit of exercise and PA. Future research should consider the perceived benefits and determine the different motivators that enable exercise and PA during cancer treatment.

The third major construct identified was cues to action which included *physical environment, family and friends, and physician encouragement*. The physical environment relates to the ease by which one can access spaces to enjoy in exercise and PA. Having a convenient place to exercise can positively influence one's motivation, thereby increasing the likelihood of partaking in exercise and PA. This subtheme is also interconnected with weather and one's perception of their risk of acquiring an infection in a public setting, as these can inhibit or enable exercise and PA. The latter two cues to action are representative of three important social relationships to every patient: family, friends and their physician. These relationships can influence how individuals feel about themselves, their condition as well as their overall outlook. These relationships can also be quite sensitive as caregivers and family members are uncertain of how much they can promote exercise and PA (Rhudy et al., 2015). Although a delicate issue, it is important to understand that patients rely on these supports to help them through their time of sickness and the practical significance of this cannot be underestimated. An extension to physician encouragement is that health care professionals need to be aware that patients look to

all of their health care providers, not just the oncologist, for support, advice and hope (Gulde et al., 2011).

The barriers, benefits and cues to action identified by this study help inform clinical services, research initiatives and policy decisions that relate to the promotion of exercise and PA for those with metastatic cancer who are undergoing chemotherapy. There are many opportunities for future research in this domain of study such as determining if any particular subtheme should take precedence over another, determining the viability of the HBM within this research context, program implementation and exercise/PA promotion utilizing the HBM, or utilizing another major health behaviour framework in further understanding the barriers, motivators and facilitators for exercise and PA. There is overwhelming evidence that exercise and PA are safe and beneficial and therefore should be promoted at each clinic visit, every encounter with a nurse or oncologist, along with educational opportunities in hospital waiting rooms. Although there is a lack of availability of formal exercise programs that cater to those with metastatic cancer, exercise and PA should continue to be promoted in any capacity by which patients and communities are able to engage. Although this study identified a number of barriers, the participants of this study unequivocally agreed that exercise and PA are beneficial from a physical and QoL standpoint.

Health Belief Model

The application of the HBM within this research context is among the first of its kind. The HBM proved instrumental in the formation and execution of this research. The six constructs (perceived susceptibility, perceived severity, perceived benefits, perceived barriers,

cues to action, and self-efficacy) were far reaching and allowed the researcher to move beyond the barriers and identify perceived benefits as well as the cues to action for the participants. Going into the investigation, the researcher was aware that the construct of perceived barriers was a consistently reliable feature of the HBM (Carpenter, 2010; Janz & Becker, 1984) which was simultaneously at the center of this research investigation. In the end, the researcher identified twelve subthemes that related to either perceived barriers (6), perceived benefits (3), and cues to action (3). There were little or no themes related to perceived susceptibility, perceived severity, and self-efficacy. There was a low likelihood that perceived susceptibility and perceived severity were going to emerge as a theme as they speak to the day to day lived experience/QoL, and not necessarily the connection between exercise, PA and QoL. Perhaps future research can consider these constructs in trying to understand the impact of anti-cancer treatments in the lives of individuals with metastatic cancer. The researcher was surprised that self-efficacy didn't emerge as a central theme as confidence in one's ability to participate in exercise and PA can be considered a key limitation due to the physical weakness that accompanies metastatic cancer.

Prior studies have used major health behavior theoretical frameworks in the formation of surveys or questionnaires (Kartolo et al., 2016), but few have used them in qualitative, interview-based research investigations. The HBM is well suited to undertake both types of research investigations and is not limited to any particular design.

Another unique feature of the HBM is that it considers ameliorating illness as a driver of health behaviour change, and has been used previously in populations affected by illness such as

metastatic cancer, hypertension, diabetes and end stage renal disease. The expanded use of the HBM presents a significant opportunity in seeking to understand health behaviour perceptions for those affected by disease, and should be considered in future research. The purpose of using the HBM in this investigation was to further understand the patient perspective. The fluidity of the HBM from a methodological and application standpoint enables it to be a useable health behaviour theoretical framework in understanding perceptions and attitudes in a multifaceted manner.

Strengths and Limitations

The strength of this study is that it is among the first of its kind to utilize a prominent health behaviour theoretical framework in understanding the barriers to exercise and PA for those with metastatic cancer who are undergoing chemotherapy. Furthermore, it used a semi-structured, interview-based approach to amplify the participant voice, and gain an account of their perspective. The results of this study will enhance the overall understanding for health care providers and academics alike. This research also moved beyond the barriers and highlighted possible motivators and enablers for exercise and PA. The use of the HBM allowed for these findings to manifest, and should be considered in future research.

The primary limitation of this study is attributed to low number of participants. Being a small community oncology clinic that sees only 20 to 25 patients with metastatic cancer per year, it was difficult to recruit a high volume of participants. As well, being in small community clinic in an urban area of Toronto, these findings may not be transferable to all individuals with metastatic cancer; rather this research is intended to add context for understanding exercise and

PA within this population. For example, those living within aging communities or those living in better weather conditions may have a different outlook toward exercise and PA in the setting of metastatic cancer. Future research should involve larger oncology programs to enhance recruitment and possibly include the barriers from the standpoint of the health care provider.

Future research considerations

This domain of research holds much promise as exercise considerations surrounding those with metastatic cancer are limited and warrant further investigation. The HBM, along with other prominent health behavior theoretical frameworks such as the theory of planned behaviour or the health action process approach, can be utilized to further understand exercise within this group. More specifically, these theoretical frameworks can be used to move beyond the barriers and delve into aspects of patient care such as individual motivators and enablers for exercise and PA, program implementation/evaluation, ranking the barriers to exercise and PA, or exercise and PA promotion within the public health care system and its financial implications.

From a clinical and cancer care policy standpoint larger studies need to be undertaken. This may involve multi-centered trials or the involvement of larger cancer institutions to enhance recruitment. The added participant volume can enhance the generalizability of the results and affirm the formal barriers to exercise and PA that can inform cancer care policy decisions. As referenced in chapter one, the guideline established by Cancer Care Ontario (CCO) regarding the benefits and safety of exercise among all cancer patients (Segal et al., 2015) does not delve deep enough into the challenges, lived experience and recommendations for persons with metastatic cancer. The guideline was developed as a general guidance for all individuals with cancer, irrespective of where they lie on the cancer continuum as the target population are, “Adult

patients living with cancer, including those on active treatment and those who have completed treatment” (Segal et al., 2015. p. 3). While this is a good first step, there is an opportunity for CCO to develop a guideline that specifically promotes and considers the barriers that affect those with metastatic cancer, as the exercise goals and objectives can differ from that of cancer survivors or others living along the cancer continuum.

Further considerations for cancer care practice, education and policy

Moving beyond the barriers, cancer care practice, education and policy needs to consider more closely the well-being and QoL of the patient irrespective of where they lie upon the cancer continuum. Currently, health care funding is directed toward therapies that decrease cancer progression and does not consider the QoL aspect of the individual. This is best characterized by Courneya (2017) who says:

Certainly, the evidence for fitness and quality-of-life benefits would seem sufficient for clinicians to at least recommend exercise to their patients and perhaps even to refer them to one of the growing number of community-based exercise programs for cancer survivors. But what would it take for cancer centres themselves to integrate high-quality exercise programs into clinical cancer care? The likely answer to that question is evidence of a direct benefit of exercise for cancer outcomes—that is, recurrence, progression, and survival. (p.8)

While the long term goal of cancer care should be to eradicate cancer, individuals who are currently living with metastatic cancer cannot wait until that time arrives and QoL needs to be considered in the mean-time. Exercise and PA are widely beneficial and should be considered

on a clinical, education and policy level. This can be achieved by offering training opportunities to front line staff (i.e. physicians, nurses and researchers) indicating the benefits of exercise and PA. These training opportunities can be administered by provincial bodies such as Cancer Care Ontario (CCO) or the Canadian Cancer Society (CCS). Changing medical practice is a difficult task and requires a coordinated effort between policy makers, health care practitioners, researchers, as well as Provincial and Federal entities such as CCO or CCS, to establish exercise and PA as a staple treatment strategy, highlight its benefits, and embed it within the cancer care treatment cycle. As exercise and PA continue to proliferate as a beneficial intervention, the barriers need to be considered in order to create a sustainable and encouraging patient experience.

Conclusion

In this hospital-based, qualitative research investigation of the barriers to exercise and PA for individuals with metastatic cancer who are undergoing chemotherapy, the researcher identified a total of 12 subthemes related to perceived barriers (6), perceived benefits (3) and cues to action (3). This is among the first study of its kind to use the HBM in informing the research investigation. The participants of this study identified unique barriers to exercise and PA that include the risk of infection in public spaces, fear of falling and age. These are real concerns for these individuals, and pose a challenge in the participation of exercise and PA. These barriers have not been identified in previous literature and serve to inform the practice of health care professionals working with those with metastatic cancer. Moving forward, research needs to incorporate larger sample sizes and utilize some of the major health behaviour theoretical frameworks such as the HBM, the theory of planned behaviour or the health action process approach in seeking to further understand the barriers to exercise and PA. From a cancer

care policy perspective, guidelines such the CCO's guidance on exercise for individuals with cancer should be inclusive of the lived experience for patients living with metastatic cancer and the nuances that affect them. Home exercise programs, and exercise and PA promotion should also be considered by clinicians, based on the proven benefit and impact on improving overall QoL.

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Appendix A: UOIT letter of approval

Date: November 24, 2016
To: Manon Lemonde
From: Shirley Van Nuland, REB Chair
Title: What are the perceived barriers to participating in exercise and physical activity for metastatic cancer patients undergoing chemotherapy?
Decision: APPROVED (effective November 22nd, 2016)
Current Expiry: November 01, 2017

Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the research proposal cited above. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 (2014)) and the UOIT Research Ethics Policy and Procedures. You are required to adhere to the protocol as last reviewed and approved by the REB.

Continuing Review Requirements (all forms are accessible from the [IRIS research portal](#)):

- Renewal Request Form:** All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed within 30 days of the expiry date will be automatically suspended by the REB; projects not renewed within 60 days of the expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- Change Request Form:** Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- Adverse or Unexpected Events Form:** Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- Research Project Completion Form:** This form must be completed when the research study is concluded.

Always quote your REB file number (**I14092**) on future correspondence. We wish you success with your study.

Dr. Shirley Van Nuland
REB Chair
shirley.vannuland@uoit.ca

Janice Moseley
Research Ethics Coordinator
researchethics@uoit.ca

NOTE: If you are a student researcher, your supervisor has been copied on this message.

☐

Appendix B: SRH letter of approval

SCARBOROUGH AND ROUGE HOSPITAL



Scarborough and Rouge Hospital Research Ethics Board

To: Riyad Akbarali
SRH File No: CAR-16-006
Study Title: What are the perceived barriers to participating in exercise and physical activity for metastatic cancer patients undergoing chemotherapy?
Re: Initial Study Approval
Approval Effective From: November 1, 2017 to November 1, 2018

This is to acknowledge that the Scarborough and Rouge Hospital Research Ethics Board by Delegated Review has approved the above titled study on **November 1, 2017**.

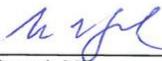
Approval is issued for the following documents.

Study Protocol, Version 1	Dated: July 20, 2017
Informed Consent, Version 5	Dated: May 26, 2017
Appendix A: Physician or Nurse Recruitment Script	
Appendix B: Letter of Invitation/Invitation Script	
Appendix F: Interview Guide, Version 1	Dated: May 26, 2017

Should this study continue beyond the expiry date noted above, you must submit a request for re-approval prior to this date. Please advise the REB annually on the progress of your research. During the course of the research, any significant deviations from the protocol or any adverse events should be brought to the attention of the REB. If the study has been completed by this date, a Completion Form should be submitted.

The Research Ethics Board of Scarborough and Rouge Hospital agrees with the principles for ethical research found in the TRI-Council Policy Statement: Ethical Conduct For Research Involving Humans 2nd edition (TCPS2), the Declaration of Helsinki, the Ontario Personal Health Information Protection Act (PHIPA) 2004, and other relevant regulations or guidelines, [e.g., Health Canada Part C, Division 5 of the Food and Drug Regulations, Part 4 of the Natural Health Products Regulations, Medical Devices Regulations, ICH/GCP Consolidated Guideline E6 and the Code of Federal Regulations: Title 45, Part 46]. The Research Ethics Board of

Scarborough and Rouge Hospital adheres to the regulations found within these documents, as appropriate.



Dr. Marek Gawel, MD
Chair, Research Ethics Board
Scarborough and Rouge Hospital



Date

Appendix C: Physician recruitment script

Physician recruitment script

There is currently a study being conducted in this department involving individuals with metastatic cancer who are undergoing chemotherapy. The researcher is a student from the University of Ontario Institute of Technology and they are trying to understand the barriers to exercise and physical activity while you are on chemotherapy. Participation is completely voluntary and not at all compulsory. Speaking with the researcher won't impact your medical care in any way. You can also speak with the researcher at a later time if you'd rather.

Are you interested in speaking with the researcher?

Appendix D: Participant invitation script

Participant invitation Script

Thank you for your time.

My name is Riyad Akbarali and I am a Master's of Health science student from the University of Ontario Institute of Technology (UOIT). I wanted to invite you to participate in a research study about exercise and physical activity for people who have cancer and are undergoing chemotherapy. Specifically, I would like to know the barriers to exercise and physical activity while on chemotherapy.

I am asking to interview individuals at one of their regularly scheduled appointments. The interview should take about 30 to 60 minutes. A consent form and a sociodemographic questionnaire will be completed prior to the interview. This research study has been approved by the Research Ethics Board of UOIT (November 22, 2016: 14092) and Scarborough and Rouge Hospital (November 1, 2017: CAR-16-006). All information will remain private and confidential. This research study is completely voluntary and there are no consequences to your care at RVHS for not participating.

If you are interested in participating we can arrange and time for the interview right now, however if you would like to think about participating you can contact me anytime at rakbarali@gmail.com.

Do you have any questions?

Appendix E: Informed consent

INFORMED CONSENT

Title of Study: What are the perceived barriers to participating in exercise and physical activity for metastatic cancer patients undergoing chemotherapy?

Principal Investigator and Supervisor:

Dr. Manon Lemonde, RN, PhD
Associate Professor
Faculty of Health Sciences
University of Ontario Institute of Technology
905-721-8668 ext. 2706
Manon.Lemonde@uoit.ca

Co-supervisor:

Dr. Robert R. Weaver
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Co-investigator/Researcher

Riyad Akbarali, R.Kin
MHSc Candidate
University of Ontario Institute of Technology
647-283-5609
rakbarali@gmail.com

Introduction

This document invites participants to take part in a research study at The Scarborough and Rouge Hospital. The study is described below. Before agreeing to participate in this study, it is important that you understand the proposed study. The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask for an explanation of any words you don't understand before signing this consent form. Make sure all of your questions have been answered to your satisfaction before signing this document.

Purpose of Study

The purpose of this research is to understand your perspective/thoughts about exercise and physical activity while you are undergoing chemotherapy. Exercise is considered a structured or planned activity with a goal in mind such as running, walking or cycling, whereas physical activity is any body movement such as gardening or grocery shopping.

Study Procedures

The researcher will provide and read through the informed consent with you. The study will involve completing a socio-demographic questionnaire and participating in a private one on one interview between the researcher and the yourself. Interviews will be conducted during one of your regularly scheduled appointments. Individual participant interviews offer a unique perspective into the lived experiences of individuals with cancer and gives insight into improving access to the participation of exercise and physical activity.

Before each interview the researcher will provide participants with the informed consent and answer any questions or concerns they might have. After signed informed consent is obtained, the participant will be asked to complete the socio-demographic questionnaire and then the interview will begin. If the participant wishes, the socio-demographic questionnaire can be submitted at a later time. The duration of the interview will be approximately 30 to 60 minutes and will vary based on the length of your responses. These interviews will be audio recorded to ensure the accuracy of the data collection. The audio recordings will be deleted after transcription. When the interview is finished the researcher will verbally thank you and notify you that your involvement is complete.

Eligibility

The participant must be an individual with metastatic cancer who is receiving chemotherapy at The Scarborough and Rouge Hospital and capable of speaking English, 18 years of age or older and deemed mentally and physically able to participate based on their physicians' professional judgement.

Expectations of the Participant

You will be asked by the researcher if you are interested in participating. If you are interested, you can choose to have the interview at one of your regularly scheduled appointments. You may ask the researcher questions before signing the consent form. When the interview begins there is no time limit for responses and you may choose not to answer any question or terminate the interview at any time without impact to your medical treatment.

Possible Benefits

There is no direct benefit to the participant, but your participation will contribute to a better understanding of the lived experience for persons with metastatic cancer undergoing chemotherapy by identifying barriers and challenges towards participating in exercise and physical activity.

Possible Risks

There are no physical risks associated with this study. There may be psychological risks associated with the interview process. During the interviews participants may feel anxious when asked a question or feel embarrassed to answer, however you have the option to terminate the interview at your discretion. If the participant begins to feel nauseous or fatigued as a result of chemotherapy, the interview will be delayed and a nurse will be notified if necessary. The hospital crisis team will also be available if the participant begins to feel symptoms of psychological distress. Participation is completely voluntary and will not impact your medical care at The Scarborough and Rouge Hospital.

Costs

There are no associated costs with the study procedures.

Compensation

There is no payment or reimbursement for any expenses related to participating in this study.

Confidentiality

Aggregate information gathered in this research study may be published or presented in public forums.

Anonymity and confidentiality are of utmost importance and will be protected at all times. All aggregate information will remain confidential and a nickname will be assigned to each participant, with no similarity to your name. The recorded information from the interview will be audio recorded and transcribed by the researcher and kept on password protected computer and an encrypted file, to which only the researcher has access.

The University of Ontario Institute of Technology and The Scarborough and Rouge Hospitals' Research Ethics Boards may review records related to the study for quality assurance purposes, as it oversees the conduct of this study.

Right as a Participant

Participation to take part in this study is voluntary. You may refuse to participate, bypass a question or you may withdraw from the study at any time. If you wish to withdraw from the study you must verbally inform the researcher. Written notification is not required. If you wish to have your data withdrawn, you must contact the researcher within 30 days of the interview so the data will not be included in the research paper. Contact information is located on page 1 of this document. Your decision not to participate or withdraw from the study will not affect your care at The Scarborough and Rouge Hospital.

Questions/Concerns

The researcher will be available to answer questions throughout the study. If you agree to participate in this research study, please sign the form on the next page. Your signature indicates your consent and that you understand the information regarding this research study. Any legal rights or recourse are not waived.

If you have any questions concerning the research study or experience any discomfort related to the study, please contact Riyadh Akbarali at 647-283-5609 or rakbarali@gmail.com. You will also be given a copy of the consent form to keep.

Should you have any questions or concerns regarding your rights as a participant in this research study, or if you wish to speak with someone who is not related to the study, you may contact the University of Ontario Institute of Technology Research Ethics and Compliance Coordinator at compliance@uoit.ca or call 905.721.8668 Ext. 3693. You may also contact Scarborough and Rouge Hospital, Research Ethics Board, Dr. Luigi Castagna and Dr. Marek Gawel, Co-Chairs at [\(416\) 438-2911 ext. 6728](tel:(416)438-2911).

Principal Investigator or designate Printed Name

Appendix F: Sociodemographic questionnaire

1. What is your sex?

- a) Male
- b) Female

2. What is your age?

- a) 18 to 29 years old
- b) 30 to 49 years old
- c) 50 to 64 years old
- d) 65 years and over

3. What is the highest level of education you have completed?

- a) Some high school
- b) High school graduate
- c) Some college
- d) Trade/technical/vocational training
- e) College graduate
- f) Some University
- g) University graduate
- h) Some post graduate work
- i) Post graduate degree

4. What is your employment status?

- a) Full-time
- b) Part-time
- c) Not employed
- d) Retired
- e) Volunteer

5. What is your household income?

- a) Less than \$19,999

- b) \$20,000 to \$29,999
- c) \$30,000 to \$39,999
- d) \$40,000 to \$49,999
- e) \$50,000 to \$74,999
- f) \$75,000 to \$99,999
- g) \$100,000 to \$150,000
- h) Greater than \$150,000
- i) Rather not say

6. What is your marital status?

- a) Single/never been married
- b) Married
- c) Common-law/partnered
- d) Separated
- e) Divorced
- f) Widowed

**7. Which of the following best represents your racial or ethnic heritage?
Choose all that apply**

- a) White, Caucasian or Euro-Canadian
- b) Black, Afro-Caribbean, or Afro-Canadian
- c) Latino or Hispanic Canadian
- d) East Asian or Asian Canadian
- e) South Asian or South Asian descent
- f) Middle Eastern or Arab Canadian
- g) First nations
- h) Other

8. When were you first diagnosed? _____

Appendix G: Interview guide

It is not necessary to ask all of the questions. This will serve as a guide due to the semi-structured nature of this study.

HBM Component	Question
Introductory questions/Comment	<ol style="list-style-type: none"> 1. Describe your day after being on chemotherapy? 2. Define exercise and physical activity. Physical activity is any movement, whereas exercise is a planned, repetitive movement at a prescribed intensity.
Perceived severity	<ol style="list-style-type: none"> 3. Describe your QoL since being on chemotherapy? 4. In what ways has your QoL changed since being on chemotherapy? 5. Did you expect these changes since diagnosed?
Perceived barriers	<ol style="list-style-type: none"> 6. Have you exercised since your cancer diagnosis? If so, why or why not 7. Describe some of the reasons why you would/wouldn't participate in exercise 8. Describe some of the reasons why you would/wouldn't participate in physical activity 9. What would prevent you from participating in exercise or physical activity?
Perceived benefits	<ol style="list-style-type: none"> 10. Exercise has been shown to have benefits for individuals with cancer, including those undergoing chemotherapy. If you understood the benefits how would you view exercise? Would that increase the likelihood of participating in exercise? 11. Physical activity has been shown to have benefits for individuals with cancer, including those undergoing chemotherapy. If you understood the benefits would you participate on your good (or even bad) days? Would that change your view on physical activity? 12. Can you see any benefit to participating in exercise or PA while on chemotherapy?
Self-efficacy	<ol style="list-style-type: none"> 13. Physical activity is defined as any body movement, whereas exercise is a planned and structured activity with a goal in mind. 1) Before your cancer diagnosis were you physically active? If so, what kind of activities did you participate in? 2) Before your cancer diagnosis did you participate in regular exercise? If so what kind of exercise did you participate in? 14. Have you been physically active since your diagnosis? 15. How does chemotherapy affect your ability to participate in exercise?

	<p>16. How does chemotherapy affect your ability to participate in physical activity?</p> <p>17. Can you describe if exercise or PA is feasible/manageable for you while on chemotherapy?</p>
Cues to action	<p>18. What social supports do you have? Family/friends/organizations etc.</p> <p>19. How would you go about participating in exercise?</p> <p>20. How would you go about participating in physical activity?</p> <p>21. Is there something the hospital, health care providers or community can do to help you participate in exercise or physical activity if you believed it to be beneficial?</p> <p>22. If you felt exercise or PA was beneficial to your QoL while undergoing chemotherapy, how best can you incorporate them into your day to day life?</p> <p>23. Would it make a difference if exercise or PA was encouraged by your oncologist or nurses?</p>

Appendix H: Participant legend

Participant initials	Age	Gender
AR	80	Female
SA	72	Female
CP	83	Female
DH	64	Female
JB	74	Male
JF	62	Male
PC	63	Female
NM	27	Female