

Leisure-Time Physical Activity in People with Advanced Cancer: Exploring the Perspectives of Adults
Diagnosed with Stage 4 Cancer and of Oncology Physiotherapists in Canada

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DEDICATION

This dissertation is dedicated to my family.

I love you.

DISSERTATION ABSTRACT

Background: Despite improving survival rates, people with advanced cancer experience high symptom burden, functional challenges, and negative impacts upon their quality of life. Moreover, these individuals frequently report unfulfilled needs related to supportive care, including rehabilitation support. Leisure-time physical activity (LPA), including exercise, has been found to be beneficial for people following diagnosis of cancer. However, little is known about LPA for individuals living with advanced cancer, particularly from a rehabilitation perspective.

Purpose and objectives: The overall purpose of my dissertation research is to explore LPA in people with advanced cancer, through the perspectives of adults diagnosed with stage 4 cancer as well as those of oncology physiotherapists. Specific objectives are: (1) to map the research and understand key concepts from the literature about LPA in individuals with advanced cancer; (2) to explore the perspectives and experiences of LPA in adults diagnosed with stage 4 cancer; and (3) to describe the clinical practices, knowledge, skills, and perspectives of oncology physiotherapists related to LPA in the advanced cancer population.

Methods: To meet these objectives, I conducted three research studies: (1) a scoping review of 92 articles exploring LPA in people with advanced cancer; (2) a qualitative interpretive-description study, involving individual, semi-structured interviews with 20 Canadian adults diagnosed with stage 4 cancer; and (3) a mixed-methods study, consisting of an online survey with 62 Canadian oncology physiotherapists, followed by qualitative, individual interviews with 13 physiotherapists.

Results: The scoping review demonstrated a recent surge in research on the topic of LPA in advanced cancer, with many studies adopting quantitative methods and investigating aerobic and resistance exercise interventions. These studies have contributed to important research developments highlighting the safety, feasibility, and benefits of such interventions for people with advanced cancer. This scoping review also identified several gaps in the literature, particularly highlighted by the few qualitative studies exploring patient perspectives and experiences with different types of LPA.

The second study helped address some of the research gaps noted in the scoping review. In this qualitative interpretive-description study, individuals with stage 4 cancer revealed the diverse and fluid nature of their experiences with LPA, necessitating intentional planning and modifications of activities. Moreover, important health benefits and psychosocial meanings of activity participation were identified. In addition, common supportive care needs related to LPA were recognized through this work. In particular, the participants desired professional LPA support that is integrated, interprofessional, accessible, and tailored to their individual abilities and preferences.

To complement the patient perspectives and experiences, the third study offered insight on the perspectives of rehabilitation professionals. This mixed-methods study with oncology physiotherapists demonstrated positive views about the safety, importance, and benefits of activity in people with advanced cancer. Key considerations with this population included addressing cancer-related issues (e.g., bone metastases), identifying individually meaningful goals, and tailoring activity recommendations. The physiotherapists also highlighted their overall roles in optimizing functional capacity and alleviating symptom burden in people with advanced cancer. The lack of awareness about the role of physiotherapy and the limited access to rehabilitation services in oncology were identified as important challenges.

Conclusions: The overall findings from this dissertation research highlight the scope of literature on LPA in advanced cancer and offer patient and professional perspectives related to this topic. As such, these findings may help inform the design and integration of supportive care resources targeted to this population. Strategies to promote LPA in this population require consideration of the complexities associated with advanced cancer and the important meanings of LPA for people living with this challenging diagnosis. Physiotherapists can be well-suited to promote safe, meaningful LPA in the advanced cancer population, as well as to optimize functional activity and symptom management. Practically, these findings support a patient-centered approach to encourage appropriate LPA in the care of people with advanced cancer. Key elements include: (1) comprehensive, regular patient assessment; (2) open communication with patients and families; (3) interprofessional collaboration between oncology care providers and specialized rehabilitation professionals; (4) integrated, routine delivery of LPA information and individualized activity recommendations; and (5) access to tailored LPA resources and programs within cancer care and community-based settings.

Additional research is warranted to examine different types of LPA and explore other rehabilitation needs, particularly in understudied subgroups of advanced cancer (e.g., non-breast cancer). Moreover, further efforts are needed to develop, evaluate, and implement clinical strategies targeting LPA within integrated care models for advanced cancer. Simultaneously, educational initiatives are necessary to enhance relevant knowledge in physiotherapists and oncology care providers. These can support the personalization of LPA resources, facilitate interprofessional collaboration, and improve the quality and integration of rehabilitation services in cancer care. Therefore, the findings of my dissertation research provide comprehensive and applicable knowledge about diverse patient and professional perspectives related to LPA in the advanced cancer population. This work can support future efforts aimed at facilitating LPA participation and enhancing supportive care experiences in individuals living with advanced cancer.

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CHAPTER 1: INTRODUCTION

Introduction

Research Problem

The lifetime probability of developing cancer in North America is around 40% (Canadian Cancer Statistics Advisory Committee in collaboration with the Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada, 2021; National Cancer Institute, 2021). In Canada, it is estimated that over 220,000 individuals were diagnosed with cancer in 2021, with over 10,000 new diagnoses annually of stage 4 lung, colorectal, prostate, and breast cancers (Canadian Cancer Statistics Advisory Committee, 2018; Canadian Cancer Statistics Advisory Committee in collaboration with the Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada, 2021). Survival rates associated with advanced cancer are fortunately improving, but people diagnosed with this health condition continue to experience frequent symptom burden, functional challenges, and negatively impacted quality of life. Leisure-time physical activity (LPA), including exercise, is becoming a growing area of interest within the cancer population. There is increasing recognition of the benefits associated with exercise after cancer diagnosis. However, the topic of LPA has not been well explored in individuals living with advanced cancer.

Thus, the overall purpose of my dissertation research is to explore LPA in people with advanced cancer through the perspectives of adults diagnosed with stage 4 cancer and of oncology physiotherapists in Canada. In this first chapter, I briefly explain the rationale for this research and the specific objectives of three studies designed to address my overarching goal. Then, I describe the organization of the dissertation. Following this section, I provide key definitions, a summary of the literature, and relevant theoretical conceptualizations informing my research. Finally, I discuss the methodological elements and ethical considerations within my dissertation work.

Rationale and Objectives

There exists a need to better understand LPA in individuals with advanced cancer, through diverse sources of information and perspectives. In this population, little is known about the experiences of LPA in people living with this health condition, as well as their perceptions and preferences related to LPA. Additionally, leisure activities besides structured exercise interventions have not been well explored in these individuals. From a rehabilitation perspective, there is limited information on how to address barriers to LPA and to support individuals with advanced cancer with appropriate LPA resources. In particular, the role of physiotherapists in optimizing LPA participation in this population is not clearly understood. Therefore, exploring the perspectives of people diagnosed with advanced cancer, as well as of health professionals who can potentially support these patients,¹ can assist the development and integration of tailored clinical strategies focused on LPA. The findings of this research can also inform educational priorities for health professionals, as well as guide future research inquiries in this area.

In order to meet the goal of exploring LPA in people with advanced cancer, my dissertation research consists of three individual studies addressing the following specific research objectives: (1) to map the research and understand key concepts from the literature about LPA in people with advanced cancer, via a scoping review; (2) to explore perspectives and experiences of LPA in Canadian adults diagnosed with stage 4 cancer, via a qualitative interpretive-description study; and (3) to describe the clinical practices, knowledge, skills, and perspectives of Canadian oncology physiotherapists related to LPA in people diagnosed with advanced cancer, using a mixed-methods study design.

¹ In clinical and research contexts, individuals with cancer are identified through the use of different terms, such as survivors and patients. I recognize there may be differences in the terms preferred by these individuals themselves or in the terms used by different health professionals, including rehabilitation specialists. As this dissertation work is conducted through a disciplinary lens situated in physiotherapy, I have decided to use the term patients to refer to people with cancer, including the participants diagnosed with stage 4 cancer in my research.

Organization of Dissertation

To further justify my dissertation research aimed at examining LPA in people with advanced cancer from different viewpoints, I provide a review of the literature in the next section of this chapter. This section describes relevant definitions and a summary of key research informing my dissertation. Following this, I discuss the research paradigm and theoretical conceptualizations that helped shape my research. In this first chapter, I also outline the detailed methodologies of the respective studies, along with ethical considerations. The second, third, and fourth chapters describe each of the three studies performed as part of my dissertation research, in manuscript form. Following this, I provide an integrated discussion in Chapter 5 to summarize the research findings and consider implications for the rehabilitation sciences. The organization of the dissertation and the manuscripts associated with this research are presented in **Table 1.1**.

Table 1.1 Organization of Dissertation

Chapter	Title	Objective	Method	Affiliated manuscript
1	Introduction	<p>Describe the research problem. Provide the rationale and study objectives. Explain the organization of dissertation. Present a review of the literature, including relevant definitions, literature review, and theoretical considerations. Describe the methodologies and methodological considerations guiding each study: - Study 1: Scoping review</p> <p>- Study 2: Qualitative interpretive-description study with patients - Study 3: Mixed-methods study with physiotherapists Explain the ethical considerations.</p>	N/A	<p>Shallwani, S.M., Brosseau, L., Thomas, R., Poitras, S., Sikora, L., Ranger, M.C. & King, J. (2019). Leisure physical activity in people with advanced cancer: a scoping review protocol. <i>Physical Therapy Reviews</i>, 24(1-2):51-58. (Appendix A)</p>
2	Scoping Review (Manuscript 1)	Map the research and understand key concepts from the literature on the topic of LPA in people with advanced cancer.	Scoping review	<p>Shallwani, S.M., Ranger, M.-C., Thomas, R., Brosseau, L., Poitras, S., Sikora, L. & King, J. (2021). A scoping review of studies exploring leisure-time physical activity in adults diagnosed with advanced cancer. <i>Palliative and Supportive Care</i>, 19(5):615-630.</p>
3	Patient Interpretive-Description Study (Manuscript 2)	Explore perspectives and experiences of LPA in adults diagnosed with stage 4 cancer.	Qualitative interpretive-description study	<p>Shallwani, S.M., Thomas, R., King, J., Toupin-April, K. & Poitras, S. Perspectives and experiences of leisure-time physical activity in adults with stage 4 cancer: a qualitative interpretive-description study. Submitted to <i>Disability and Rehabilitation</i> (June 2022).</p>

4	Physiotherapist Mixed-Methods Study (Manuscript 3)	Describe the clinical practices, knowledge, skills, and perspectives of oncology physiotherapists related to PA in people with advanced cancer.	Mixed-methods study	Shallwani, S.M., Thomas, R., Poitras, S., Toupin-April, K., Sheill, G. & King, J. Clinical practices, knowledge, skills and perspectives of oncology physiotherapists related to physical activity and advanced cancer: a Canadian mixed-methods study. Submitted to <i>Physiotherapy Theory and Practice</i> (April 2022).
5	Integrated Discussion	Provide an integrated discussion with practical, educational, and research implications.	Descriptive synthesis	N/A

LPA: leisure-time physical activity; PA: physical activity

Review of Literature

Relevant Definitions

In this section, I discuss definitions pertinent to my dissertation work. The definitions of three terms key to this dissertation are provided in **Table 1.2**: (a) advanced cancer; (b) physical activity (PA); and (c) LPA. Further explanations and a rationale for the selection of these particular definitions appear after the table. Next, other definitions and descriptions of relevance to my research are provided.

Table 1.2 *Definitions of Key Terms*

Term	Definition
Advanced Cancer	<i>“Cancer that has spread to other places in the body and usually cannot be cured or controlled with treatment”</i> (National Cancer Institute, 2007) <i>“Cancer that is unlikely to be cured or controlled with treatment. The cancer may have spread from where it first started to nearby tissue, lymph nodes, or distant parts of the body. Treatment may be given to help shrink the tumor, slow the growth of cancer cells, or relieve symptoms”</i> (National Cancer Institute, 2017)
Physical Activity (PA)	<i>“The behavior that involves human movement, resulting in physiological attributes including increased energy expenditure and improved physical fitness”</i> (Petee Gabriel et al., 2012)
Leisure-Time or Leisure Physical Activity (LPA)	<i>“The activities one participates in during free time, based on personal interests and needs. These activities include formal exercise programs as well as walking, hiking, gardening, sport, dance, etc.”</i> (Howley, 2001)

Definition of Advanced Cancer

There have been challenges noted with standardizing the definition of advanced cancer in palliative care research (S. S. Lowe et al., 2016). The previous definition of advanced cancer developed by the U.S. National Cancer Institute emphasizes two key aspects: disease spread and lack of cure or control (National Cancer Institute, 2007). This definition was recently updated to highlight the unlikelihood of disease cure or control, while considering cancer spread and treatment intent (National Cancer Institute, 2017). The focus on incurability has been adopted by the Canadian Cancer Society in their brief definition of advanced cancer as *“cancer that is unlikely to be cured”* (Canadian Cancer

Society, 2020) as well as in a 2011 American Society of Clinical Oncology statement which defined it as “*incurable disease*” (Peppercorn et al., 2011). For my research, I use the National Cancer Institute definitions for advanced cancer, as the main notions underlying these descriptions have been recognized and adopted by the national cancer agencies in both the U.S. and Canada. Moreover, the National Cancer Institute definitions have been frequently published in the literature. For instance, they have been used in a highly cited report on delivering quality cancer care (Levit et al., 2013), in supportive care guidelines on advanced cancer (B. Alderman et al., 2022; Davies et al., 2020), as well as in a relevant systematic review examining exercise interventions in people with metastatic cancer (Beaton et al., 2009). As such, these definitions provide a basis upon which the concept of advanced cancer can be effectively understood and operationalized within my research.

Definitions of PA and LPA

In the conceptual model by Pettee Gabriel et al. (2012), PA is described as “*a complex and multidimensional behavior*” which is characterized by human movement. This framework is based on the assumptions that PA behaviour enhances health outcomes through “*increased energy expenditure and improved physical fitness,*” while sedentary behaviour compromises health outcomes. The four domains of PA include: (a) leisure-time or leisure (LPA); (b) occupation; (c) household, domestic, or self-care; and (d) transport. LPA has been described as activities, including exercise, that are considered non-essential to daily living, performed during “*free time,*” and based on personal preferences, interests, and needs (Howley, 2001; Moore et al., 2012; Sallis et al., 2006). As noted in **Table 1.2**, LPA can include diverse activities, such as formal exercise programs, gardening, sports, and dance. Exercise is considered LPA that is “*planned, structured, repetitive*” and purposeful (Caspersen et al., 1985; Dasso, 2019). For my research, I further differentiate structured exercise programs with aerobic, strengthening, and flexibility components from mind-body activities, such as yoga, Tai Chi, and Qigong. These distinctions are based

on categories previously employed by Dr. Lucie Brosseau and her team for the development of the Ottawa Panel clinical practice guidelines on the management of knee osteoarthritis (Brosseau, Taki, Desjardins, Thevenot, Fransen, Wells, Mizusaki Imoto, Toupin-April, Westby, Álvarez Gallardo, Gifford, Laferrière, Rahman, Loew, De Angelis, et al., 2017, 2017b, 2017a). It is necessary to differentiate the concepts of PA, LPA, and exercise as these terms are often used interchangeably in the research literature (Caspersen et al., 1985; Pettee Gabriel et al., 2012). I have selected these definitions and descriptions for PA and LPA as they reflect the growing interest in different domains of PA behaviour. Moreover, they provide methodological and practical considerations to guide the operationalization of these concepts within research contexts.

Other Relevant Definitions

Additional definitions and descriptions relevant to my dissertation work are provided in **Appendix B**. Supportive care is a term commonly used within oncology clinical and research practice. It refers to *“care given to improve the quality of life of people who have an illness or disease by preventing or treating, as early as possible, the symptoms of the disease and the side effects caused by treatment of the disease”* (National Cancer Institute, 2022). It involves multidimensional aspects (e.g., physical, psychological, social, and spiritual) of care for patients and families *“from the time of diagnosis until the end of life”* (National Cancer Institute, 2022). As described within the Multinational Association of Supportive Care in Cancer definition, *“enhancing rehabilitation, secondary cancer prevention, survivorship and end of life care are integral to Supportive Care”* (Olver et al., 2020; Rittenberg et al., 2010). Supportive care can include different types of support, such as *“pain management, nutritional support, counseling, exercise, music therapy, meditation, and palliative care”* (National Cancer Institute, 2022). Moreover, it can involve different disciplines, including medical oncology, palliative care, nursing, pharmacy, and allied health (e.g., physiotherapy, occupational therapy, psychology) (Olver et al., 2020).

My applied research in rehabilitation is conducted through a disciplinary lens situated in physiotherapy and its associated profession. Moreover, LPA and exercise are considered strategies that can support quality of life and symptom management in the cancer population. Thus, these descriptions help position my dissertation research in rehabilitation within the supportive care umbrella of cancer care.

The overarching objective of rehabilitation is to *“assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments”* (World Health Organization, 2011). Physiotherapy is a professional discipline within the rehabilitation sciences. The description provided by the Canadian Physiotherapy Association (2012) highlights the focus of physiotherapy in *“improving quality of life”* through optimizing aspects of mobility, PA, functional independence, and physical performance (Canadian Physiotherapy Association, 2012). Physiotherapists are health practitioners expected to possess a range of competencies (e.g., knowledge, skills, attributes) at entry-to-practice and at different milestones during their professional career (Canadian Physiotherapy Association, 2012; Chartered Society of Physiotherapy, 2020). For the purpose of this research, particularly the mixed-methods study with physiotherapists (Study 3), I focus on describing the knowledge and skills of physiotherapists. The Chartered Society of Physiotherapy framework describes physiotherapy knowledge as *“the theoretical knowledge required for physiotherapy practice”* (Chartered Society of Physiotherapy, 2020). Physiotherapy practice skills are *“the practical (psycho-motor) skills used by the physiotherapy workforce”* and include *“exercise, movement, manual therapy, electro-physical modalities and other physical approaches.”* Other generic behaviour, knowledge and skills of physiotherapists include communication, teamwork, diversity, lifelong learning, information gathering, critical thinking, decision-making, as well as evidence-based practice (Chartered Society of Physiotherapy, 2020; Ontario Council of University Programs in Rehabilitation Sciences, 2019). These descriptions are relevant to help guide the design and conduct of the mixed-methods study with physiotherapists (Study 3). Having provided an explanation of the

relevant definitions associated with my research, I turn now to a brief review of the literature that informs my dissertation.

Literature Review

Given my focus on exploring LPA in people with advanced cancer, my literature review examines three general areas of research. First, I describe the diverse challenges experienced by individuals diagnosed with advanced cancer. Next, I report on the research examining LPA in the advanced cancer population. Finally, I briefly examine the role of physiotherapists in supporting people with advanced cancer. Through this review, I highlight limitations of the current literature in order to inform future research inquiries. The findings of my scoping review (Study 1), performed as part of my research, also add further depth to these topics and are shared in Chapter 2 of this dissertation.

Challenges Experienced by People with Advanced Cancer

Progress in cancer detection and therapy options has contributed to declining mortality rates for the general cancer population, including advanced cancer (Canadian Cancer Statistics Advisory Committee, 2018; Canadian Cancer Statistics Advisory Committee in collaboration with the Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada, 2021; Peppercorn et al., 2011). Despite improvements in cancer control therapies, individuals with advanced cancer face several challenges, especially related to symptom burden and impairments in physical function. For example, in a study by Cheville et al. (2008), 92% of participants with metastatic breast cancer, presented with at least one physical impairment, such as lymphedema, motor weakness, and deconditioning. Moreover, these issues were commonly associated with challenges in physical function, including activities of daily living and mobility (Cheville et al., 2008). Other research shows that individuals with different types of advanced cancer also commonly experience moderate to severe symptoms, such as fatigue, dyspnea,

pain, nutritional concerns, insomnia, and neuropathies (Cardoso et al., 2016; Cheville et al., 2008; Henson et al., 2020; Hummler et al., 2014; LeBlanc et al., 2015; Li et al., 2019; Mayrbäurl et al., 2016; Rojas-Concha et al., 2021; Sheean et al., 2015; Yee et al., 2014). Furthermore, these cancer-related and treatment-related symptoms generally appear to worsen over the course of the disease trajectory, particularly towards the end of life.

Along with these concerns, deteriorations in physical performance measures, particularly aerobic fitness and muscle strength, also frequently occur in people with advanced cancer (Cheville et al., 2008; Hummler et al., 2014; Yee et al., 2014). My Master's thesis research shows that individuals diagnosed with advanced lung cancer experience rapid declines in measures of muscle strength and endurance capacity with chemotherapy treatment (Shallwani et al., 2016). Additional disease-specific concerns experienced by people with advanced lung cancer include reduced ventilatory capacity, and closer to the end of life, appetite concerns and coughing symptoms (Hummler et al., 2014; LeBlanc et al., 2015). Issues that are more common in individuals with metastatic breast cancer include weight gain and obesity, particularly among those on hormone therapies (Sheean et al., 2015). Thus, the literature shows that physical well-being is significantly impacted in patients due to the effects of advanced cancer and its treatments.

In addition to high symptom burden and prevalent physical impairments, psychosocial challenges are also of concern in people with advanced cancer. Some individuals experience feelings of worry and anxiety, depressive symptoms, isolation, and declined social support (Cardoso et al., 2016; Dunn et al., 2017; Hummler et al., 2014; LeBlanc et al., 2015). Clearly, people with advanced cancer face a wide range of physical and psychosocial concerns, which further contribute to issues with daily functioning and quality of life.

The impact of advanced cancer upon functioning has been demonstrated in patients through reported challenges with managing self-care, maintaining mobility (e.g., walking and stairs), performing

household tasks, and engaging in leisure activities (Cardoso et al., 2016; Cheville et al., 2009; Di Lascio & Pagani, 2017; LeBlanc et al., 2015; Yee et al., 2014). In a study of women with metastatic breast cancer, over half reported loss of income related to employment challenges (Cardoso et al., 2016). Although cancer control therapies are improving, survivors living with advanced cancer face tremendous functional challenges that impact their quality of life.

Supportive care initiatives are focused on providing tailored, interdisciplinary, and collaborative care in order to improve quality of life and address diverse issues experienced by people with cancer (Hui et al., 2021; Olver et al., 2020). However, many patients with advanced cancer report challenges with retrieving appropriate information related to diagnosis and treatment options, communicating with health professionals, obtaining emotional support, and accessing different types of multidisciplinary care, including rehabilitation support (Cardoso et al., 2016; Cheville et al., 2008; Dunn et al., 2017; Houldin & Lewis, 2006; Kemp et al., 2018; Lam et al., 2014; Lewis et al., 2015; Pollak et al., 2007; Wang et al., 2018). In the study by Cheville et al. (2008) with people with metastatic breast cancer, less than a third (30%) of physical impairments needing rehabilitation interventions received suitable treatment. Moreover, less than a quarter (21%) of impairments specifically requiring physical therapy and/or occupational therapy were appropriately addressed in these individuals. These findings demonstrate that unmet supportive care needs are common in people with advanced cancer. Further exploration is needed, including from a rehabilitation perspective, to develop, evaluate, and implement clinical strategies and interventions that better support this patient population throughout the continuum of cancer care.

LPA in Advanced Cancer

As the recognition of supportive care priorities in oncology is increasing, there is growing interest in modifiable health behaviours, such as PA and, more specifically, exercise and LPA, within the

cancer population. As reported in the recent American College of Sports Medicine guidelines, the positive effects of exercise for cancer survivors have been well established (Campbell et al., 2019). Important benefits supported by strong empirical evidence include reduced fatigue symptoms, improved anxiety and depressive symptoms, increased physical function, and enhanced quality of life (Campbell et al., 2019). In addition, pre- and post-diagnosis PA² levels have been found to be associated with decreased cancer-specific and all-cause mortality (Friedenreich et al., 2020; McTiernan et al., 2019). However, as noted in recent reviews (including my team's appraisal of clinical practice guidelines examining PA in cancer survivors), most research on this topic has been concentrated on people diagnosed with common cancers (e.g., breast, prostate, and colorectal cancers), who have early-stage disease, and who have completed active treatment for cancer (Campbell et al., 2019; Shallwani et al., 2019). People with other types of cancer, such as gastrointestinal and gynecological cancers, who might benefit from LPA are not well represented within the general cancer literature. Moreover, the potential effects of LPA in people receiving long-term cancer treatments for chronic or advanced cancers have not been well researched.

In individuals with advanced cancer specifically, most earlier reviews have focused primarily on intervention studies exploring structured exercise programs and have highlighted the lack of research on this topic (Albrecht & Taylor, 2012; Beaton et al., 2009; S. S. Lowe et al., 2009; Salakari et al., 2015). More recently, a systematic review of 25 studies confirmed the safety and feasibility of exercise interventions for people with advanced cancer (Heywood et al., 2017). Since then, several systematic reviews and meta-analyses published within the last five years have further supported these findings (Chen et al., 2020; De Lazzari et al., 2021; Dittus et al., 2017; Heywood et al., 2018; Nadler et al., 2019; Rodríguez-Cañamero et al., 2022). Moreover, they have also identified benefits with exercise for several

² When citing relevant research studies, I use the term described in the publications of interest (e.g., if the authors refer to physical activity (PA) in the publication, then I also use PA).

clinical outcomes, including quality of life, physical function (self-reported and clinically-assessed measures), fatigue symptoms, sleep quality, and social function. In a meta-analysis of 11 studies, higher PA levels in people with advanced cancer were associated with reduced mortality risk in non-randomized studies, but this finding was not supported by randomized trials (Takemura et al., 2021). Nonetheless, there is mounting evidence supporting the benefits of PA participation for the advanced cancer population.

While these findings are promising, several limitations exist in the current body of literature. Most previous reviews have been limited to intervention studies and as such, they have not considered other topics of relevance to people with advanced cancer. Little is known about studies exploring patient experiences with participating in LPA, as well as specific facilitators, barriers, and preferences identified by these individuals. Furthermore, other leisure activities besides structured aerobic and resistance exercise programs have not been well studied in the cancer literature (Bradt et al., 2015; Buffart et al., 2012; Campbell et al., 2019; Wayne et al., 2018; Yang et al., 2021). Such activities include gardening, dance, sports, as well as mind-body exercises (e.g., yoga, Tai Chi, and Qigong). Like structured exercise programs, these activities may be beneficial in terms of improving clinical outcomes of interest. Moreover, the meaningfulness and enjoyability of such leisure activities for individuals with advanced cancer have not been well explored. Thus, the findings of this review highlight increasing evidence of benefits with exercise for people with advanced cancer but indicate there remain important gaps in the research literature related to this topic.

Role of Physiotherapists in Advanced Cancer

Along with these research limitations, little is also known from a rehabilitation perspective on how to develop and personalize supportive care strategies in order to assist individuals with advanced cancer through LPA. People with advanced cancer have reported they feel capable of and interested in

PA (Burke et al., 2020; S. S. Lowe et al., 2010), but experience several barriers to participating in PA. Barriers include cancer-related and treatment-related symptoms (e.g., fatigue, pain, weakness), apprehensions about injury, limited professional guidance, and lack of accessible, suitable settings (Burke et al., 2020; Cheville et al., 2012; Frikket et al., 2020; Sheill, Guinan, Neill, et al., 2018a). Trained rehabilitation professionals, particularly physiotherapists, may be able to support patients in managing barriers to activity and safely participating in PA (Barnes et al., 2020; Campbell et al., 2022). Moreover, there may be benefits with physiotherapy interventions on symptom management and functional status in the advanced cancer population (Bernabeu-Wittel et al., 2021; Pyszora et al., 2017). The inclusion of specialized rehabilitation professionals within cancer care models has been proposed to incorporate routine functional screening, to provide exercise support and supervision, particularly for those with physical impairments and co-morbidities, and to offer other tailored rehabilitation strategies (Barnes et al., 2020; Schmitz et al., 2019). However, little is known on the ability of physiotherapists to specifically support individuals living with advanced cancer. Specific needs for increased knowledge about bone metastases, physical examination, intervention safety, and PA prescription have been identified in previous studies with Dutch and Irish physiotherapists (Sheill, Guinan, O Neill, et al., 2018; Ten Tusscher et al., 2020). Within a Canadian context though, the clinical practices, as well as the knowledge and skills of physiotherapists related to people with advanced cancer have not been well explored (Canestraro et al., 2013; Dunphy & McNeely, 2022). Increased understanding of these aspects of physiotherapy practice can help guide the development and integration of LPA resources, as well as other types of rehabilitation support in the care of people with advanced cancer.

Summary of Literature Review

The literature review on this topic demonstrates that individuals with advanced cancer face significant health-related challenges, resulting in issues with daily functioning, impacted quality of life,

and unmet supportive care needs. While the benefits of LPA are becoming increasingly recognized for people following cancer diagnosis, less is known about this topic in people with advanced cancer. In particular, there appears to be limited research knowledge on patient perceptions and experiences of LPA, especially related to different types of leisure activities. In addition, there are gaps in understanding the specific role and ability of physiotherapists to support these patients through LPA, particularly within a Canadian context. The findings of this brief literature review have highlighted the need for a more comprehensive review of the research on the topic. Moreover, they have helped identify important research questions informing my dissertation work, namely to explore LPA from the perspectives of people with stage 4 cancer and to describe knowledge, skills, and perspectives in physiotherapists related to working with advanced cancer. Having provided a review of the literature on this topic, I now discuss theoretical considerations informing my research.

Theoretical Considerations

In this section, I first briefly describe research paradigms and explain the rationale for selecting a pragmatic view to guide this dissertation work. Next, I explore theories of health behaviour to understand factors that may influence LPA participation. These theoretical conceptualizations help inform the methodological components of this research.

Positioning My Research: A Pragmatic Paradigm

Personal reflections and learnings of different research paradigms have helped me establish my own position within this research. Traditionally, research in the rehabilitation sciences has been conducted using quantitative approaches, guided by positivism. This paradigm is centralized around the concept of a single objective truth, which is independent from the mind (Creswell & Creswell, 2018). It emphasizes deductive reasoning (theory testing and verification) and is based on “*empirical observation*

and measurement" (Creswell & Creswell, 2018). However, there is increasing recognition of the need to study phenomenon in greater depth, to appreciate individual variations, to understand lived experiences within social contexts, and to acknowledge the role of the researcher in generating knowledge. This evolving appreciation has resulted in a rising popularity of qualitative approaches employed within rehabilitation research (VanderKaay et al., 2018). Qualitative research is often informed by a constructivist view. Constructivism acknowledges the existence of multiple realities, emphasizes knowledge is socially constructed, and involves inductive processing to generate new theories (Creswell & Creswell, 2018).

As a researcher with a clinical background in physiotherapy, I recognize the value of both post-positivist and constructivist paradigms within the context of rehabilitation research. For example, there is empirical evidence of the positive effects associated with exercise in people diagnosed with cancer, such as the recently published American College of Sports Medicine exercise guidelines for cancer survivors (Campbell et al., 2019). However, there are different ways in which individuals personally experience health conditions, such as cancer, and participate in exercise behaviour. Moreover, I appreciate that contextual factors can shape individual experiences. This recognition supports an ontological position, which acknowledges the existence of singular and multiple realities. In terms of epistemology, I accept my position and assumptions as a researcher can affect the research processes and analytical interpretations. For example, I recognize my professional discipline, clinical practice, and personal experiences have contributed to shaping my own views towards PA and rehabilitation in people affected by cancer. Thus, my pre-conceived assumptions and biases can influence my research findings. However, I also appreciate suggestions to differentiate clinical and research roles in order to enhance neutrality as a researcher, as well as recommendations to improve personal reflection, transparency, and rigor in research (Thorne, 2016). From a methodological standpoint, I recognize exploring multiple perspectives and employing different methodologies can help me gain a diverse,

inclusive understanding of my area of research interest. Therefore, my personal belief is that research conducted through multiple research paradigms can improve comprehensive knowledge in rehabilitation sciences and guide different aspects of clinical practice. As described in a paper which explores mixed-methods research to support physiotherapy practice, *“it is the integration of evidence from both qualitative and quantitative research approaches that will allow research to inform the education, empowerment, and treatment of patients for physiotherapy practice that is comprehensively evidence based”* (Shaw et al., 2010).

These personal reflections have led me to embrace a pragmatic paradigm for my dissertation research. In pragmatism, the research question is central to the process, and ontological and epistemological grounds are based on practicality, or *“what works”* (Creswell & Creswell, 2018; Creswell & Plano Clark, 2017). As explained by Yvonne Feilzer (2010), *“pragmatism, when regarded as an alternative paradigm, sidesteps the contentious issues of truth and reality, accepts, philosophically, that there are singular and multiple realities that are open to empirical inquiry and orients itself toward solving practical problems in the ‘real world’”* (Yvonne Feilzer, 2010). Thus, this approach is both problem-oriented and practice-oriented, and focuses on producing applicable solutions to real-world problems (Creswell & Creswell, 2018). The concepts of abductive reasoning (moving between inductive and deductive processes), intersubjectivity (duality of subjectivity and objectivity), and transferability (context-dependent) are supported within pragmatism (Creswell & Plano Clark, 2017; Morgan, 2007). Taking this *“pluralistic”* approach permits the exploration and identification of methods most useful and appropriate in addressing diverse research questions (Creswell & Creswell, 2018; Johnson & Onwuegbuzie, 2004). In pragmatism, methods are matched to specific research questions and selected based on which will offer the best opportunities to answer questions in *“real-world practice”* (Creswell & Plano Clark, 2017; Johnson & Onwuegbuzie, 2004; Mackenzie & Knipe, 2006). Thus, pragmatism can serve as a valuable, all-encompassing epistemological orientation to address the different research

questions identified within my dissertation work and help inform practical solutions in the area of cancer rehabilitation.

Theories of Health Behaviour

Complementing existing research findings and my selected paradigm, theoretical conceptualizations of health behaviour can assist in explaining individual, interpersonal, and environmental factors that influence PA behaviour. For the purpose of my dissertation, I briefly describe the Ecological Model of 4 Domains of Active Living, along with the Health Belief Model. These theories are relevant in informing my research inquiries and methods to explore LPA as a health behaviour in people with advanced cancer (**Table 1.3**).

Table 1.3 *Theories of Health Behaviour*

Theory	Overview
Ecological Model of 4 Domains of Active Living	Developed in 2006, the Ecological Model of 4 Domains of Active Living acknowledges multiple levels of influence on four active living domains: recreation, transport, occupation, and household. The multilevel model considers intrapersonal factors, perceived environments, behaviour (active living domains), behavioural settings (including access and characteristics), and policy environment (Sallis et al., 2006; Sallis & Owen, 2015).
Health Belief Model	First developed in the 1950's with four constructs, the Health Belief Model currently includes six constructs as conceptual factors influencing health behaviours (Champion & Skinner, 2008; Janz & Becker, 1984). These include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action, and self-efficacy.

Extensive research has supported the application of current individual and interpersonal theories of health behaviour in understanding and targeting change in PA behaviour. Examples of these models include the Health Belief Model, the Theory of Planned Behavior, and the Social Cognitive Theory (Armitage, 2005; Basen-Engquist et al., 2013; Dzewaltowski et al., 1990; Godin & Kok, 1996;

Keller et al., 1999; Marcus et al., 1996). While individual and interpersonal health behaviour models have been widely used, single-level models provide a limited perspective in understanding PA behaviour and related constructs (Bauman et al., 2002; Burke et al., 2020; Marcus et al., 1996; Sherwood & Jeffery, 2000). In relatively more recent literature, the roles of socio-environmental influences, such as social support, perceived environment, and accessibility, have been highlighted in facilitating or impeding PA behaviour (Burke et al., 2020; Fleury & Lee, 2006; Yen & Li, 2019). An ecological approach considers multiple, interactive factors at the individual and environmental levels that directly impact health behaviours (Sallis et al., 2006; Sallis & Owen, 2015). Further research is needed to identify the most important environmental variables influencing PA behaviour and to test multi-level models, particularly in understudied populations. However, an ecological perspective is promising and offers a comprehensive and exploratory approach to PA research within different contexts and populations (Burke et al., 2020; Sallis & Owen, 2015; Yen & Li, 2019). Research employing the Ecological Model of 4 Domains of Active Living to examine environmental factors affecting PA participation in individuals with cancer supports the notion that there are multiple levels of influence on health behaviour within this population (Burke et al., 2020; Chou et al., 2017; A. Jones & Paxton, 2015).

Intrapersonal (individual) factors are acknowledged within the Ecological Model of 4 Domains of Active Living, but researchers propose the use of existing psychosocial theories to establish additional specificity within this level (Sallis et al., 2006). For the purpose of my dissertation, combining the theoretical conceptualizations from the multi-level approach of the Ecological Model of 4 Domains of Active Living with those from the widely supported Health Belief Model are useful in guiding my research inquiries and informing the designs and methods of the individual studies.

Summary of Literature and Theoretical Considerations

To conclude this section, my review of the literature demonstrates several gaps in the existing research knowledge related to understanding LPA in people with advanced cancer, from a rehabilitation perspective. These research limitations, along with theoretical considerations of pragmatism and ecological factors influencing LPA behaviour, have informed the rationale and research objectives of my dissertation. Furthermore, they have guided the development of the research design and methodologies for the individual studies within my dissertation research, which I further describe in the next section.

Methodological Considerations

The pragmatic paradigm and existing research and theoretical knowledge described earlier in this chapter are key in informing the methodological considerations within my dissertation work. To address the overall purpose of exploring LPA in people with advanced cancer, my research consisted of three separate studies: (1) a scoping review of 92 articles (Study 1); (2) a qualitative interpretive-description study involving individual interviews with 20 Canadian adults diagnosed with stage 4 cancer (Study 2); and (3) a mixed-methods study consisting of online survey with 62 Canadian physiotherapists, followed by qualitative individual interviews with 13 physiotherapists (Study 3).

In this section, I describe the methodological approaches guiding each study within this research. Following this, I briefly explain the methods, in terms of data sources and recruitment strategies, as well as the data collection and analytic processes. The methods for Study 1, Study 2 and Study 3 are shared in greater detail within Chapters 2, 3, and 4, respectively, of this dissertation. In addition, the scoping review protocol for Study 1 has been published in the journal *Physical Therapy Reviews*. The accepted manuscript for the review protocol is provided in **Appendix A**. Here, I focus on the methodological decisions made within the context of this dissertation work and outline the specific methodologies and methods employed in the individual research studies. I also outline how theoretical

conceptualizations help inform my research methodologies and methods within this dissertation work.

An overview of the research methods is provided in **Table 1.4**.

Table 1.4 Overview of Research Methods

Overall purpose of dissertation: To explore LPA in people with advanced cancer through the perspectives of adults diagnosed with stage 4 cancer and of oncology physiotherapists in Canada			
	Study 1: Scoping review	Study 2: Patient study	Study 3: Physiotherapist study
Objectives	To map the research and understand key concepts from the literature about LPA in people with advanced cancer	To explore the experiences and perspectives of LPA in adults diagnosed with stage 4 cancer	To describe the clinical practices, knowledge, skills and perspectives of oncology physiotherapists related to PA in people with advanced cancer
Methodology	Scoping methodology (Arksey & O'Malley, 2005)	Qualitative interpretive-description methodology (Thorne, 2016)	Explanatory, sequential mixed-methods study design (Creswell & Plano Clark, 2017); interview component informed by qualitative interpretive-description methodology (Thorne, 2016)
Methods	Scoping review of 11 electronic databases and supplementary sources	Qualitative semi-structured individual interviews	Online cross-sectional survey with closed and open-ended questions, followed by qualitative semi-structured, individual interviews
Inclusion criteria	English-language, peer-reviewed journal articles on original primary research studies exploring LPA in adults diagnosed with advanced cancer	Canadian adults diagnosed with stage 4 (metastatic) cancer - Recruited through social media, local cancer institutions and word-of-mouth	Canadian oncology physiotherapists with current or past clinical experience working with people with advanced cancer - Recruited through CPA Oncology Division and word-of-mouth
Number of studies / participants	N = 92 studies	N = 20 patient participants	N = 62 physiotherapist participants (surveys) and 13 physiotherapist participants (follow-up interviews)

CPA: Canadian Physiotherapy Association; LPA: leisure-time physical activity; PA: physical activity

Methodologies

In this section, I describe the methodologies guiding each research study and explain the rationale for selecting the respective methodologies. In doing so, the methodological connections between the three individual studies are further highlighted.

Scoping Methodology (Study 1)

The objectives of Study 1 are to map the research and to understand key concepts from the literature exploring LPA in people with advanced cancer. To achieve this, I conducted a scoping review of the literature on this topic. My scoping review was guided by the Arksey & O'Malley (2005) methodology, as well as subsequent recommendations on scoping methodology that build on this foundational framework (Daudt et al., 2013; Davis et al., 2009; Levac et al., 2010; Peters et al., 2015).

As described by Daudt et al. (2013), the aim of scoping reviews is *“to map the literature on a particular topic or research area and provide an opportunity to identify key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking, and research”* (Daudt et al., 2013). Scoping reviews can provide an extensive review of relevant literature (literature mapping) and help clarify terms (concept mapping), and this approach may be particularly valuable to employ in understudied or complex research areas (Anderson et al., 2008; Arksey & O'Malley, 2005; Levac et al., 2010; Rumrill et al., 2010). Research applications in oncology illustrate the use of scoping methodology to address inquiries related to survivorship issues, symptom management, PA participation and exercise programs, as well as the use of patient-reported outcomes (Howell et al., 2015; Neil-Sztramko et al., 2022; Nichol et al., 2016; Pearson et al., 2018; Richardson et al., 2011; L. Smith et al., 2015).

There were several reasons to select the scoping review methodology to fulfill the first objectives of my dissertation research. Firstly, as noted in recent guidelines and reviews, the topic of LPA, including exercise, has not been well studied in the advanced cancer population (Campbell et al.,

2019; Shallwani et al., 2019). Moreover, most previous reviews on this topic have been limited to studies examining exercise interventions (Chen et al., 2020; Heywood et al., 2017, 2018; Nadler et al., 2019). Thus, it was important to broadly “map” the different types of research currently available and identify clear gaps in the literature to inform the subsequent studies of my dissertation work. Secondly, as noted earlier in this chapter, there exist challenges with defining and operationalizing the term advanced cancer. It was necessary to examine the specific criteria and descriptions used to characterize the advanced cancer population in the literature. Along the same lines, there is often uncertainty and interchangeable use between PA, LPA, and exercise, despite efforts to clearly define and conceptualize these individual terms. Moreover, as noted in my review of the literature in this chapter, LPA beyond exercise, may be meaningful and this has not been well explored in the literature. For these reasons, there was a need to comprehensively review the current research on LPA in advanced cancer and understand how key concepts are described and studied on this important topic.

Through the adoption of scoping methodology, this review provides an extensive understanding of the research evidence on LPA in people with advanced cancer. In particular, the information from this review can be useful to improve knowledge about the safety, feasibility, effects, and experiences of LPA for this population, and understand the applicability of research findings to certain population subgroups or types of LPA. Moreover, this approach can help identify gaps in the current literature to guide future research inquiries related to this topic. The recognition of research gaps and clarification of key concepts through the scoping review are key in informing the designs and methods of my dissertation research studies with the patients with stage 4 cancer (Study 2) and the oncology physiotherapists (Study 3), which are described next.

Interpretive-Description Methodology (Study 2)

The objective of Study 2 is to explore perspectives and experiences of LPA in Canadian adults diagnosed with stage 4 cancer. To address this research question, I conducted a qualitative study, consisting of individual, semi-structured interviews. This study was informed by the interpretive-description methodology (Thorne, 2016; Thorne et al., 1997, 2004).

First established in the field of nursing, the interpretive-description methodological approach is useful to generate knowledge about health-illness experiences within a variety of applied health sciences. Informed by existing theoretical and research knowledge, this approach aims to address new experiential questions and provide relevant implications for clinical practice. It involves recognizing commonalities and shared meanings in lived experiences, while appreciating individual differences, in order to develop novel understandings and conceptualizations of the phenomena under study (Thorne et al., 2004). The interpretive-description methodology has been adopted in other studies focused on PA in individuals with cancer and non-cancer diagnoses (Rathanaswami et al., 2016; C. Smith et al., 2009; Weisenbach & McDonough, 2014).

I selected the interpretive-description approach for Study 2 to better understand perspectives and experiences of LPA in people with advanced cancer, from a rehabilitation perspective. The findings of the scoping review (Study 1) demonstrate there has been valuable progress in research examining the effects of aerobic and resistance exercise interventions with this population. However, less is known about real-life experiences, perceptions, facilitators, barriers, and preferences of LPA and how this information can be applied to support cancer care. In particular, there is a need for research to help guide the development of clinical resources and services in the area of cancer rehabilitation. The interpretive-description approach provides a framework of how to establish new knowledge on this topic within the context of previous existing knowledge and identify relevant applications to clinical practice. Moreover, it provides direction on how to situate myself as a physiotherapist with experience in oncology and differentiate my clinical and research roles within the context of this work. Thus, the

interpretive-description methodology serves as a valuable approach to addressing my research objective regarding LPA experiences in the advanced cancer population, while informing considerations for rehabilitation practice.

Guided by the interpretive-description methodology, this work provides a deeper understanding of patient experiences and perspectives of LPA in people with stage 4 cancer, particularly from a rehabilitation perspective. This knowledge, along with the viewpoints of rehabilitation professionals, can further inform the development of rehabilitation and supportive care resources in oncology practice. Thus, the methodological approaches of this study with individuals with stage 4 cancer (Study 2), as well as the study described next with oncology physiotherapists (Study 3), both aim to guide practical applications for the clinical care of people with advanced cancer.

Mixed-Methods Approach (Study 3)

The objective of Study 3 was to describe the clinical practices, knowledge, skills, and perspectives of Canadian oncology physiotherapists related to LPA³ in people with advanced cancer. For this study, I selected an explanatory, sequential mixed-methods approach, which involved two parts: a cross-sectional online survey, followed by qualitative, individual interviews. The interviews were also guided by the qualitative interpretive-description methodology (used in Study 2). The interpretive-description methodology supports utilizing different data collection methods to develop new experiential knowledge and to determine clinical implications for practice-based disciplines, such as physiotherapy (Olsen et al., 2013; Thorne, 2016).

³ The overall focus of my dissertation research is leisure-time physical activity (LPA). In the mixed-methods study with the physiotherapists (Study 3), the survey questions were based on a previously developed survey examining views on physical activity (PA) and PA-related recommendations and concerns. The interview questions sought perspectives about LPA and exercise. Since the survey questions did not specify LPA, I have used the general term PA for the manuscript related to this study (presented in Chapter 4), except when LPA was specifically indicated.

Mixed-methods research involves the use of both quantitative and qualitative information to answer certain types of research questions. This approach can address research problems benefitting from more comprehensive and validated findings, by capturing generalized information through a quantitative component, as well as detailed information through a qualitative component (Creswell & Plano Clark, 2017). In some cases, qualitative data collection and analysis can also help explain initial quantitative findings (i.e., explanatory, sequential mixed-methods study design) (Creswell & Plano Clark, 2017). There is increasing recognition of the use of mixed-methods approaches in patient-level and professional-level research in rehabilitation, including work specifically exploring rehabilitation and exercise strategies for the cancer population (Dennett et al., 2017, 2022; Hauken et al., 2019; Rauscher & Greenfield, 2009; Shaw et al., 2010; Ten Tusscher et al., 2019, 2020; Tsianakas et al., 2017).

I chose a mixed-methods approach to gain comprehensive information related to the third objective of my dissertation research concerning Canadian physiotherapy practice. The survey component allows me to obtain broad, general information about clinical practices, knowledge, and skills from a large number of physiotherapist participants. Therefore, this step helps provide an overall descriptive understanding of current trends in physiotherapy oncology practice within Canada. The interview component provides detailed information on the perspectives of physiotherapists towards LPA in people with advanced cancer, as well a deeper comprehension of their generalized clinical experiences with this clinical population. In addition to providing a more complete understanding of this topic, the interview component helps provide clarifications and additional insight to the survey findings. Finally, the mixed-methods approach offers a practical and feasible approach to collecting different types of data to address research questions, within a reasonable timeframe. Thus, this approach is useful to understand different aspects of clinical practice in Canadian oncology physiotherapists working with advanced cancer.

The mixed-methods design of this research study with physiotherapists can improve knowledge about generalized physiotherapy practice in the care of people with advanced cancer, as well as specific views and perspectives of physiotherapists related to LPA. Moreover, through a practice-oriented approach, it can inform rehabilitation initiatives aimed at improving the care of people with advanced cancer. In particular, this work can help elucidate the specific roles of physiotherapists in clinical oncology practice. Furthermore, it can identify information and training needs in physiotherapy and guide educational strategies to further support health professionals in oncology.

To summarize, the methodologies selected for the three individual studies include scoping methodology for the review (Study 1), interpretive-description methodology for the study with patients with cancer (Study 2), and a mixed-methods approach with interpretive-description methodology for the study with physiotherapists (Study 3). These methodological approaches can appropriately address the research objectives of my dissertation work. Moreover, the resultant findings can help inform future initiatives aimed at improving LPA resources and supportive cancer care services for people with advanced cancer. Having provided an overview of the methodologies guiding my research studies, I now briefly describe the methods of each study, with respect to data sources, recruitment, data collection, and analysis.

Data Sources and Recruitment

In this section, I describe the three sources of data for my dissertation research: (1) literature review; (2) patient participants; and (3) physiotherapist participants. Detailed information on the specific methods for each study is provided within Chapters 2, 3, and 4. Here, I focus on the rationale for my choice of research methods. I also briefly explain the recruitment process and strategies for each study involving participants. Additional recruitment materials are provided in **Appendix C**.

Literature Review (Study 1)

For the scoping review in Study 1, the article selection criteria consisted of original primary research studies that: (a) included adults diagnosed with advanced cancer (e.g., stages 3-4 cancer, incurable, palliative) at any phase of the disease trajectory and in any clinical setting; (b) explored LPA post-cancer diagnosis as a main study focus; (c) adopted any study design or methodology; and (d) were published in peer-reviewed journal articles with English full texts available.

Several considerations supported the development of the article selection criteria for this review. As the purpose of the scoping review was to comprehensively review the scope of literature, the criteria were designed to be broad and inclusive. At the time of planning the scoping review, I adopted the earlier National Cancer Institute definition of advanced cancer (**Table 1.2**), which focused primarily on disease spread as well as the unlikelihood of cure or control (National Cancer Institute, 2007). Thus, examples of terms included for the study population included stages 3-4, incurable, palliative / hospice, as well as limited life expectancy and survival rates. Moreover, to address gaps in the literature, the other criteria were inclusive of study populations in various disease phases and clinical settings, of diverse leisure activities, as well as of different study designs. The article selection criteria were established *a priori* and refined post-hoc following a pilot trial exercise and iterative discussions with the research team (Levac et al., 2010; Pham et al., 2014).

In collaboration with librarians at the University of Ottawa Health Sciences Library, I developed an extensive literature search of 11 electronic databases and supplementary sources (e.g., reference lists, grey literature, citation analysis). Two reviewers, including myself, independently screened the abstracts and full texts to determine eligibility for inclusion. Following an initial literature search in February 2018 and an updated search in January 2020, 92 articles were identified for inclusion in the scoping review. Thus, these review procedures supported the goal of Study 1 to broadly examine the literature on LPA in people with advanced cancer.

Patient Participants (Study 2)

For the qualitative interpretive-description study with patient participants (Study 2), I recruited a sample of 20 individuals with advanced cancer. Specifically, the following inclusion criteria were applied: (a) adults diagnosed with different types of stage 4 (metastatic) solid tumour cancers at any phase of the cancer trajectory; (b) English-speaking; and (c) living in Canada.

The inclusion criteria and recruitment strategies for the participants of Study 2 were established according to several factors. During the development of the dissertation proposal, the definitions of advanced cancer focused on the concept of incurability (Canadian Cancer Society, 2020; National Cancer Institute, 2017; Peppercorn et al., 2011). Moreover, the findings of the scoping review (Study 1, which was completed prior to the dissertation proposal) highlighted the heterogeneity of advanced cancer and established the need for specific criteria to identify study populations. These considerations informed the decision to select stage 4 disease and solid tumour cancers as part of the inclusion criteria for this study. In addition, to address the population-related gaps (e.g., cancer type, age, gender) noted in the scoping review (Study 1), deliberate efforts were made to recruit a diverse sample of patients with advanced cancer within this study. The target sample size was set to 20 participants based on similar studies related to this topic (Adamsen et al., 2012; Cheville et al., 2012; Sheill, Guinan, Neill, et al., 2018a). As well, through this sample size, I aimed to capture population differences that could yield individual variations within the participants' perspectives and experiences (Thorne, 2016).

Eligible participants were recruited to the study through purposeful sampling in two stages. First, I contacted relevant cancer-related and patient support groups using social media channels. Based on the preferences of each contact, the study recruitment poster was posted online by myself or the administrator of the social media page or group. Next, I requested local cancer centres and clinics located in Ottawa, Ontario and Montreal, Quebec to disseminate the study information through email

lists, as well as online posts on websites and social media. Halfway through the study, I specifically targeted participants with non-breast cancer diagnoses to achieve a more diverse representation of stage 4 cancer, in terms of cancer type. These recruitment strategies supported the exploration of perspectives and experiences in people with different types of advanced cancer for Study 2.

Physiotherapist Participants (Study 3)

For the mixed-methods study with physiotherapist participants (Study 3), the inclusion criteria included the following: licensed physiotherapists practicing in Canada, with current or recent (within last five years) clinical experience working with adults diagnosed with advanced cancer.

Several considerations informed the selection and recruitment of physiotherapist participants for Study 3. Physiotherapists located in Canada were recruited to provide specific contextual information on Canadian physiotherapy practice in oncology. Due to the focus of this research in advanced cancer, I also sought physiotherapists with relevant experience working with this patient population. The survey for Study 3 was disseminated through the Canadian Physiotherapy Association Oncology Division member email list (membership n=195). The average response rate for online surveys with health care professionals is around 30% to 40% (Cho et al., 2013). As my focus was a subset of physiotherapists with specific experience in advanced cancer, I selected a conservative target sample size of 39 physiotherapists (20% of Oncology Division group members). For the interview phase of the study, I targeted 10 participants to gain diverse perspectives that would supplement the survey findings (Creswell & Plano Clark, 2017).

Through convenience sampling, eligible physiotherapists were recruited to participate in the survey, mainly from the Canadian Physiotherapy Association Oncology Division member email list. Other sources of recruitment included social media posts on the Canadian Physiotherapy Association Oncology Division Twitter and Facebook pages, as well as by word-of-mouth through personal contacts (i.e.,

Canadian researchers and physiotherapy clinicians specialized in cancer rehabilitation). The survey was active over a six-week period, during which information about the study was shared at regular intervals (e.g., three emails through Division email list over six weeks). In the last question of the survey questionnaire, the respondents were asked to provide their contact information if they wished to participate in follow-up interviews. These physiotherapists were contacted within two months following the end of the survey period. Those that responded and confirmed their interest were invited to participate in the interviews. The actual sample sizes of the study (n=62 survey respondents and n=13 interview participants) were higher than originally anticipated. Thus, these recruitment strategies contributed to providing a thorough understanding of Canadian physiotherapy oncology practice with advanced cancer in Study 3.

Data Collection and Analysis

In this section, I briefly describe the processes of data collection for the three individual studies. Additional materials related to data collection that are not provided within the chapters are shared in **Appendix D**. I also describe the analytic methods for the different types of data in my dissertation research. These include the literature from the scoping review (Study 1), the qualitative interview data (Studies 2 and 3), and the mixed-methods survey data (Study 3). Again, these are discussed in more depth in each manuscript, but what is provided here is an overview of the study methods, as well as particular links between the methods of the individual research studies (e.g., qualitative data analysis in both Studies 2 and 3).

Scoping Review Data Extraction (Study 1)

To map the literature on LPA in advanced cancer in Study 1, two reviewers extracted and verified relevant data from the included articles: (a) study descriptive characteristics (e.g., publication

year, location); (b) study methodological characteristics (e.g., type, design, methods); and (c) population characteristics (e.g., age, gender, diagnosis). To address the secondary objectives of understanding key concepts, we recorded the specific terms used to describe the advanced cancer population within the included articles (e.g., stage, metastatic, palliative, incurable). We also reviewed how the concept of LPA was operationalized (e.g., as a quantitative outcome, a qualitative theme, or a study intervention) and examined the specific components of LPA that were explored within each included study. Draft data extraction forms are provided in the published review protocol (see **Appendix A**).

Scoping Review Data Analysis (Study 1)

Following the literature search, there were 92 articles retrieved for inclusion in the scoping review. To map the literature, I performed a narrative, descriptive synthesis of information related to the characteristics and methods of each included study, as well as the study populations. In consultation with the research team members, I also conducted thematic analyses of the content on study inclusion criteria and descriptive characteristics, in order to understand how advanced cancer populations are described within research contexts. Finally, I examined how LPA was explored within the studies (e.g., as a main quantitative outcome, as a qualitative focus, or as an intervention or clinical program) and characterized details regarding the assessment or implementation of LPA. As the included studies were heterogenous in nature, I did not perform any quality appraisal or formal data synthesis in this review.

Patient Interview Data Collection (Study 2)

To obtain information on the experiences and perspectives of people with advanced cancer, I developed an interview guide for Study 2 (see **Appendix D**). This process was guided by the interpretive-description methodology and informed by previous theoretical and research knowledge (Thorne, 2016). The interview questions addressed the following areas: (a) experiences with LPA pre- and post-cancer

diagnosis; (b) perceptions and beliefs related to LPA; (c) facilitators and barriers of LPA; (d) professional information and support about LPA received following cancer diagnosis; (e) preferences related to LPA programs and resources; and (f) the impact of COVID-19 on LPA.⁴ A pre-interview questionnaire was also created to obtain descriptive information on demographics, cancer history, and past and current participation in LPA.

Following initial contact with the research team, the participants completed the consent form and the pre-interview questionnaire online. Subsequently, I conducted individual, semi-structured interviews with the study participants virtually using an online video-conferencing program (Zoom version 5.9.1). The interviews were recorded through built-in features of the video-conferencing program and a second external recorder. In addition, I recorded field notes and observations in an interview journal. I transcribed over half of the interviews independently with the aid of a transcription software program and the remaining interviews were transcribed professionally. Following transcription, transcript summaries were shared with the participants for review and feedback.

Physiotherapist Survey Data Collection (Study 3, Part 1)

For the first part of Study 3 with the physiotherapists, I utilized a mixed-methods survey questionnaire (see Chapter 4). The questions were adapted, with permission, from a previously developed survey (Sheill, Guinan, O Neill, et al., 2018). Closed-ended questions addressed participant characteristics (e.g., gender, age, years of professional experience, clinical setting), components of clinical practice with advanced cancer (e.g., types of patients, types of services provided), as well as views towards PA in people advanced cancer (using a Likert scale). The final component of the survey

⁴ As this research study was conducted during the COVID-19 pandemic, I asked about the impact of COVID-19 to better understand contextual factors which may influence participation in leisure-time physical activity. This data did not significantly shape the overall research findings, so I did not include it for the purpose of the manuscript in Chapter 3. However, this data may be further examined within future research addressing this specific topic.

sought PA recommendations and concerns related to two clinical case scenarios of advanced cancer, through the use of open-ended questions. The survey was administered using the online SurveyMonkey program (SurveyMonkey Inc., San Mateo, California).

Physiotherapist Interview Data Collection (Study 3, Part 2)

To obtain detailed information on the perspectives and experiences of physiotherapists working with advanced cancer, I developed an interview guide for Study 3 (see **Appendix D**). The interview questions explored the following areas: (a) clinical setting and experience; (b) perspectives about LPA in people with advanced cancer; and (c) overall perspectives and experiences related to working with this population. Similar to the study with patient participants (Study 2), the physiotherapist participants completed a consent form online and were provided with a shortened interview guide prior to the interviews. I conducted the interviews online using Zoom or over the phone, depending on participant preference. The interviews were recorded, while field notes and observations were captured in an interview journal. I transcribed the majority of the interviews independently. Following transcription, transcript summaries were shared with the participants for review.

Qualitative Interview Data Analysis (Study 2 and Study 3, Part 2)

There were qualitative data obtained from the interviews with both the patient participants (Study 2) and the physiotherapists participants (Study 3, Part 2). Inductive analysis consistent with interpretive-description was undertaken with the goals of generating thematic summaries, forming new understandings of health-illness experiences, and identifying applications for clinical practice (Thorne, 2016; Thorne et al., 2004). With the use of the qualitative analytical software, NVivo (QSR International, release version 1.6.1), I coded and analyzed the verbatim transcripts of the interviews. The analysis

occurred concurrently during data collection to develop and test the analytical framework, which further informed and guided the conduct of subsequent interviews.

To ensure the quality of the research interpretations, I implemented the following processes. Through the use of interview memos and reflective journaling, I documented ongoing methodological decisions, researcher observations and thought processes, and evolving analytic findings over the course of the research. I also emailed participants a summary of their interview transcript, as an opportunity to provide feedback and additional insight. Finally, my research team members (supervisors and committee members) were collaboratively involved in developing and reviewing the research findings.

Mixed-Methods Survey Data Analysis (Study 3, Part 1)

For the online survey with the physiotherapist participants (Study 3, Part 1), the response rates were tracked and reported. The quantitative data from the closed-ended questions concerning the physiotherapists' demographics and clinical practices, as well as their views towards PA, were analyzed descriptively. The qualitative data from the open-ended questions addressed PA-related concerns and strategies for the advanced cancer clinical case scenarios. These data were coded line-by-line and categorized using the NVivo software program. Through iterative analysis with the research team, the data were organized into broader themes and summarized to produce general recommendations related to PA in people with advanced cancer.

Theoretical Conceptualizations Informing Research Methodology

In this section, I describe how theoretical conceptualizations help inform my dissertation research methodology. The concept of PA behaviour can be comprehended through the model developed by Pettee Gabriel et al. (2012). This framework conceptualizes PA as a behaviour consisting of human movement and outlines four domains of PA, including LPA. Throughout my dissertation research,

I have applied this model to clearly describe and differentiate the concepts of PA and LPA. For example, this conceptualization helped elucidate the focus on LPA within the scoping review in Study 1, as well as within the interviews with the patient participants in Study 2 and the physiotherapist participants in Study 3. Moreover, it informed the development of the article selection criteria and the literature search strategy for the scoping review in Study 1 (see **Appendix A** and Chapter 2). Thus, this conceptualization of PA behaviour and its domains provides a clear, consistent framework within which the topic of LPA can be effectively studied for my dissertation research.

As described previously within this chapter, theories of health behaviour can also facilitate understanding of PA behaviour. For my dissertation research, I have selected the Ecological Model of 4 Domains of Active Living and Health Belief Model to help inform certain aspects of my data collection tools (see **Appendix D**). Ecological models consider different levels of influence on PA behaviour, namely intrapersonal, interpersonal, and environmental factors (Sallis et al., 2006; Sallis & Owen, 2015). Therefore, in my interviews with the patient participants for Study 2, I sought information on factors within the participants themselves, within their relationships, and within their environments that influenced their LPA. With respect to the Health Belief Model, there is evidence supporting the influence of individual factors, particularly perceived barriers, perceived benefits, and self-efficacy, on participation in PA behaviour (Buchan et al., 2012; Skinner et al., 2015; Wu et al., 2020). To explore these factors, I obtained information from the patient participants in Study 2 about their perspectives on the importance, benefits, and risks of LPA participation, as well as facilitators and barriers to LPA. In addition, the Health Belief Model was key in informing the development of the original survey questionnaire (Sheill, Guinan, O'Neill, et al., 2018), which was used with the physiotherapist participants in Study 3 (presented in Chapter 4). For example, the survey questions sought information from the physiotherapists about the importance and safety of PA for people with advanced cancer (perceived benefits and barriers), encouragement from family and friends regarding PA (cues to action), as well as

confidence to prescribe PA (self-efficacy). Therefore, the theories of health behaviour were helpful in informing the data collected within my dissertation research.

While theoretical conceptualizations were relevant in framing my research questions and determining certain methodological aspects of my work, it is important to note how the use of theories is integrated within the interpretive-description methodology (Thorne, 2016). In my dissertation research, the study with the patient participants (Study 2) and the study with the physiotherapist participants (Study 3) were both informed by this methodology. As described by Thorne (2016), interpretive-description does not require *“that all studies must be explicitly positioned within one or another formal theory”* (Thorne, 2016, p. 70). This methodological approach acknowledges existing theoretical and research information and emphasizes the importance of reflecting on different influences contributing to the research design and analytical interpretations. However, this methodology *“explicitly distinguishes itself from qualitative research whose primary object is theorizing”* (Thorne, 2016, p. 77). Interpretive-description is disciplinary-oriented rather than theory-oriented. As such, the goal of interpretive-description is understanding health-illness phenomena, in order to advance disciplinary knowledge and to identify practical implications for applied health disciplines. For my dissertation research, this direction guided the analytical approaches adopted within the studies involving participants. In particular, I aimed to develop a deeper understanding of patient and professional perspectives related to LPA in people with advanced cancer to help inform the design of rehabilitation and supportive care resources in cancer care. Thus, the interpretive-description methodology acknowledges the contribution of theoretical perspectives, but emphasizes generating disciplinary knowledge and developing practical applications informed by research findings.

Summary of Methodological Considerations

To summarize, this section highlights the methodological considerations informing the rationale and design of my dissertation research methods. Scoping methodology in the literature review (Study 1) facilitates a comprehensive overview of the current research literature exploring LPA in people with advanced cancer. Moreover, this review serves as a foundational basis for the other elements of this dissertation work and guides future research inquiries on this topic. Meanwhile, the interpretive-description methodology informing the interviews within the patient study (Study 2) and the physiotherapist study (Study 3) results in enhanced knowledge of diverse perspectives related to LPA in the advanced cancer population. Furthermore, the mixed-methods approach in the study with physiotherapists (Study 3) allows a generalized understanding of clinical practices, knowledge, and skills among oncology physiotherapists through the survey component, as well as detailed knowledge on perspectives and experiences of working with advanced cancer through the interview component. These practice-oriented methodological approaches can also help identify clinical applications and thus, may facilitate the development of supportive care strategies targeting LPA in oncology care. Therefore, the methodological considerations in this research support the development of a comprehensive, detailed understanding of LPA in people with advanced cancer and the identification of relevant implications to support clinical practice. In the next section, I highlight ethical considerations within my dissertation work.

Ethical Considerations

In the final section of this introduction chapter, I describe the ethical considerations in my dissertation research, with respect to the two studies involving participants (Study 2 and Study 3). Elements of the ethical research procedures, as well as privacy considerations within the interviews and the survey are explained.

Prior to commencing data collection, I outlined the research procedures for the two studies involving patient and physiotherapist participants and submitted this information to the University of Ottawa Research Ethics Board for review and approval. The certificates of ethics approval are provided in **Appendix E**. Before enrolling in the research studies, the patient and physiotherapist participants were asked to review and sign online consent forms through the use of SurveyMonkey. The consent forms are also provided in **Appendix E**. These consent forms informed the participants about the study objectives and procedures, as well as of their rights to voluntarily participate in the study and to withdraw at any point over the course of the study. The interview participants in both studies were also asked to clearly provide their consent verbally before starting the interviews. Verbal approvals for consent were captured through audio-recording.

To minimize participant burden for the individuals with stage 4 cancer (Study 2), I administered the consent forms and pre-interview questionnaires online. This procedure allowed the participants to review and complete the documentation at their own convenience and make informed decisions independently. Moreover, I shared the interview guides with the patient and physiotherapist participants prior to the interviews. This step provided them with the opportunity to familiarize themselves with the questions and to minimize risks of fatigue or discomfort during the interviews. Finally, I shared transcript summaries with the interview participants shortly after their interviews. This process permitted the participants to provide clarifications and offer additional insight, when feasible and convenient to them.

To respect the privacy and confidentiality of the interview participants in both studies (Study 2 and Study 3), I entered the research data in electronic databases, where the participants' names were replaced with coded identifiers. A coding list with identification and contact information of the interview participants was kept in a separate electronic database. All electronic databases were password-protected to preserve data security and could only be accessed by myself and my supervisors. I also

stored the digitally signed consent forms, interview recordings, and verbatim transcripts electronically on two password-protected storage devices (USB key and external hard drive). The reflection journals containing interview field notes were kept in a locked cabinet in my research office. I used the coded identifiers to identify each participant within the journal entries. In order to enhance the anonymity of the research participants, I used numbers and broad descriptive categories to identify them within any published or publicly shared document related to the studies. I also avoided sharing additional identifying details associated with the individual participants (e.g., hospital names, work setting).

To preserve the privacy and confidentiality of the respondents for the physiotherapist survey (Study 3), I used the online SurveyMonkey program. This program uses secure and encrypted data storage within Canada. I also disabled email and IP address tracking options on SurveyMonkey. Moreover, the survey questions were developed to avoid collecting any potentially identifying information from the respondents. The final survey question, which requested contact information for the follow-up interviews, was designed so it was not linked to the remaining survey questions. Similar to the interview data, I stored the survey data in a password-protected electronic database accessible to my supervisors and myself. For both studies, all paper and electronic data records will be stored for five years following study completion, at which point they will be destroyed securely.

Summary of Introduction Chapter

The purpose of my dissertation work is to explore LPA in people with advanced cancer, through the perspectives of individuals diagnosed with stage 4 cancer and of oncology physiotherapists. The objectives of the three research studies within my dissertation are to map the literature on the topic of LPA in advanced cancer; to explore perspectives and experiences of LPA in adults diagnosed with stage 4 cancer; and to describe the clinical practices, knowledge, skills, and perspectives of oncology physiotherapists related to LPA and advanced cancer. In this chapter, I provided an overview of key

definitions, a review of the literature, as well as theoretical considerations, which inform the research design and methodological elements of my dissertation work. Following this, I described the methodological approaches adopted in my research studies, namely scoping methodology, interpretive-description methodology, and mixed-methods. I also explained the rationale and procedures for data sources, recruitment, data collection, and analysis. Finally, I outlined the ethical considerations within my dissertation work. In the next three chapters of my dissertation, I describe each of the individual studies conducted as part of my research and share their respective study findings.

CHAPTER 2: SCOPING REVIEW (MANUSCRIPT 1)

Relationship of Manuscript 1 to the Dissertation

The manuscript presented in this chapter describes a scoping review of studies exploring LPA in adults diagnosed with advanced cancer (Study 1). While there is increasing awareness of the benefits associated with exercise after cancer diagnosis, less is known about LPA in people with advanced cancer. Thus, the objectives of the scoping review were to map the research and understand key concepts from the literature on this topic. This review was guided primarily by the Arksey & O'Malley (2005) scoping methodology, with the consideration of additional recommendations on this methodological approach. The main findings of the review highlight a recent surge in research exploring LPA in people with advanced cancer, particularly studies using quantitative methods and examining aerobic and resistance exercise interventions. These studies have contributed to recent reviews and meta-analyses demonstrating positive effects with exercise on several clinical outcomes in this patient population, including physical function and quality of life (Chen et al., 2020; Heywood et al., 2018; Nadler et al.; 2019). However, there remains limited knowledge about important topics concerning patient experiences and perspectives related to LPA. Moreover, other leisure activities beyond standard exercise programs, such as yoga, Tai Chi, dance, sports, and gardening, have not been well explored in this population.

Through the identification of research gaps and clarification of key concepts, this scoping review helped inform the other elements of my dissertation research. Importantly, it demonstrated the need to explore patient perspectives, experiences, and preferences from a rehabilitation perspective, in order to support the development and integration of appropriate LPA resources in cancer care. These findings were key in informing the research questions for the subsequent two studies of my dissertation work with patient participants (Study 2) and physiotherapist participants (Study 3). From a population

perspective, my review highlighted the need for research on a diverse group of people with advanced cancer, representing different ages and cancer types, and within different phases of the disease trajectory. This information guided my sampling methods for the qualitative study with people diagnosed with stage 4 cancer (Study 2). Finally, the scoping review assisted in providing clarity on how to define and describe key concepts, including advanced cancer and LPA. For example, it helped determine and specify the inclusion criteria of stage 4 cancer diagnosis for the patient interpretive-description study (Study 2). Moreover, the findings of the review supported the decision to explore LPA in a broader sense, beyond aerobic and resistance exercise training alone. This approach was also an important element of both Studies 2 and 3. Therefore, the scoping review findings were valuable in providing a comprehensive overview of the current literature on this topic and shaping the research questions and methods for the other components of my dissertation work.

In this chapter, I present the accepted version of the peer-reviewed scoping review manuscript that was published in the *Palliative and Supportive Care* journal in 2021. The manuscript sections and references have been prepared in accordance with the journal requirements, but the numbering of the tables, figures, and appendices has been modified according to the formatting of this dissertation. The published version of the article can be viewed:

Shallwani, S.M., Ranger, M.-C., Thomas, R., Brosseau, L., Poitras, S., Sikora, L. & King, J. (2021). A scoping review of studies exploring leisure-time physical activity in adults diagnosed with advanced cancer. *Palliative and Supportive Care*, 19(5):615-630. DOI: 10.1017/S1478951520001327, licenced under CC-BY-NC-ND.

In addition, the protocol for the scoping review was published in the journal *Physical Therapy Reviews*. The accepted version of the peer-reviewed manuscript has been provided in **Appendix A**. The published version of the article can be viewed:

Shallwani, S.M., Brosseau, L., Thomas, R., Poitras, S., Sikora, L., Ranger, M.C. & King, J. (2019). Leisure physical activity in people with advanced cancer: a scoping review protocol. *Physical Therapy Reviews*, 24(1-2):51-58. DOI: 10.1080/10833196.2019.1582201, licenced under CC-BY-NC.

Manuscript 1: A Scoping Review of Studies Exploring Leisure-Time Physical Activity in Adults Diagnosed with Advanced Cancer

Abstract

Objectives: Despite improving survival rates, people with advanced cancer face several physical and psychosocial concerns. Leisure-time physical activity (LPA) has been found to be beneficial after cancer diagnosis, but little is known about the current state of research exploring LPA in advanced cancer. Our objectives were to: a) map the literature examining LPA in people with advanced cancer; b) report on the terms used to describe the advanced cancer population within the literature and; c) examine how the concept of LPA is operationalized within the literature.

Methods: Our scoping review followed the Arksey and O'Malley (2005) methodology. We performed a search of 11 electronic databases and supplementary sources (February 2018; database search updated January 2020). Two reviewers independently reviewed and selected articles according to the inclusion criteria: English-language journal articles on original primary research studies exploring LPA in adults diagnosed with advanced cancer. Descriptive and thematic analyses were performed.

Results: Ninety-two articles met our criteria. Most included studies were published in the last decade (80%) and used quantitative methods (77%). Many study populations included mixed (40%), breast (21%) or lung (17%) cancers. Stages 3-4 or metastatic disease were frequently indicated to describe study populations (77%). Several studies (68%) described a LPA program/intervention. Of these, 78% involved structured aerobic/resistance exercise, while 16% explored other LPA types.

Significance of Results: This review demonstrates a recent surge in research exploring LPA in advanced cancer, particularly studies examining exercise interventions with traditional quantitative methods.

There remains insufficient knowledge about patient experiences and perceptions towards LPA.

Moreover, little is known about other leisure activities (e.g. Tai Chi, dance, sports) for this population. To optimize the benefits of LPA in people with advanced cancer, research is needed to address the gaps in the current literature and to develop personalized, evidence-based supportive care strategies in cancer care.

Keywords: neoplasms; palliative care; leisure activities; exercise; rehabilitation

Introduction

Living with Advanced Cancer

In Canada, it is estimated that over 200,000 people were diagnosed with cancer in 2019 and the lifetime probability of developing cancer is almost 50% (Canadian Cancer Society, 2019; National Cancer Institute, 2017). Advanced cancer has been previously defined by the National Cancer Institute (NCI) as *“cancer that has spread to other places in the body and usually cannot be cured or controlled with treatment”* (National Cancer Institute, 2007). In this review, we are using the NCI definition for advanced cancer as it has been widely used in the literature (Beaton et al., 2009; Courneya & Friedenreich, 2010; Levit et al., 2013) and provides a basis upon which the concept of advanced cancer can be operationalized within research and clinical contexts.

Generally, cancers that have spread regionally (stage 3) or metastasized to distant sites (stage 4) are associated with lower survival rates (Canadian Cancer Society, 2018; National Cancer Institute, 2017). There are vast differences in stage distribution according to cancer type with cancers, such as lung, pancreatic and stomach, being more likely to present at a later stage at diagnosis than cancers such as breast, prostate and thyroid. In a recent special report on cancer incidence by stage, the Canadian Cancer Society (2018) estimated more than 10,000 cases annually of lung, colorectal, prostate and breast cancers that have already metastasized at diagnosis (Canadian Cancer Society, 2018). Given these figures do not consider individuals with other cancer diagnoses, those with early-stage cancer who have disease progression and those diagnosed in previous years and presently living with the disease (Mariotto et al., 2017; National Cancer Institute, 2017), these findings suggest a higher prevalence of Canadians currently impacted by advanced cancer.

Progress in cancer detection and treatment options has resulted in declined mortality rates for the general cancer population, including advanced cancer. However, increased survival rates have had

an impact on quality of life which remains underexplored, particularly in people diagnosed with advanced cancer (Canadian Cancer Society, 2019; Peppercorn et al., 2011). Despite improved cancer control and palliative therapies, individuals with this health condition face several physical and psychosocial concerns. Some challenges include declined aerobic fitness and muscle strength, high symptom burden (including fatigue and dyspnea), concerns of worry and anxiety, impaired physical and social functioning, financial distress and affected quality of life (Cheville et al., 2008; Dunn et al., 2017; Hummler et al., 2014; Liao et al., 2014; Mayrbaurl et al., 2016; Shallwani et al., 2016; Teo et al., 2019; Yee et al., 2014). In recent studies of people with advanced cancer, issues with daily activities, such as self-care, household tasks and leisure activities, have also been reported (Cardoso et al., 2016; Cheville et al., 2009; Di Lascio & Pagani, 2017; LeBlanc et al., 2015; Yee et al., 2014). Moreover, unmet needs related to information, communication, emotional support and supportive care have been frequently described in this population (Cardoso et al., 2016; Cheville et al., 2008; Dunn et al., 2017; Houldin & Lewis, 2006; Kemp et al., 2018; Lam et al., 2014; Pollak et al., 2007).

Leisure-Time Physical Activity and Advanced Cancer

As the recognition of supportive care priorities in oncology is increasing, leisure-time physical activity (LPA), including exercise, is becoming a growing focus of interest within the cancer population. LPA is considered one domain of physical activity (PA) (Petee Gabriel et al., 2012) and has been described as *“the activities one participates in during free time, based on personal interests and needs. These activities include formal exercise programs as well as walking, hiking, gardening, sport, dance, etc.”* (Howley, 2001). Exercise is considered LPA that is *“planned, structured, repetitive”* and purposeful (Caspersen et al., 1985; Dasso, 2019). The benefits associated with PA after general cancer diagnosis have been well established and include reduced fatigue symptoms, improved physical functioning and psychosocial well-being, better treatment outcomes, enhanced quality of life and decreased mortality

(Ballard-Barbash et al., 2012; Campbell et al., 2019; Fong et al., 2012; Segal et al., 2017; Speck et al., 2010). However, the majority of research in this area has focused on patients with common cancer types (e.g. breast, prostate, lung, colorectal), within early-stage disease and within post-treatment phases (Campbell et al., 2019; Shallwani, King, et al., 2019).

In advanced cancer specifically, earlier reviews examining LPA have focused primarily on intervention studies exploring traditional structured exercise programs with aerobic and resistance components (Albrecht & Taylor, 2012; Beaton et al., 2009; Dittus et al., 2017; Heywood et al., 2017, 2018; Lowe et al., 2008; Salakari et al., 2015). Despite the lack of research previously reported in this area, recent reviews have confirmed the safety and feasibility of exercise interventions in people with advanced cancer and have reported benefits with exercise for several clinical outcomes, including physical function and quality of life (Dittus et al., 2017; Heywood et al., 2017, 2018; Lowe et al., 2008).

Nonetheless, several limitations exist in the current body of literature exploring LPA for people with advanced cancer. Previous reviews have been limited to intervention study designs and have not considered topics of potential relevance to this population, such as personal experiences and perceptions related to engaging in LPA, reported facilitators and barriers or preferred activities. Within intervention studies, further research is needed to establish optimal exercise dosage parameters for different subgroups of the advanced cancer population (Heywood et al., 2017). Moreover, leisure activities beyond structured aerobic and resistance exercise programs, such as mind-body exercise (e.g. yoga), dance, gardening or sports, may be meaningful for patients and potentially beneficial for various clinical outcomes. However, these types of activities have not been well researched in the general and advanced cancer literature alike (Bradt et al., 2011; Buffart et al., 2012; Campbell et al., 2019).

As the evidence on PA in cancer is rapidly expanding, it is necessary to update and broaden our understanding of the scope of research on this topic and to identify particular research gaps in the current body of literature. Moreover, challenges in this area of research exist with standardizing the

definition of advanced cancer (Lowe, 2010; Lowe et al., 2016) and understanding how key concepts, such as LPA, have been examined in the literature. While systematic reviews have been the most common approach to synthesize literature, other approaches have been recently considered to address questions that are broader in nature and more inclusive of different evidence types (Grimshaw, 2010). Scoping reviews can provide an extensive review of relevant literature (literature mapping) and help clarify terms (concept mapping) and this approach may be particularly useful to adopt in research areas that are not well understood (Anderson et al., 2008; Arksey & O'Malley, 2005; Levac et al., 2010; Rumrill et al., 2009). The objectives of our scoping review were to map the current research and understand key concepts from the literature about LPA in people with advanced cancer. Specifically, our research questions were the following:

1. What is the extent, nature and range of the existing literature examining LPA in people with advanced cancer?
2. What terms are used to describe the advanced cancer population within the studies included in the scoping review?
3. How is the concept of LPA operationalized within the studies included in the scoping review?

Methods

The methods for our scoping review have been previously described (Shallwani, Brosseau, et al., 2019). Briefly, our review followed the steps of the methodological framework established by Arksey and O'Malley (2005), with the consideration of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco et al., 2018) and additional recommendations on scoping methodology (Arksey & O'Malley, 2005; Daudt et al., 2013; Davis et al., 2009; Levac et al., 2010; Peters et al., 2017; Pham et al., 2014; Rumrill et al., 2009).

Literature Search

The literature search strategy was established and modified in consultation with an interdisciplinary group of researchers (Daudt et al., 2013; Levac et al., 2010; Shallwani, Brosseau, et al., 2019). The search strategy was pilot tested in February 2018 by running the search in one electronic database, scanning 114 abstracts and reviewing 31 full texts. This exercise permitted the researchers to determine the feasibility of the scoping review and refine the article selection criteria. Following this pilot testing, the search strategy was finalized, and the following steps were completed:

1. *Initial search of 11 electronic databases (performed Feb. 20, 2018):* Cumulative Index to Nursing and Allied Health Literature (CINAHL; 1940–current); Cochrane Database of Systematic Reviews (CDSR; 2005–current); Database of Abstracts of Reviews of Effects (DARE; first quarter of 2016); Cochrane Central Register of Controlled Trials (CENTRAL; 2018); Excerpta Medica Database (EMBASE; 1947–current); Medical Literature Analysis and Retrieval System Online (MEDLINE; 1946–current); Physiotherapy Evidence Database (PEDro; 1999–current); Psychological Abstracts (PsycINFO; 1806–current); US National Library of Medicine Database (PubMed; 1966–current); National Rehabilitation Information Center Database (REHABDATA; 2002–current); and Sports Medicine Database (SPORTDiscus; –current) (**Supplementary Appendix A**)
2. *Supplementary search of references lists*:* 15 relevant literature reviews, editorials and commentaries identified during the electronic database search (**Supplementary Appendix B**)
3. *Grey literature search of selected organizational websites (performed Nov. 26, 2018):* Canadian Cancer Society (Canada), NCI, American Cancer Society (USA), National Cancer Research Institute (UK), European Cancer Organisation, European Society of Medical Oncology (ESMO) (Europe) and Cancer Australia (Australia)
4. *Updated search of electronic databases (performed Jan. 24, 2020):* see initial search

5. *Citation analysis using the Scopus database**: six relevant literature reviews from initial search and one from updated search (**Supplementary Appendix B**)

*Due to the high number of articles, we did not scan the references lists and perform citation analyses of all included articles, as originally indicated in the review protocol (Shallwani, Brosseau, et al., 2019).

All retrieved articles from the literature search were exported into the EndNote X7.8 software (Clarivate Analytics, PA, USA). Upon automatic and manual removal of duplicates, citations were exported into the online Covidence program (Veritas Health Innovation Ltd ACN 600 366 274). Two reviewers (SMS and MCR) independently scanned articles at the title/abstract level in blocks of 500 to 1000 articles and at the full text level in blocks of 50 to 100 articles. Conducting the article selection process in blocks permitted ongoing discussions between the reviewers to further refine the selection criteria, resolve conflicts and consult senior researchers (JK and RT), as needed (Levac et al., 2010; Pham et al., 2014; Shallwani, Brosseau, et al., 2019). Thus, the selection of articles for inclusion was based on criteria established *a priori* that were refined post-hoc (**Table 2.1**). As per the scoping review approach, we did not apply any quality cut-off criteria in order to identify all published literature of relevance (Arksey & O'Malley, 2005; Pham et al., 2014).

Table 2.1 Refined Article Selection Criteria

Inclusion Criteria	Exclusion Criteria
<p>Study population</p> <p>1) Adults aged ≥ 18 years</p> <p>2) Diagnosis of advanced cancer, specifically indicated as at least one of the following*:</p> <ul style="list-style-type: none"> a) Stage[#] 3 and/or 4 and/or metastatic; b) “Terminal”, “incurable” or “untreatable”; c) “Palliative” disease/status or receiving “palliative” or “hospice” care, therapies or treatment; d) Limited life expectancies or survival rates; e) “Recurrent” or “relapsed” disease, only if meeting any previously mentioned criteria for advanced cancer 	<p>1) Children or adolescents, animals</p> <p>2) Non-cancer diagnoses (e.g. other health conditions, cancer prevention)</p> <p>3) Diagnosis of non-advanced cancer, indicated as*:</p> <ul style="list-style-type: none"> a) Stage 1-2; b) “Locally advanced” or “nonlocalized” cancer and not meeting any other mentioned criteria for advanced cancer <p>4) Mixed populations including cancer and non-cancer or advanced and non-advanced cancer*</p> <p>5) Caregivers, family members, health care professionals</p>
<p>Concept</p> <p>1) Post-cancer diagnosis LPA</p> <p>2) Leisure-time domain of PA, such as structured aerobic and resistance exercise (including leisure walking), mind-body exercise (yoga, Tai Chi, Qigong), sports, gardening, hiking, bowling and dance</p> <p>3) LPA examined as:</p> <ul style="list-style-type: none"> a) A main study outcome (quantitative research); b) A focus of inquiry or an emerging theme (qualitative research); c) A main component of a study intervention or program 	<p>1) Pre-cancer diagnosis LPA</p> <p>2) Other domains of PA (e.g. self-care, occupation, transport, total) (Petee Gabriel et al., 2012)</p> <p>3) LPA:</p> <ul style="list-style-type: none"> a) Not examined as a separate outcome (quantitative research; e.g. questionnaire with 1 item or subscale on LPA, objective or self-reported measures of total PA or daily step count, functional tests of exercise capacity or aerobic fitness); b) Not explored as a main qualitative focus (qualitative research); c) Not considered LPA (e.g. therapeutic-focused / rehabilitation programs or exercises, such as breathing, swallowing, passive, range of motion and coordination exercises; e.g. mindfulness-based or meditation programs, muscle relaxation techniques not clearly involving major physical movement); d) Not a main component of a multidimensional program / intervention
<p>Context</p> <p>1) Any phase of the disease trajectory post-diagnosis of advanced cancer (e.g. newly diagnosed, during treatment, end of life)</p>	

2) Within any clinical setting (e.g. home-based, community-based, hospital-based, hospice care)	
Types of studies 1) Original primary research studies 2) Any study design and any methodology 3) English-language articles 4) Full texts available	1) Literature reviews, practice guidelines, position documents, editorials, commentaries, letters, research protocols, conference abstracts, dissertations, book chapters, books and magazine articles* 2) Program descriptions with no primary data collection 3) Non-English language articles

LPA: leisure-time physical activity; PA: physical activity

#Studies using other diagnostic criteria without overall staging information were not included

*Modifications or clarifications to selection criteria indicated in original protocol (Shallwani, Brosseau, et al., 2019)

Data Extraction

Upon completion of the selection process, articles included in the review were exported into the Microsoft Excel software (version 14.7.7, Redmond, WA). The draft data extraction forms (Shallwani, Brosseau, et al., 2019) were pilot tested independently by two reviewers (SMS and MCR) using Excel for over 10% of the included studies from the initial search (n=8) and the extracted information was compared between the reviewers (Daudt et al., 2013; Levac et al., 2010; Pham et al., 2014). This step permitted the researchers to test the usability and clarity of the data forms and headings, to make adjustments to the forms and to create drop-down categories further enhancing their ease of use. Data for the remaining studies were extracted by the primary researcher (SMS) and subsequently verified by the second researcher (MCR). These data included study characteristics (e.g. publication year, location and methodology) and population characteristics (e.g. diagnosis, gender and age). To address the secondary objectives, key terms to describe the advanced cancer population were searched based on the article selection criteria (e.g. stage 3-4, palliative, hospice, terminal, life expectancy). To locate and

document these terms, the study population criteria and descriptions were reviewed within the abstract, the methods and/or the results section of the included articles. In addition, the relevance of LPA within each study (e.g. study outcome, theme or intervention) and the specific components of LPA explored were recorded for each included article.

Data Analysis

A narrative, descriptive review was performed of the search results, the study characteristics and the population characteristics. General trends according to publication year were demonstrated through the use of linear graphs. Thematic content analyses were conducted related to descriptions of the advanced cancer population and the specific relevance of LPA within the studies as a main outcome (quantitative research), as a focus of inquiry or as an emerging theme (qualitative research) or as a component of a study intervention or program. Similar studies of particular relevance (i.e. qualitative studies and other types of LPA programs) were described in detail. Due to the volume and heterogeneity of the included studies, there was no formal quality appraisal or data synthesis performed for this review.

Results

Search Results

The initial database search in February 2018 resulted in 63 articles included in the scoping review, while the supplementary search of relevant review articles and grey literature yielded an additional two included articles. The grey literature search also identified three patient education booklets targeted to patients with advanced cancer (Canadian Cancer Society, 2017; ESMO Palliative Care Working Group, 2011; National Cancer Institute, 2014). These were not included in the review, but were referred to for

guidance on practical implications. The updated search in January 2020 yielded an additional 27 articles for inclusion. Upon completion of the entire literature search, there were 92 articles included in our scoping review (**Figure 2.1**). A list of included articles is provided (**Supplementary Appendix C**).

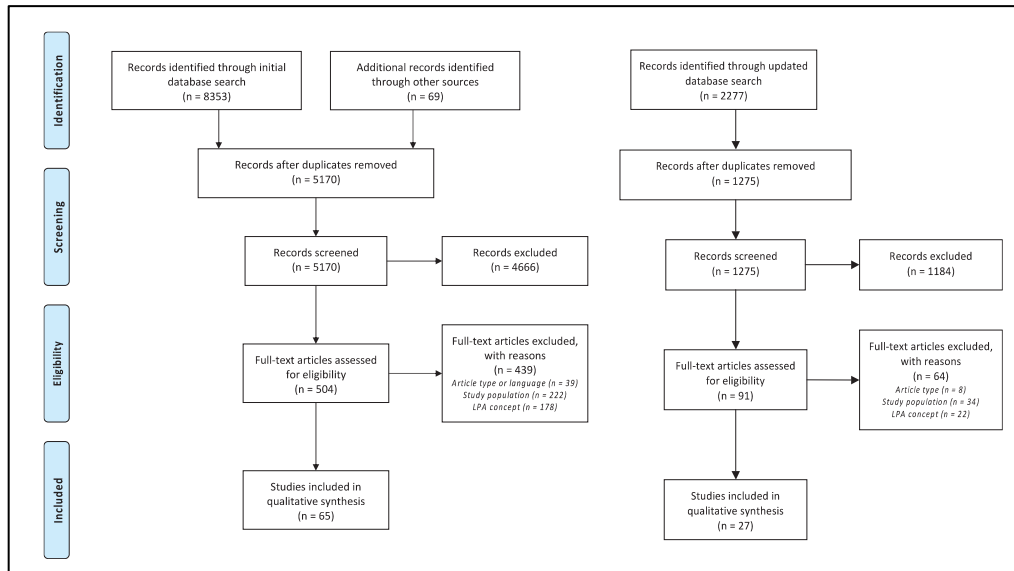


Figure 2.1 PRISMA Flow Diagram (Moher et al., 2009)

Study Characteristics

Most studies were published in the last decade (2010-2019/2020: 80%, n=74) (**Table 2.2**) and occurred within Europe (43%, n=40) or North America (37%, n=34), followed by Australia (14%, n=13) and Asia (5%, n=5). The majority of studies used quantitative methods (77%, n=71) while 14% (n=13) and 9% (n=8) described qualitative and mixed methods, respectively.

Table 2.2 *Descriptive Characteristics of Included Studies (N=92)*

Publication year, n (%)	
2000-2003	5 (5.4%)
2004-2007	8 (8.7%)
2008-2011	11 (12.0%)
2012-2015	22 (23.9%)
2016-2019/20*	46 (50.0%)
Cancer diagnosis, n (%)	
Breast	19 (20.7%)
Colorectal	4 (4.3%)
Gastrointestinal	3 (3.3%)
Lung	16 (17.4%)
Prostate	5 (5.4%)
Mixed	37 (40.2%)
Other**	8 (8.7%)
Total	92 (100%)

*The search was performed in January 2020 and yielded four included articles published in 2020

(included in the 2016-2019/20 category)

**Examples of other cancer types include melanoma, ovarian and pancreatic

Methodological characteristics of the studies including a quantitative approach are described in **Table 2.3**. Most studies involved evaluating a controlled intervention (n=57) and followed one or two groups over time. Six quantitative studies and one mixed-methods study adopted a case-study design.

Table 2.3 Methodological Characteristics of Included Studies with Quantitative Approach (N=79)

	Quantitative studies (n=71)	Mixed-methods studies (n=8)
Study design, n (%)		
Observational	19 (26.7%)	3 (37.5%)
<i>Cross-sectional</i>	12 (16.9%)	3 (37.5%)
<i>Longitudinal</i>	7* (9.9%)	0 (0.0%)
Intervention	52 (73.2%)	5 (62.5%)
<i>2-group CCT or RCT</i>	27 (38.0%)	2 (25.0%)
<i>>2-group RCT</i>	3 (4.2%)	0 (0.0%)
<i>Single-group</i>	15 (21.1%)	2 (25.0%)
<i>Case series</i>	2 (2.8%)	0 (0.0%)
<i>Case study</i>	5 (7.0%)	1 (12.5%)

CCT: controlled clinical trial; RCT: randomized controlled trial

*Within the seven longitudinal observational studies, one study adopted a case study design

An overview of the 13 studies following an exclusively qualitative approach is provided (**Table 2.4**). Few articles clearly stated the qualitative methodological approaches, such as phenomenology (n=3) or grounded-theory (n=2). All included studies used semi-structured or unstructured interviews as a primary method of data collection.

Table 2.4 Overview of Qualitative Studies Included in Review (N=13)

Objective (study)	Study population	Qualitative approach	Data collection
To explore the feasibility and the experienced health benefits and barriers of participation in an exercise and relaxation intervention from the patients' perspective (Adamsen et al., 2012)	Patients with advanced-stage lung cancer (stage III-IV NSCLC and extensive disease SCLC) undergoing chemotherapy	Explorative, feasibility study; thematic analysis	Individual semi-structured interviews (n=15) and one semi-structured focus group (n=8)
To explore participants' perceptions to rehabilitation palliative care; specifically perceptions of symptoms, perceptions of rehabilitation services received and attitudes and beliefs about rehabilitation received (Belchamber, 2009)	Older patients post-palliative treatment experiencing one of three distressing cancer symptoms: pain, dyspnoea and fatigue	Phenomenological orientated psychological approach	Semi-structured interviews (n=8)
To develop an understanding of the potential physical and psychosocial impact of yoga on the wellbeing of advanced cancer patients; and to create a foundation for the development of a yoga programme for patients at the end of life (Carr et al., 2016)	Women with advanced (stage 4) cancer	Pilot study with descriptive qualitative approach; qualitative content analysis	Individual semi-structured interviews (n=3)
To explore the beliefs of patients with late-stage lung cancer regarding exercise, its relationship to their symptoms and their clinicians' roles in providing counseling (Cheville et al., 2012)	Patients with stage 3B / 4 NSCLC	Qualitative study; content analysis	Individual semi-structured interviews (n=20)
To identify the impact of key aspects of Chinese culture on the responses of mid-aged Chinese Australians to their advanced cancer (Chui et al., 2005)	Mid-aged Chinese Australians with advanced cancer followed from recruitment until death	Glaserian grounded-theory approach	Face-to-face interviews, telephone contacts, observation and research field notes (n=11)
To explore how palliative cancer patients with poor performance status experience participation in physical activity (Guide et al., 2011)	Palliative cancer patients from different palliative home care units	Qualitative design; qualitative content analysis	Semi-structured interviews (n=11)

To gain knowledge on experiences of older women with cancer receiving hospice care (that can be used by physical therapists (Mackey & Sparling, 2000)	Older women with cancer receiving hospice care	Qualitative single-case study with replication; analysis by grounded theory techniques	Unstructured interviews (n=3) and research field notes (including information from family members and hospice nurses)
To investigate how patients and palliative care team members perceive the option of horticultural therapy in a hospital-based palliative care ward (Masel et al., 2018)	Advanced cancer patients on a palliative care ward	Qualitative methodology; thematic analysis (applied as a theoretically flexible method)	Semi-structured interviews (n=15 patients and n=5 palliative care team members)
To explore attitudes towards and experiences with PA and exercise among older patients with advanced cancer during palliative oncological treatment (Mikkelsen et al., 2019)	Patients aged ≥65 years with advanced cancer receiving first-line palliative treatment	Qualitative interview study; thematic analysis	Semi-structured interviews (n=23)
To gain a comprehensive understanding of palliative cancer patients' perceptions and experiences of taking part in a group exercise program and to explore the meaning of such an intervention for the individual patient (Paltiel et al., 2009)	Palliative cancer patients' with 2-12 months life expectancy	Qualitative interviews; phenomenological-hermeneutical perspective for analysis	Semi-structured interviews (n=5)
To explore the experiences and perceptions of patients and healthcare professionals regarding the feasibility, acceptability, benefits and burdens of palliative rehabilitation as a component of advanced lung cancer management (Payne et al., 2018)	Adults with advanced (stage 3b-4) NSCLC receiving systemic therapy with palliative intent	Qualitative exploration; thematic analysis	Individual semi-structured interviews (n=8 patients and 6 health care professionals)
To examine the views of men diagnosed with metastatic prostate cancer towards physical activity (Sheill, Guinan, Neill, et al., 2018)	Men with metastatic prostate cancer	Qualitative exploration; content analysis	Semi-structured interviews (n=20)
To gain insight into the experiences of patients living with incurable advanced cancer receiving hospice care taking part in exercise classes, the meaning they attached to participation and to understand how they perceived participation to have affected their lives (Turner et al., 2016)	Patients living with incurable advanced cancer receiving hospice care	Heideggerian (hermeneutic / interpretive) phenomenological approach	Individual semi-structured interviews (n=9)

NSCLC: non-small cell lung cancer; SCLC: small cell lung cancer

Of eight studies describing quantitative and qualitative methods of data collection, three explicitly identified as “mixed-methods” (Poletti et al., 2019; Ten Tusscher et al., 2019; Tsianakas et al., 2017). The study designs are indicated within **Table 2.3**. Regarding the qualitative components of these studies, three studies specified a qualitative analytic approach, including social validity, interpretive phenomenology and the framework approach. Half of the mixed-methods studies described interviews for the qualitative data collection (n=4), while the remaining used focus groups (n=2) or surveys (n=2).

Population Characteristics

Of 92 studies in our review, 24% (n=22, including two case studies) included only females and 11% (n=10, including five case studies) included only males. Over half of the studies (55%, n=51) provided enough information to determine an average participant age of or above 60 years and over a third (36%, n=33) under 60 years of age. Three studies indicated average ages for different study groups, where one group was ≥ 60 years and the other was < 60 . Half of the eight studies with ages under 50 years were case studies (50%, n=4). The remaining studies either did not include age information (n=1) or provided age ranges only (n=4). Population characteristics with respect to cancer diagnosis are provided (**Table 2.2**). Most articles described study groups with mixed types of advanced cancer (40%, n=37) or focused exclusively on patients with advanced breast or lung cancers (38%, n=35). Cancer type by publication year is demonstrated in **Figure 2.2**.

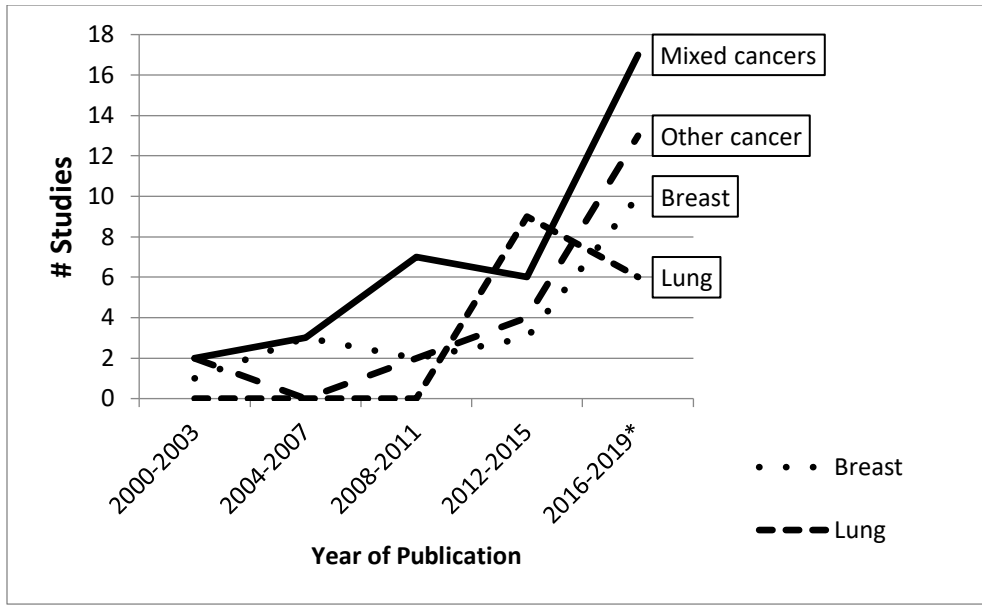


Figure 2.2 Cancer Diagnosis in Included Studies by Publication Year (N=92)

*The search was performed in January 2020 and yielded four included articles published in 2020 (included in the 2016-2019 category)

Although studies focusing on caregivers and health care professionals were not included in the review, one study examined a yoga intervention in patients with lung cancer with their family caregivers (dyads) (Milbury et al., 2015). Masel et al. (2018) also interviewed palliative care team members about their perspectives regarding a horticultural therapy intervention, while Payne et al. (2018) included health care professionals in their qualitative exploration of palliative rehabilitation for advanced lung cancer.

Description of Advanced Cancer Population

The terms used to describe the advanced cancer population varied between studies, with the majority indicating stages 3-4 or metastatic disease (76%, n=70). Of these, 53% (n=37) focused on stage 4 or metastatic cancer only, while 9% (n=6) included only stage 3 cancer and 39% (n=27) included both stages 3 and 4. In addition, 22 studies (24%) indicated “palliative” or “hospice” to describe the patient

population, treatment intent, or care approach, while 18 studies (20%) used terms, such as “terminal”, “incurable”, “untreatable”, “inoperable” or “until death.” Some studies (10%, n=9) specified life expectancies or survival rates; more precisely, seven studies indicated estimated life expectancies between three and 12 months (n=5), between three months and two years (n=1), between six months and 5 years (n=1), while two studies indicated expected 5-year survival rates of ≤50%. Descriptive terms used in the included studies by publication year are demonstrated in **Figure 2.3**. With respect to cancer diagnosis, studies focusing on specific cancer types used staging more frequently in their population descriptions compared to the mixed cancer groups. Within the breast cancer and lung cancer studies (n=35), 100% mentioned staging, 6% (n=2) indicated “palliative” and 11% (n=4) used terms such as “untreatable” and “inoperable”. Meanwhile, within the mixed cancer studies (n=37), 46% (n=17) used staging, 49% (n=18) reported “palliative” or “hospice”, 35% (n=13) indicated terms such as “terminal” and “incurable”, and 22% (n=8) specified life expectancies or survival rates.

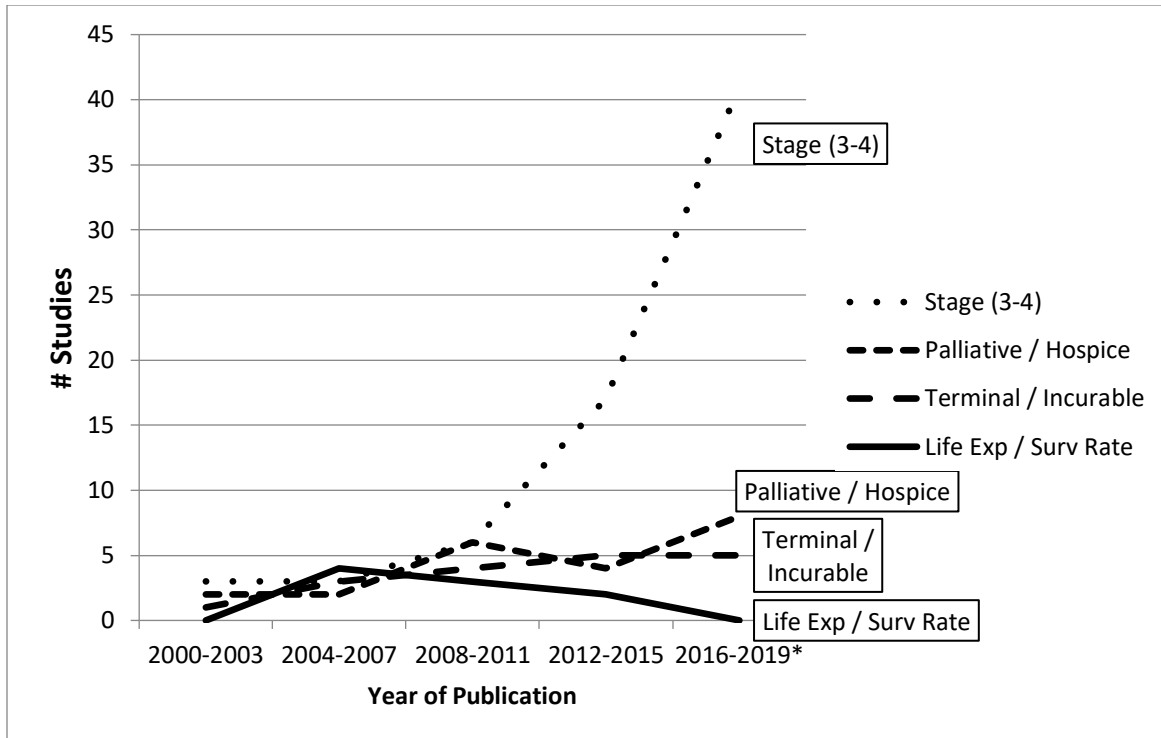


Figure 2.3 Terms Used to Describe Advanced Cancer Population in Included Studies by Publication Year

(N=92)

life exp: life expectancy; surv rate: survival rate

*The search was performed in January 2020 and yielded four included articles published in 2020

(included in the 2016-2019 category)

Operationalization of LPA

In over half of the included studies (60%, n=55), LPA was examined quantitatively as a study outcome. The majority of these assessed outcomes related to adherence and acceptability. The outcome measurement tool used most frequently to assess LPA within these studies was the patient-reported Godin Leisure-Time Exercise Questionnaire (n=9).

Twenty-one studies (23%) included in the review explored LPA qualitatively. In most studies, the researchers sought to examine experiences and perceptions related to LPA (focus of inquiry). Two

studies reported emerging themes related to LPA; that is, LPA was not the focus of these studies, but was part of a theme identified during data analysis (Chui et al., 2005; Mackey & Sparling, 2000).

Many studies (68%, n=63) described an intervention or a program focused on LPA. Most of these (78%, n=49) involved structured exercise programs with components of aerobic and resistance training. Specifically, 35 studies described programs focused on both aerobic and resistance training, while the remaining focused on aerobic (n=10) or resistance (n=4) components only. Besides these, 16% (n=10) explored other types of LPA, including mind-body exercise (e.g. yoga, Qigong, gardening), while four studies (6%) described combined LPA programs (**Table 2.5**). Of these, half (n=7) included only women with breast cancer (n=6) or mixed types of cancer (n=1).

Table 2.5 Studies Exploring Other (Non-Structured Exercise) LPA Programs (N=14)

Study population (study)	LPA program description	Main study findings (from abstract)
Other LPA programs (n=10)		
3 women with advanced (stage 4) cancer (mixed types) (Carr et al., 2016)	Kripaulu & restorative yoga: Three 45-min personalized home-based yoga sessions	Descriptive qualitative study: - Physical, mental & emotional benefits - Alleviation of illness impacts - Enhancement of mind-body & body-spirit connections
21 women with metastatic breast cancer (Carson et al., 2007)	Yoga of Awareness: Eight 120-min weekly group yoga sessions	Pilot / feasibility study: - 13 women completed intervention - Significant pre-post increases in invigoration & acceptance - Improved fatigue, pain, invigoration, acceptance & relaxation on days after increased yoga practice
15 advanced cancer (mixed types) patients on a palliative care ward (Masel et al., 2018)	Horticultural therapy: One to three group sessions on palliative care ward	Qualitative study: - Themes of wellbeing, variation of clinical routine, creation & building relationships - Positive perception of intervention, but high dropout
15 dyads of advanced (stage 3) lung cancer patients undergoing radiotherapy & caregivers (Milbury et al., 2015)	Vivekananda yoga: 15 (2-3x/wk x 5-6 wks) 60-min yoga sessions	Single-arm feasibility trial: - 9 dyads completed intervention - No adverse events - Mean 10 sessions completed - 95.5% rated as very useful - Improved mental health (patients) & sleep disturbances (caregivers)
27 women with metastatic breast cancer (Oh et al., 2014)	Medical Qi Gong: 15 60-min weekly group sessions (vs. meditation control intervention)	Phase II randomized controlled trial (feasibility): - 9/14 completed MQ intervention - No adverse events - Medical Qi Gong vs. meditation: no differences in QOL, fatigue, stress & sexual function; significant difference in neuropathic symptoms
20 patients with metastatic cancer (Poletti et al., 2019)	Mindfulness-based stress reduction*: Eight 2.5-hr weekly meetings & one 4.5-hr session	Mixed-method study: - 75% meeting attendance & adherence to home practice - Promoted accepting attitude to metastatic cancer disease - Improved self-regulation of mood state

63 women with metastatic breast cancer (Porter et al., 2019)	Mindful yoga: Eight 120-min weekly group sessions (vs. support group control)	Randomized pilot study: - 65% attended ≥ 4 yoga sessions - 80% highly satisfied with yoga - Yoga vs. support: modest improvements in some outcomes with yoga
91 women with metastatic breast cancer (Rao et al., 2017)	Integrated yoga based stress reduction: 24 (2x/wk x12 wks) 60-min sessions (vs. education & supportive therapy)	Two-arm prospective RCT: - Significant improvements in symptom distress, sleep quality post-intervention - Decreased morning waking cortisol post-intervention (yoga only) - Yoga vs. control: improved NK cell percent post-intervention
91 women with metastatic breast cancer (Vadiraja et al., 2017)	Integrated yoga based stress reduction: 24 (2x/wk x12 wks) 60-min sessions (vs. education & supportive therapy)	Two-arm prospective RCT: - Yoga vs. control: improved perceived stress, fatigue and diurnal variation - Positive correlation between change in fatigue severity & 9 a.m. salivary cortisol
24 patients with advanced (stage 3-4) NSCLC or GI cancer receiving chemotherapy (Vanderbyl et al., 2017)	Medical Qigong: 12 (2x/wk x 6 wks) x 45-min group sessions (vs. SET)	Two-arm randomized cross-over study: - 19 patients completed both interventions - No differences between groups in anxiety, depression or QOL changes - Qigong vs. SET: SET better at improving strength and walking distance; greater benefits with SET for symptoms & walking distance when offered as first intervention
Combined LPA programs (n=4)		
55 women with stage III breast cancer during radiotherapy (Arun et al., 2017)	Comprehensive lifestyle intervention x 4-6 wks followed by video-conference sessions over 12 months including behavioural counseling / social support, exercise (aerobic & resistance), nutritional counseling & mind-body practice (meditation & yoga)	RCT (in progress): - High accrual & low dropout rates - High attendance to in-person session & video counseling - Qualitative findings: importance of comprehensive nature, especially mind-body/mindfulness component & social support, & meaningful lifestyle transformations
90 women with metastatic breast cancer (Block et al., 2009)	Comprehensive integrative cancer care program combining conventional treatments with nutrition and supplementation, fitness (including interval / endurance training, strengthening, adapted yoga / Pilates / qi gong)) &	Consecutive case-series: - Five-year survival rate 27% (vs. 17% for comparison patients)

	mind-spirit instruction (psycho-social education)	
28 patients with metastatic melanoma treated with immunotherapy (Lacey et al., 2019)	Tailored supportive care intervention x 8 wks including exercise, dietary advice, non-invasive complementary therapies (massage, reflexology yoga, qigong, mindfulness meditation, or acupuncture) & psychology consultation	Pre-post-test feasibility cohort study (supportive care & usual care vs. usual care): - Intervention group: 50% completed all prescribed exercise sessions & overall 85% exercise adherence; integrative therapies accessed by 85% participants
9 patients with advanced cancer (mixed types) from home hospice care (Porock et al., 2000)	Duke energizing exercise plan x 28 days consisting of home-based individualized exercise program / physical activities (e.g. walking, marching, dancing, gardening)	Pilot pre-test post-test study with case analysis approach: - Increased activity levels with no increase in reported fatigue - Trend towards increased QOL and decreased anxiety

Hr: hour; min: minute; wk: week

GI: gastro-intestinal; LPA: leisure-time physical activity; NSCLC: non-small cell lung cancer; QOL: quality of life; RCT: randomized controlled trial; SET: standard endurance and strength training

*Including training and practical meditation, body scan, light yoga, simple walking meditation and Aikido exercises

Discussion

To our knowledge, this is the first scoping review examining the published literature on LPA in people with advanced cancer. In the last decade, there has been a surge of research exploring LPA in people with advanced cancer, particularly in Europe and North America. These findings support the recent focus in advanced cancer care on developing and implementing tailored supportive and palliative care strategies throughout the care continuum in order to address patients' individual needs and to enhance their quality of life (Ferrell et al., 2017; Peppercorn et al., 2011).

While significant progress has been made to advance the knowledge on LPA in people with advanced cancer, there remain important limitations and gaps in the current evidence base.

Methodological limitations of the current research base include small sample sizes in quantitative

research and a lack of sufficient studies and well-defined methodological approaches in qualitative research. As many published articles on this topic used quantitative study methods examining controlled exercise interventions, these research findings are limited in their applicability to real-life settings and to different clinical populations. Moreover, few studies utilized qualitative methods and even fewer implemented mixed-method approaches in this area of research, resulting in limited knowledge on the experiences, perceptions and preferences of people living with advanced cancer related to engaging in LPA. Of the studies using qualitative methods that were included in our review, including the mixed-methods studies, several did not explicitly indicate the qualitative methodology (e.g. phenomenology, grounded theory), highlighting a need for better designed studies in this area.

Advanced Cancer Population

The term “advanced cancer” can represent a particularly heterogeneous group of people with cancer and there are several challenges with establishing a clear definition for this term (Haun et al., 2017). In our review, there was considerable variability within the population characteristics of the included studies and many studies involved mixed groups of people with different types of advanced cancer. Several recent articles focused primarily on individuals with one cancer type, a specific treatment approach or a particular demographic (e.g. elderly) to address some of these challenges of heterogeneity. Many of these focused exclusively on advanced breast or lung cancer populations, limiting the applicability of these findings to other cancer types. The inclusion of patient groups with only lung cancer or other cancer types was fairly recent, despite the poor prognosis and relatively low survival rate associated with lung cancer (Canadian Cancer Society, 2018, 2019). Our findings emphasize the need to continue extending research efforts examining LPA in advanced cancer patient groups besides breast cancer.

To characterize people living with advanced cancer, cancer staging (stages 3-4) or the presence of metastatic disease were commonly indicated in the studies included in our review, particularly for studies focusing on one cancer type. The increasing use of staging and decreasing relative use of other criteria (e.g. life expectancy) to describe advanced cancer is likely related to the advancements of disease staging criteria, improvements in cancer control therapies and increases in cancer survival rates (Canadian Cancer Society, 2018, 2019). The evolving definition of advanced cancer, which currently highlights the unlikelihood of cure and the potential presence of disease spread, demonstrates the ongoing challenges with standardizing this definition (National Cancer Institute, 2007, 2020). There remains tremendous heterogeneity within the advanced cancer population and, as noted, a shift towards focusing on specific disease, treatment or demographic characteristics (e.g. cancer type, presence of metastases) has been adopted to address this concern. The continued identification of specific patient-related characteristics is valuable in order to enhance the transferability of research findings to real-life clinical situations and to recognize apparent population-related gaps.

The characteristics of the studies in our review also demonstrate that more research efforts related to LPA in advanced cancer are focused in older adults (over 60 years) and in women, particularly with breast cancer. Fewer studies in advanced cancer have been conducted with men or young adults. The under-representation of these subgroups in cancer rehabilitation research has been previously highlighted (Høybye et al., 2008; Johansen, 2007). In particular, young adults with cancer face unique needs and challenges, such as psychosocial difficulties, physical symptoms and health-related concerns, and the need to develop tailored care approaches for this population has been emphasized (Avery et al., 2020; Brunet et al., 2018; Trevino et al., 2013; Zebrack, 2011). As supportive care research in cancer evolves, more concentrated efforts are warranted to include under-represented subgroups, in general cancer studies and advanced cancer studies alike.

Although we did not formally search the literature for studies on the perspectives or involvement of family caregivers or health care providers and only included studies of patients with advanced cancer, one study in our review included patient-caregiver dyads participating in a yoga intervention and two others examined the views of patients and professionals (Masel et al., 2018; Milbury et al., 2015; Payne et al., 2018). Previous research examining the external perspectives of family caregivers, physicians and physiotherapists has demonstrated these groups believe promoting PA in people with advanced cancer is important and beneficial (Rhudy et al., 2015; Sheill, Guinan, L, et al., 2018; Sheill et al., 2017). However, in these studies, the presence of specific concerns related to activity recommendations, particularly for patients with bone metastases, and the need for formal education and professional training has been highlighted. Other research within the cancer population also emphasizes the roles of socio-environmental influences, such as social support, perceived environment and accessibility, in facilitating or impeding PA behaviour (Burke et al., 2020; Fleury & Lee, 2006; Yen & Li, 2019). These findings support ecological models, which consider multiple, interactive factors at the individual, interpersonal and environmental levels that directly impact health behaviours (Glanz & Rimer, 2005). As health professionals and family members can play a critical role in providing support, guidance and resources for patients with advanced cancer over the care continuum, these areas may benefit from further exploration in the literature.

LPA Programs

Consistent with other research findings, most studies included in our review explored a program or an intervention with a component of LPA. The majority of these included structured exercise programs of aerobic and resistance training. Findings from these research studies have contributed to an earlier review by Heywood et al. (2017), confirming the safety and feasibility of such types of LPA programs in the advanced cancer population. Recent systematic reviews, including two meta-analyses,

have also identified benefits with exercise in people with advanced cancer for certain clinical outcomes, including physical function and quality of life (Chen et al., 2020; Dittus et al., 2017; Heywood et al., 2018; Lowe et al., 2008; Nadler et al., 2019). Other outcomes that may improve with exercise in this population include fatigue, sleep quality, psychosocial function as well as body composition (Chen et al., 2020; Heywood et al., 2018).

Leisure activities besides structured aerobic and resistance exercise programs, such as mind-body exercises (e.g. yoga, Tai Chi and Qigong), gardening, dance or low-impact sports have not been well studied in this population. These activities may be meaningful, enjoyable and beneficial for patients with advanced cancer and may address some of the barriers experienced by patients towards LPA, such as lack of motivation, lack of enjoyment or familiarity, and challenges with accessibility (Clark et al., 2007; Hyatt et al., 2019; Mikkelsen et al., 2019; Sheill, Guinan, Neill, et al., 2018; Tsianakas et al., 2017). Moreover, mind-body activities, such as yoga and Tai Chi, may be particularly helpful in managing some of the psychosocial impacts experienced by people with advanced cancer. As noted in our review findings, several of the studies exploring these types of programs have been limited to women with advanced breast cancer. Research efforts are needed to understand the diverse interests and preferences of patients with different types of advanced cancer and to develop LPA programs that are tailored, meaningful and accessible for this population.

LPA Outcomes

Many studies with quantitative approaches also examined LPA as a study outcome. Most of these studies assessed adherence to LPA programs or collected information on patient-reported levels of LPA without the use of validated questionnaires. Of those that used questionnaires, the most commonly used one was the Godin Leisure-Time Exercise Questionnaire (Godin, 2011; Shephard, 1997). This patient-reported questionnaire has demonstrated reliability and validity and has been extensively

used in different patient populations, including cancer survivors (Amireault et al., 2015). As advanced cancer is frequently characterized by high resting energy expenditure (Bosaeus et al., 2002; Dev et al., 2015), PA assessment tools that are based on estimates of energy expenditure may not be accurate or applicable for this population. Objective measures of PA and other aspects of physical functioning may be feasible and informative (Gresham et al., 2018; Jones et al., 2007), but these may be limited in distinguishing different domains of PA without the supplementary use of patient-reported measures. Wearable technology is becoming a growing area of interest to facilitate the accurate assessment of PA and energy expenditure and to support the delivery of interventions targeting PA (Freedson et al., 2012; McClung et al., 2018). In recent studies with cancer survivors, the use of digital activity tracking monitors has demonstrated potential value in promoting PA and improving clinical outcomes (Maxwell-Smith et al., 2019; Nguyen et al., 2020). Further exploration of patient-reported and objective PA assessment tools specifically in the advanced cancer population is warranted.

Overall, there were few studies qualitatively exploring LPA in this population and within these studies, several were focused on patients receiving palliative or hospice care and frequently close to the end of life. Women or patients with lung cancer were the subgroups most often included in qualitative reports. Moreover, few studies have specifically explored perceptions related to other leisure activities, such as Tai Chi, Qigong, yoga, dance and sports. Findings from this scoping review suggest there is limited knowledge on the actual experiences, perceptions and preferences of people living with different types of advanced cancer related to engaging in LPA.

Review Limitations

Despite our efforts to maintain a broad definition of advanced cancer, it was necessary to refine our inclusion criteria through the selection of specific terms to describe the study population in the research articles reviewed. Using the earlier NCI definition of advanced cancer as our overarching

framework (National Cancer Institute, 2007), we limited our selection criteria to include study population descriptions that indicated stage 3-4 cancers or specified other key terms (e.g. palliative, incurable, limited life expectancy). Moreover, during the review process, we decided to exclude articles that involved mixed study populations (i.e. studies including patients with advanced cancer as a subgroup).

Another limitation of our review was based on the decision to focus on the leisure-time domain of PA. Several studies excluded from our review examined and targeted other aspects of PA beyond leisure alone, such as total PA, which also considers activities involving physical movement related to occupation, transport and domestic and self-care (Petee Gabriel et al., 2012). These types of activities may be of importance to patients with advanced cancer and, as highlighted within recent qualitative studies, maintaining responsibility and routine through daily life activities is particularly meaningful in this population and may help explain the disconnect between intentions and actual participation in LPA (Cheville et al., 2012; Lowe et al., 2020; Peoples et al., 2017). Finally, we excluded non-English texts during the article screening process. While these limitations may have resulted in missing valuable information on pertinent topics, we have identified through this review an extensive volume and a wide range of studies focusing on LPA in advanced cancer, which provide a global understanding of the scope of published literature and help highlight major gaps in the literature to shape future research inquiries.

Practical Implications

In addition to gaps in the current published literature, the translation of research knowledge to practice has not been well examined in this area. Despite the recent emergence of research supporting exercise interventions, patient education materials targeted to the advanced cancer population are lacking pertinent, updated information on this topic (Canadian Cancer Society, 2017; ESMO Palliative Care Working Group, 2011; National Cancer Institute, 2014). Novel knowledge translation strategies are

needed to transfer and implement research information to practice and to facilitate access to appropriate, evidence-based knowledge in patients and health professionals.

As the importance of LPA is increasingly recognized for people with advanced cancer, clinicians specialized in oncology and rehabilitation may wish to further consider their role in optimizing leisure activities that are meaningful to patients and guiding effective LPA programs to improve clinical outcomes, such as physical function and fatigue. With access to updated relevant literature, health professionals and researchers in these areas can establish and deliver evidence-based supportive care strategies and programs for this patient population. Further efforts are needed to translate and personalize research findings in cancer rehabilitation practice through the development and implementation of tailored clinical programs and educational materials.

Conclusion

To our knowledge, this is the first scoping review of published research exploring LPA in people with advanced cancer. Research on this topic is rapidly expanding, with a focus on studies examining structured aerobic and resistance exercise interventions using traditional quantitative methods. There is insufficient knowledge on the experiences and perceptions of patients with advanced cancer towards engaging in LPA. Moreover, little is known about leisure activities, such as yoga, dance and sports, particularly in patients with non-breast cancer diagnoses. To optimize the potential benefits of LPA on physical function and quality of life in individuals with advanced cancer, more research is needed to address the gaps in the current body of literature and to develop personalized evidence-based supportive care strategies for this population.

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Supplementary Appendix A

Search Strategy for MEDLINE

1. ((advance* or metasta* or stage 3 or stage III or stage 4 or stage IV or incurable or nonresectable or non-resectable or unresectable or inoperable or nonoperable or non-operable or end stage or end-stage or late stage or late-stage) adj3 (cancer* or neoplas* or carcinom* or adenocarcinom* or malignan* or tumor* or tumour* or oncolog* or cyst*)).tw.
2. exp Palliative Care/
3. (end* adj2 life).tw.
4. (last year of life or LYOL).tw.
5. palliat*.tw.
6. exp Terminally Ill/
7. hospice*.tw.
8. 2 or 3 or 4 or 5 or 6 or 7
9. exp Neoplasms/
10. (cancer* or neoplas* or carcinom* or adenocarcinom* or malignan* or tumor* or tumour* or oncolog* or cyst*).tw.
11. 9 OR 10
12. 8 AND 11
13. 1 OR 12
14. (physical* adj2 activ*).tw.
15. exp Exercise/
16. exp Exercise Therapy/
17. exercis*.tw.
18. exp Leisure Activities/
19. (leisur* adj2 activit*).tw.
20. recreation*.tw.
21. ((aerobic or cardiovascular or interval) adj2 training).tw.
22. (walking or running or jogging or cycling or bicycl* or swimming or danc*).tw.
23. ((strength* or resistance) adj2 training).tw.
24. (weightlifting or weight lifting or weight training).tw.
25. (stretch* or yoga or pilates or tai ji or tai chi or qi gong or qigong or martial art*).tw.
26. sports/ or baseball/ or basketball/ or bicycling/ or boxing/ or football/ or golf/ or gymnastics/ or hockey/ or martial arts/ or mountaineering/ or racquet sports/ or running/ or skating/ or snow sports/ or soccer/ or swimming/ or "track and field"/ or volleyball/ or weight lifting/ or wrestling/
27. (sport* or baseball or basketball or boxing or football of golf* or gymnastics or hockey or mountaineering or tennis or squash or soccer or (track and field) or volleyball or wrestling).tw.
28. (bowling or hiking or skiing or skating or snowboarding or rollerblading* or gardening).tw.
29. (active video gam* or wii or kinect or playstation move).tw.
30. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29
31. 13 AND 30

Supplementary Appendix B

List of Relevant Reviews (for Supplementary Search)

1. *Albrecht, T. A., & Taylor, A. G. (2012). Physical activity in patients with advanced-stage cancer: a systematic review of the literature. *Clinical Journal of Oncology Nursing*, *16*(3), 293-300. doi:10.1188/12.cjon.293-300
2. *Beaton, R., Pagdin-Friesen, W., Robertson, C., Vigar, C., Watson, H., & Harris, S. R. (2009). Effects of exercise intervention on persons with metastatic cancer: a systematic review. *Physiotherapy Canada*, *61*(3), 141-153.
3. Chasen, M., Bhargava, R., & MacDonald, N. (2014). Rehabilitation for patients with advanced cancer. *CMAJ*, *186*(14), 1071-1075.
4. *Dittus, K. L., Gramling, R. E., & Ades, P. A. (2017). Exercise interventions for individuals with advanced cancer: A systematic review. *Preventive Med*, *104*, 124-132. doi:10.1016/j.ypmed.2017.07.015
5. Eyigor, S. (2010). Physical activity and rehabilitation programs should be recommended on palliative care for patients with cancer. *Journal of Palliative Medicine*, *13*(10), 1183–1184
6. Eyigor, S., & Akdeniz, S. (2014). Is exercise ignored in palliative cancer patients? *World Journal of Clinical Oncology*, *5*(3), 554.
7. Hart, N. H., Galvao, D. A., & Newton, R. U. (2017). Exercise medicine for advanced prostate cancer. *Current Opinion in Supportive and Palliative Care*, *11*(3), 247-257.
8. *Heywood, R., McCarthy, A. L., & Skinner, T. L. (2017). Safety and feasibility of exercise interventions in patients with advanced cancer: a systematic review. *Supportive Care in Cancer*. doi:10.1007/s00520-017-3827-0
9. Kowalski, S. L. (2016). Physical therapy and exercise for hospice patients. *Home Healthcare Now*, *34*(10), 563-568.
10. Lin, C. C. (2015). Does physical activity have value in end-of-life cancer care? *Cancer Nursing*, *38*(4), 251-252.
11. *Lowe, S. S., Watanabe, S. M., & Courneya, K. S. (2008). Physical activity as a supportive care intervention in palliative cancer patients: a systematic review. *The Journal of Supportive Oncology*, *7*(1), 27-34.
12. Navigante, A., & Morgado, P. C. (2016). Does physical exercise improve quality of life of advanced cancer patients? *Current Opinion in Supportive and Palliative Care*, *10*(4), 306-309.
13. *Payne, C., Larkin, P. J., McIlfratrick, S., Dunwoody, L., & Gracey, J. H. (2013). Exercise and nutrition interventions in advanced lung cancer: a systematic review. *Current Oncology*, *20*(4), e321.
14. Salakari, M. R., Surakka, T., Nurminen, R., & Pylkkanen, L. (2015). Effects of rehabilitation among patients with advanced cancer: a systematic review. *Acta Oncologica*, *54*(5), 618-628. doi:10.3109/0284186x.2014.996661
15. Wittry, S. A., Lam, N. Y., & McNalley, T. (2018). The value of rehabilitation medicine for patients receiving palliative care. *American Journal of Hospice and Palliative Medicine*, *35*(6), 889-896.

*Heywood, R., McCarthy, A. L., & Skinner, T. L. (2018). Efficacy of exercise interventions in patients with advanced cancer: a systematic review. *Archives of Physical Medicine & Rehabilitation*, 99(12), 2595-2620.

*Reviews used for citation analysis (five from initial search and one additional from updated search)

Supplementary Appendix C

List of Articles Included in Scoping Review (n=92)

1. Adamsen, L., Stage, M., Laursen, J., Rørth, M. & Quist, M. (2012). Exercise and relaxation intervention for patients with advanced lung cancer: a qualitative feasibility study. *Scandinavian Journal of Medicine & Science in Sports*, 22(6), 804-815.
2. Arun, B., Austin, T., Babiera, G.V., Basen-Engquist, K., Carmack, C.L., Chaoul, A., Cohen, L., Connelly, L., Haddad, R., Harrison, C., Li, Y., Mallaiah, S., Nagarathna, R., Parker, P. A., Perkins, G.H., Reuben, J.M., Shih, Y. T., Spelman, A., Sood, A., Yang, P. & Yeung, S.J. (2017). A comprehensive lifestyle randomized clinical trial: design and initial patient experience. *Integrative Cancer Therapies*, 16(1), 3-20.
3. Belchamber, C.A. (2009). Participants' perceptions of groupwork in the management of cancer symptoms in older people. *Groupwork*, 19(2), 79-100.
4. Block, K.I., Gyllenhaal, C., Tripathy, D., Freels, S., Mead, M.N., Block, P.B., Steinmann, W.C., Newman, R.A. & Shoham, J. (2009). Survival impact of integrative cancer care in advanced metastatic breast cancer. *The Breast Journal*, 15(4), 357-366.
5. Born, T. & Stuiver, M.M. (2010). The effect of a therapeutic exercise program "life in balance" on the quality of life in a patient with metastatic breast cancer: a case report, *Rehabilitation Oncology*: 28(2), 19-22.
6. Brown, P., Clark, M.M., Atherton, P., Huschka, M., Sloan, J. A., Gamble, G., Girardi, J., Frost, M.H., Piderman, K. & Rummans, T.A. (2006). Will improvement in quality of life (QOL) impact fatigue in patients receiving radiation therapy for advanced cancer? *American Journal of Clinical Oncology*, 29(1), 52-8.
7. Carr, T., Quinlan, E., Robertson, S., Duggleby, W., Thomas, R. & Holtslander, L. (2016). Yoga as palliation in women with advanced cancer: a pilot study. *International Journal of Palliative Nursing*, 22(3), 111-117.
8. Carson, J.W., Carson, K.M., Porter, L.S., Keefe, F.J., Shaw, H. & Miller, J.M. (2007). Yoga for women with metastatic breast cancer: results from a pilot study. *Journal of Pain and Symptom Management*, 33(3):331-41.
9. Chasen, M.R., Feldstain, A., Gravelle, D., Macdonald, N. & Pereira, J. (2013). An interprofessional palliative care oncology rehabilitation program: effects on function and predictors of program completion. *Current Oncology*, 20(6), 301-309.
10. Cheville, A.L., Alberts, S.R., Rummans, T.A., Basford, J.R., Lapid, M.I., Sloan, J.A., Satele, D.V. & Clark, M.M. (2015). Improving adherence to cancer treatment by addressing quality of life in patients with advanced gastrointestinal cancers. *Journal of Pain and Symptom Management*, 50(3), 321-327.
11. Cheville, A.L., Dose, A.M., Basford, J.R. & Rhudy, L.M. (2012). Insights into the reluctance of patients with late-stage cancer to adopt exercise as a means to reduce their symptoms and improve their function. *Journal of Pain and Symptom Management*, 44(1), 84-94.
12. Cheville, A.L., Kollasch, J., Vandenberg, J., Shen, T., Grothey, A., Gamble, G. & Basford, J.R. (2013). A home-based exercise program to improve function, fatigue, and sleep quality in patients with Stage

- IV lung and colorectal cancer: a randomized controlled trial. *Journal of Pain and Symptom Management*, 45(5), 811–821.
13. Cheville, A.L., Moynihan, T., Herrin, J., Loprinzi, C. & Kroenke, K. (2019). Effect of collaborative telerehabilitation on functional impairment and pain among patients with advanced-stage cancer: a randomized clinical trial. *JAMA Oncology*, 5(5), 644–652.
 14. Chiarotto, J.A., Akbarali, R., Bellotti, L. & Dranitsaris, G. (2017). A structured group exercise program for patients with metastatic cancer receiving chemotherapy and CTNNB1 (β -catenin) as a biomarker of exercise efficacy. *Cancer Management and Research*, 9, 495-501.
 15. Chui, Y.Y., Donoghue, J. & Chenoweth, L. (2005). Responses to advanced cancer: Chinese-Australians. *Journal of Advanced Nursing*, 52(5), 498-507.
 16. Clark, M.M., Vickers, K.S., Hathaway, J.C., Smith, M., Looker, S.A., Petersen, L.R., Pinto, B.M., Rummans, T.A. & Loprinzi, C.L. (2007). Physical activity in patients with advanced-stage cancer actively receiving chemotherapy. *The Journal of Supportive Oncology*, 5(10), 487-493.
 17. Coats, V., Moffet, H., Vincent, C., Simard, S., Tremblay, L., Maltais, F. & Saey, D. (2020) Feasibility of an eight-week telerehabilitation intervention for patients with unresectable thoracic neoplasia receiving chemotherapy: a pilot study. *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine*, 4(1), 14-24.
 18. Cormie, P., Galvão, D.A., Spry, N., Joseph, D., Taaffe, D.R. & Newton, R.U. (2014). Functional benefits are sustained after a program of supervised resistance exercise in cancer patients with bone metastases: longitudinal results of a pilot study. *Supportive Care in Cancer*, 22(6), 1537-1548.
 19. Cormie, P., Newton, R.U., Spry, N., Joseph, D., Taaffe, D.R. & Galvao, D.A. (2013). Safety and efficacy of resistance exercise in prostate cancer patients with bone metastases. *Prostate Cancer and Prostatic Diseases*, 16(4), 328-335.
 20. Crevenna, R., Schmidinger, M., Keilani, M., Nuhr, M., Fialka-Moser, V., Zettinig, G. & Quittan, M. (2003). Aerobic exercise for a patient suffering from metastatic bone disease. *Supportive Care in Cancer*, 11(2), 120-122.
 21. Crevenna, R., Schmidinger, M., Keilani, M., Nuhr, M., Nur, H., Zöch, C., Zielinski, C., Fialka-Moser, V. & Quittan, M. (2003). Aerobic exercise as additive palliative treatment for a patient with advanced hepatocellular cancer. *Wiener Medizinische Wochenschrift*, 153(9-10), 237-240.
 22. Delrieu, L., Vallance, J.K., Morelle, M., Fervers, B., Pialoux, V., Friedenreich, C., Dufresne, A., Bachelot, T., Heudel, P.E., Trédan, O., Pérol, O. & Touillaud, M. (2020). Physical activity preferences before and after participation in a 6-month physical activity intervention among women with metastatic breast cancer. *European Journal of Cancer Care*, 29(1), e13169.
 23. Dhillon, H.M., Bell, M.L., van der Ploeg, H.P., Turner, J.D., Kabourakis, M., Spencer, L., Lewis, C., Hui, R., Blinman, P., Clarke, S.J., Boyer, M.J. & Vardy, J.L. (2017). Impact of physical activity on fatigue and quality of life in people with advanced lung cancer: a randomized controlled trial. *Annals of Oncology*, 28(8), 1889–1897.
 24. Egegaard, T., Rohold, J., Lillelund, C., Persson, G. & Quist, M. (2019). Pre-radiotherapy daily exercise training in non-small cell lung cancer: a feasibility study. *Reports of Practical Oncology and Radiotherapy*, 24(4), 375–382.

25. Ellis, K.R., Janevic, M.R., Kershaw, T., Caldwell, C.H., Janz, N.K. & Northouse, L. (2017). Engagement in health-promoting behaviors and patient–caregiver interdependence in dyads facing advanced cancer: an exploratory study. *Journal of Behavioral Medicine*, 40(3), 506-519.
26. Fairman, C.M., Nilsen, T.S., Newton, R.U., Taaffe, D.R., Spry, N., Joseph, D., Chambers, S.K., Robinson, Z.P., Hart, N.H., Zourdos, M.C., Focht, B.C., Peddle-McIntyre, C.J. & Galvão, D.A. (2020). Reporting of resistance training dose, adherence, and tolerance in exercise oncology. *Medicine and Science in Sports and Exercise*, 52(2), 315–322.
27. Galvão, D.A., Taaffe, D.R., Spry, N., Cormie, P., Joseph, D., Chambers, S.K., Chee, R., Peddle-McIntyre, C.J., Hart, N.H., Baumann, F.T., Denham, J., Baker, M. & Newton, R.U. (2018). Exercise preserves physical function in prostate cancer patients with bone metastases. *Medicine and Science in Sports and Exercise*, 50(3), 393–399.
28. Gross, A.M., Liu, Q. & Bauer-Wu, S. (2007). Prevalence and predictors of complementary therapy use in advanced-stage breast cancer patients. *Journal of Oncology Practice*, 3(6), 292-295.
29. Gulde, I., Oldervoll, L. M. & Martin, C. (2011). Palliative cancer patients’ experience of physical activity. *Journal of Palliative Care*, 27(4), 296-302.
30. Hartland, M.C., Davison, K., Nelson, M.J., Buckley, J.D., Parfitt, G. & Fuller, J.T. (2019). A case study of exercise adherence during stereotactic ablative radiotherapy treatment in a previously active male with metastatic renal cell carcinoma. *Journal of Sports Science & Medicine*, 18(3), 462–470.
31. Headley, J.A., Ownby, K.K. & John, L.D. (2004). The effect of seated exercise on fatigue and quality of life in women with advanced breast cancer. *Oncology Nursing Forum*, 31(5), 977-983.
32. Henke, C.C., Cabri, J., Fricke, L., Pankow, W., Kandilakis, G., Feyer, P.C. & De Wit, M. (2014). Strength and endurance training in the treatment of lung cancer patients in stages IIIA/IIIB/IV. *Supportive Care in Cancer*, 22(1), 95-101.
33. Hwang, C.L., Yu, C.J., Shih, J.Y., Yang, P.C. & Wu, Y.T. (2012). Effects of exercise training on exercise capacity in patients with non-small cell lung cancer receiving targeted therapy. *Supportive Care in Cancer*, 20(12), 3169–3177.
34. Hyatt, A., Drosdowsky, A., Williams, N., Paton, E., Bennett, F., Andersen, H., Mathai, J. & Milne, D. (2019). Exercise behaviors and fatigue in patients receiving immunotherapy for advanced melanoma: a cross-sectional survey via social media. *Integrative Cancer Therapies*, 18, 1534735419864431.
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CHAPTER 3: PATIENT INTERPRETIVE-DESCRIPTION STUDY (MANUSCRIPT 2)

Relationship of Manuscript 2 to the Dissertation

In this chapter, I present the manuscript on the qualitative interpretive-description study conducted with individuals with stage 4 cancer (Study 2). There is a need to improve knowledge of patient perceptions, facilitators, barriers, and preferences related to LPA in people with advanced cancer. The objective of this study was to explore perspectives and experiences of LPA in Canadian adults diagnosed with stage 4 cancer. This qualitative study was guided by the interpretive-description methodology and consisted of individual, semi-structured interviews with 20 participants. Key findings of the study highlight the diversity and fluidity of individual experiences of LPA and important connections of LPA to health benefits and psychosocial meanings. The participants also identified a need for tailored professional support related to LPA in this population that is integrated and accessible within standard cancer care.

As described in previous chapters, the scoping review (Study 1) helped inform the research question and methods for the present study. More specifically, there was a need to better understand LPA in people with advanced cancer, from the perspectives of individuals living with this health condition. Further information about personal beliefs, facilitators, and barriers of LPA can help inform the development of tailored supportive care strategies and resources for this population. Moreover, this study was guided by the interpretive-description methodology and offered practical implications for rehabilitation practice. In particular, the patient participants described their experiences with, and preferences for, professional support related to LPA. Thus, this research is closely linked to the focus and implications of the mixed-methods study with the physiotherapists (Study 3), which examined clinical physiotherapy practices and health professional views related to LPA in advanced cancer. Together, the different components of my dissertation research provide relevant applications in order to further

advance rehabilitation priorities focused on LPA and other supportive care needs within the advanced cancer population.

This manuscript has been submitted for publication in the journal *Disability and Rehabilitation* and is formatted as per the journal requirements. The submitted version of the manuscript which is currently under review is presented in this chapter.

Manuscript 2: Perspectives and Experiences of Leisure-Time Physical Activity in Adults with Stage 4 Cancer: a Qualitative Interpretive-Description Study

Abstract

Purpose: Leisure-time physical activity (LPA) may be beneficial for individuals with advanced cancer, but little is known on how to tailor rehabilitation strategies targeting LPA in cancer care. Our objective was to explore perspectives and experiences of LPA in people with stage 4 cancer.

Materials and methods: Guided by interpretive-description methodology, our qualitative study consisted of individual, semi-structured interviews with 20 Canadian adults diagnosed with stage 4 cancer. Interviews were transcribed verbatim and analyzed inductively.

Results: The participants' median age was 51.5 (range, 35-73) years. Cancer types included breast (n=12), lung (n=4) and other (n=4). Participants highlighted their experiences of LPA as diverse and fluid, necessitating consideration of cancer-related symptoms and risks. They emphasized being intentional with LPA through activity planning and modification. LPA participation was linked to health benefits, social connections, and meanings of accomplishment and loss. Many participants desired tailored support related to LPA, that is integrated, interprofessional, and accessible in cancer care.

Conclusion: The experiences of LPA for people with stage 4 cancer are personal and connected to health and psychosocial meanings. Further efforts in rehabilitation are needed to address the challenges faced by people with advanced cancer and optimize safe, meaningful participation in LPA.

Keywords: physical activity, exercise, advanced cancer, palliative care, rehabilitation

Implications for Rehabilitation:

- Experiences of leisure-time physical activity in individuals with stage 4 cancer are personal and linked to health benefits and psychosocial meanings.
- Activity participation frequently involves consideration of cancer-related symptoms, management of risks, and intentional planning and modification of activities.
- Trained rehabilitation professionals integrated in cancer care may be well suited to support people with stage 4 cancer through personalized activity recommendations.
- This research can help inform future clinical, research and educational efforts in rehabilitation aimed at targeting physical activity in individuals with advanced cancer.

Introduction

Advanced cancer has been defined by the National Cancer Institute (2017) as “*cancer that is unlikely to be cured or controlled with treatment*” [1]. Individuals with advanced cancer experience high symptom burden, declined physical function, and frequent psychosocial concerns, associated with common challenges in daily functioning, impacted quality of life, and increased healthcare utilization [2–6]. There exist important gaps in understanding and supporting the survivorship experiences of people living with incurable cancer [7]. In particular, physical activity (PA) and rehabilitation interventions warrant further exploration in people with advanced or incurable cancers [7–9].

Traditionally, this patient population has not been well studied in PA research as most previous studies have focused on survivors of early-stage breast and prostate cancer following treatment completion [8,9]. Fortunately, there is increasing evidence recently demonstrating the safety and feasibility of exercise for people with advanced cancer [10–12]. Furthermore, exercise participation in this population can ameliorate several clinical outcomes, including physical function, fatigue, sleep, and quality of life [13–15]. However, people with different types of advanced cancer have reported several individual and socio-environmental challenges to adopting PA [16–19] and identified many unmet supportive care needs, including rehabilitation support [20,21].

Despite the increasing awareness of the benefits of PA in cancer, little is known on how to develop and tailor PA programs and resources to best support the advanced cancer population. There exist several limitations in the current body of literature on this important topic, as highlighted in our recent scoping review [12] and other supporting research. Firstly, few studies have employed qualitative or mixed-methods approaches to explore experiences, beliefs, and preferences of patients with advanced cancer related to PA. This information would be useful to inform personalized PA resources within cancer care and optimize individual PA participation in this population [13,17]. Moreover, missing

from the general and advanced cancer literature alike is attention to leisure physical activities that extend beyond traditional aerobic and resistance training programs. Potential benefits with yoga, Tai Chi, Qigong, and dance have been demonstrated in different cancer populations [9,22–25], but such activities have not been well investigated in advanced cancer. In addition to these limitations, several qualitative studies have focused on exploring PA in older adults, individuals with lung cancer, or patients within palliative or hospice care settings who may be closer to the end of life [19,26–32]. As patients with advanced cancer are benefitting from longer survival rates, there remains a need to further explore PA in people with different demographics and cancer types and along the entire spectrum of the cancer experience [17]. Finally, although rehabilitation professionals may be well positioned to support people facing functional challenges due to cancer [33–35], few qualitative studies have explored PA in this population from a rehabilitation perspective [27,28,31].

The gaps in the literature indicate the need for further rehabilitation research exploring PA in people representing different subgroups of advanced cancer. Moreover, examining the leisure-time domain of PA [36] in a broader sense, beyond exercise alone, may be helpful to recognize varied activities that are important and enjoyable to patients [12]. Understanding distinct patient experiences, perceptions and preferences related to leisure-time PA (LPA) can help guide the development and implementation of tailored rehabilitation strategies targeting LPA in cancer care [37]. Thus, the objective of our study was to explore the perspectives and experiences of LPA in a diverse group of Canadian adults diagnosed with stage 4 cancer.

Materials and Methods

Qualitative Methodology

We undertook a qualitative study informed by the interpretive-description methodology [37,38]. Grounded in the field of nursing, this research approach is useful to develop an understanding of experience phenomena with relevant implications for practice-based disciplines within a variety of applied health sciences, including rehabilitation [37,39]. It recognizes commonalities and shared experiences within the patient population while acknowledging individual real-life variations, with the goals of *“informing clinical reasoning, extending available insight for practice decisions and creating a sense-make structure for variations in real-world health-care application”* [38]. The use of this methodological approach has been described in previous research to explore PA in cancer and non-cancer populations [40–42] as well as in cancer rehabilitation and palliative care research [43,44].

Participants

Through purposeful sampling, we recruited individuals meeting the following inclusion criteria: (a) aged ≥ 18 years; (b) diagnosed with stage 4 solid tumour cancers; (c) English-speaking; and (d) living in Canada. We targeted a sample of 20 participants to aim for diversity in the participants, as well as based on similar studies on this topic [18,19,26]. We considered diversity in terms of age, gender and cancer type, in order to address population-related gaps noted in the literature [12] and to help capture individual variations in experiences of LPA [37]. Eligible participants were recruited to the study through social media posts, through local community-based cancer centres and clinics, as well as by word-of-mouth (i.e., snowballing technique). If interested in participating, the individuals were requested to contact the research team via email.

Data Collection

Following contact via email, eligible participants were asked to complete an online pre-interview form. This form included the consent form and an information questionnaire, and was administered

through the SurveyMonkey program (SurveyMonkey Inc., San Mateo, California). Descriptive information on demographics, cancer history, as well as past and current participation in LPA was collected through the questionnaire. Upon completion of the online form, we contacted the participants via email to schedule the interviews.

Guided by the interpretive-description methodology [37], we used an interview guide to explore the following areas related to LPA: (a) experiences pre- and post-diagnosis; (b) perceptions and beliefs; (c) facilitators and barriers; (d) professional information and support received following cancer diagnosis; and (e) preferences related to programs and resources (**Table 3.1**). The interview questions were developed in collaboration with the research team and informed by theoretical assumptions and existing research knowledge of links between LPA behaviour and intrapersonal, interpersonal and environmental factors [17,45,46]. The interview guide and interviewing techniques were pre-tested with a peer researcher (MCR) and modified according to feedback. Additionally, the research team collaboratively reviewed the transcript of the first interview and further refined the questions and delivery for subsequent interviews.

Table 3.1 Interview Guide

<p>Leisure physical activity (LPA)~ includes <i>activities you do in your free time, based on your personal interests</i>. These activities might include exercise, walking, yoga, Tai Chi, biking, golf, gardening, hiking, sports, dance and more – anything that gets you moving for fun.</p>	
Interview Questions	Follow-Up Questions / Prompts
<p>Experiences</p> <ul style="list-style-type: none"> • Can you tell me about your experience with any LPA before cancer diagnosis? • Can you tell me about your experience with any LPA right now? 	<ul style="list-style-type: none"> • What type of LPA did you / do you participate in? • How did your experience with LPA change following diagnosis?
<p>Perceptions and beliefs</p> <ul style="list-style-type: none"> • How do you feel about participating in LPA after your cancer diagnosis? • What do you believe are some benefits of LPA for you? • What do you believe are some risks of LPA for you? 	<ul style="list-style-type: none"> • Do you believe LPA is important for you (or someone with a similar diagnosis)? • Do you believe it's safe for you to participate in LPA? • Do you believe you are able to participate in LPA?
<p>Facilitators and barriers</p> <ul style="list-style-type: none"> • What do you feel are important factors within you* that influence your LPA? • What do you feel are important factors within your relationships* and your environment* that influence your LPA? 	<ul style="list-style-type: none"> • Can you describe factors that help you participate in LPA? • Can you describe factors limit you from participating in LPA?
<p>Professional support</p> <ul style="list-style-type: none"> • Can you describe any information or professional support you received during your cancer experience about LPA? • If you could design the ideal LPA program for yourself, what would it look like? 	<ul style="list-style-type: none"> • Can you describe the source of LPA support or program (e.g., professional, independent)? • Can you describe the details of LPA support or program (e.g., types of activities, location / setting, timing, use of technology)?

~No abbreviations used during the actual interviews

*Potential individual, interpersonal and environmental factors influencing leisure physical activity

Prior to the interviews, a shortened version of the interview guide was shared with the participants. This guide included a description of LPA as well as an overview of sample interview questions. The primary researcher (SMS) conducted individual, semi-structured interviews using an online video-conferencing program (Zoom version 5.9.1). Before commencing the interview, informed

consent was reobtained from each participant verbally. The interviews were recorded using built-in features of the video-conferencing program, as well as a second external voice recorder (Sony ICDPX370). Field notes (memos) and observations were recorded in an interview journal [47]. The primary researcher transcribed over half of the interviews independently with the aid of an automatic transcription program. The remaining seven interviews were transcribed by a research assistant and then verified by the primary researcher. Additionally, we shared transcript summaries with each participant within four to six weeks after the interviews and requested their review and feedback.

Data Analysis

Baseline characteristics of the participants were analyzed descriptively. Consistent with the interpretive-description approach, we inductively analyzed the interview transcript data [37,38]. The primary researcher reviewed the transcripts and generated preliminary codes manually using Microsoft Excel (Microsoft, version 16.58). The preliminary codebook was discussed with research team members (RT and JK). Following these steps, the primary researcher coded the transcript data using the qualitative analytic software NVivo (QSR International, release version 1.6.1). Through an iterative, collaborative process, the research team identified themes based on common and meaningful patterns, with a focus on relevance to rehabilitation practice [37,38].

Quality Criteria

To minimize the influence of the researchers in shaping the data collection [37], the interviewer disclosed her role as a Ph.D. candidate in rehabilitation sciences, but not her professional training and clinical experience as a physiotherapist, unless this information was requested by the participants. The interview questions were also designed to ask about different aspects of LPA participation (e.g., benefits and risks, facilitators and barriers), as well as general experiences and preferences related to

professional support (i.e., not specifically rehabilitation). Moreover, we created a list of follow-up questions and prompts to assist the interviewer in seeking additional details and clarifications during the interviews, without suggesting a preferential direction.

To further enhance the quality of our research, we considered four evaluation criteria informed by the interpretive-description approach [37]. The research question was developed with consideration of the epistemological standpoint and guided the methodological processes and analytic decisions adopted within this research (epistemological integrity). Through purposeful sampling, we aimed for diversity within the study population (representative credibility). Although prolonged engagement is recommended through repeat interviews, this was not advisable with our study population due to increased participation burden. Instead, we shared transcript summaries with participants so they could provide clarification and additional insights at times convenient for them. In addition, memos were tracked during interviews and reflections on research design, recruitment, data collection and data analysis procedures were documented in a journal (analytic logic). These steps provided supplementary information and helped capture thought processes, potential biases and evolving analytical interpretations [48,49]. Moreover, interpretive claims were supported with exemplary quotes of verbatim data. Finally, trustworthiness of the research findings was reinforced through regular discussions within the research team during the processes of data analysis and transformation (interpretive authority). We also consulted peer examiners (KTA and SP) to review the research design and analytical interpretations [50]. Finally, there was deliberate inclusion and clear indication of experiences that were commonly shared between participants, as well as individual variations.

Ethical Approval

This study was approved by the University of Ottawa Research Ethics Board (H-07-20-5937). All participants consented to participate in this study.

Results

Participant Characteristics

Between November 2020 and November 2021, we interviewed 20 participants (**Table 3.2**). Of these, 9 participants were under the age of 50 years, and 11 over this age. Median ages were similar in participants with primary diagnoses of breast (n=12) and non-breast cancer (n=8) (50 years vs. 53 years), while time since initial diagnosis was longer in breast cancer (5.5 years vs. 1.5 years). On the pre-interview information questionnaire, most participants reported engaging in LPA pre-diagnosis (n=19) and post-diagnosis (n=19). Common activities post-diagnosis included walking (n=17), biking / cycling (n=10), and yoga (n=8). Other reported activities included hiking (n=5), gardening (n=5), jogging / running (n=4), fitness classes (n=4), skiing (n=3), resistance training (n=2), kayaking (n=2), playing with kids (n=2), swimming (n=1), sports (n=1) and personal training (n=1).

Table 3.2 Participant Characteristics

Characteristic	N (%)
Age in years, median (range)	51.5 (35-73)
Gender identity	
Female	17 (85%)
Male	2 (10%)
N/A	1 (5%)
Urban or rural community	
Urban	17 (85%)
Rural	3 (15%)
Province	
ON	16 (80%)
BC	2 (10%)
AB	1 (5%)
QC	1 (5%)
Marital status	
Married	13 (65%)
Common-law	3 (15%)
Single	3 (15%)
Separated	1 (5%)
Children living at home	
No	10 (50%)
Yes	10 (50%)
Highest education level	
Graduate	8 (40%)
Undergraduate	7 (35%)
College	4 (20%)
Middle/high school	1 (5%)
Current employment status	
Working (full-time, part-time, occasional)	5 (25%)
Not working (on leave, retired, unemployed)	15 (75%)
Annual income	
>80K	10 (50%)
60-80K	3 (15%)
40-60K	1 (5%)
20-40K	1 (5%)
<20K	1 (5%)
N/A	4 (20%)
Cancer type	
Breast	12 (60%)
Lung	4 (20%)
Colon	2 (10%)

	Thyroid	1 (5%)
	Prostate	1 (5%)
Years since initial diagnosis, median (range)		5 (1-17)
On active treatment		20 (100%)
Treatment(s) received		
	Surgery	14 (70%)
	Chemotherapy	16 (80%)
	Radiation	8 (40%)
Other health issues		6 (30%)
Total		N=20

AB: Alberta; BC: British Columbia; ON: Ontario; QC: Quebec

Perspectives and Experiences of LPA

There were five major themes related to LPA within the interviews: (1) diverse, fluid experiences; (2) being intentional; (3) health benefits; (4) psychosocial meanings; and (5) seeking tailored support (**Table 3.3**). Descriptive characteristics associated with the participant quotes are limited to broad categories of age and primary cancer type (breast or non-breast cancer) in order to preserve anonymity of the individuals.

Table 3.3 Summary of Themes Related to Perspectives and Experiences of LPA

Theme	Sub-Themes
1. Diverse, fluid experiences of LPA	a) Diverse, changing experiences b) Considerations of symptoms and risks
2. Being intentional with LPA	a) Intentionally planning and prioritizing activities b) Finding balance through activity modifications
3. Health benefits of LPA	a) Symptoms and physical function b) Health outcomes
4. Psychosocial meanings of LPA	a) Accomplishment vs. loss b) Social connections
5. Seeking tailored support related to LPA	a) Lack of professional support in cancer care b) Desire for tailored, integrated support c) Other preferences (e.g., group-based settings, accessibility, accountability)

Theme 1: Diverse, fluid experiences of LPA: The participants emphasized the diverse nature of their individual experiences with LPA. They explained that people with stage 4 cancer often have different physical abilities, goals and expectations, past experiences, and activity levels, as well as personal preferences related to LPA.

There's such a wide spectrum of people and their abilities, and what people are doing already to begin with. (P11, <50 years, breast cancer)

Similar to the pre-interview questionnaire, the participants highlighted, within the interviews, the variety of LPA that they participated in and found enjoyable. Additional leisure activities identified

during the interviews included skating, Qigong, hockey and soccer. Some participants also described activities such as pottery, playing musical instruments, dancing, singing, active video games, as well as home organization.

Individual experiences of LPA also changed over time, attributed mainly to the fluctuating course of stage 4 cancer and “*different trajectories of metastatic (cancer)*” (P3, >50 years, breast cancer), along with the specific side effects associated with various cancer therapies.

I think the main thing is that, you know, as a person with a metastatic disease, your physical health changes and it always fluctuates depending on your treatment (P12, <50 years, breast cancer)

Several participants particularly emphasized the need for a “*personalized*” approach to LPA in the stage 4 cancer population in order “*to respect each individual on an individual basis*” (P18, >50 years, non-breast cancer).

In addition to highlighting the personal nature of LPA experiences, the participants discussed specific considerations required to safely engage in LPA. Many participants adapted their LPA according to cancer-related symptoms and treatment side effects, such as fatigue, recurrent infections, peripheral neuropathies, and skin changes (e.g., hand-foot syndrome). Persistent fatigue symptoms that fluctuated during cancer therapies were often described.

A constant is the fatigue... No amount of sleep seems to make you feel rested, it's just an ongoing thing. And then if you factor in where you are in a particular cycle. Maybe the end of the cycle is harder or your week off or your time in between. (P6, <50 years, breast cancer)

Along with cancer-related symptoms, the participants often needed to consider certain risks within LPA, including fractures, falls, overexertion, pain, lymphedema, infections, and bleeding, as well as recovery from potential injuries. For example, Participant 15 spoke about being cautious with activities such as “*road cycling and mountain biking*”.

If I do get injured, there's that, I don't know whether it's a perception or, I have heard this, that if you get injured and you're in the hospital, it's a longer haul back when you have cancer. And I don't need to put myself in that situation. (P15, >50 years, non-breast cancer)

Another participant also described a cautious approach, stating they adjusted certain exercises during fitness classes due to a bone metastasis in the hip and were *“worried about breaking something that will either take a long time to repair or won't repair well”* (P2, >50 years, breast cancer). For some participants, physical equipment, such as chemotherapy pumps and catheters, required safety considerations in LPA. One example provided included the search for a catheter sealant to allow a participant to *“go out on the water in a canoe”* (P16, <50 years, non-breast cancer). Concerns of overexertion and exhaustion with LPA and the reduced ability to carry out other daily activities were also identified by several participants.

I would say one of them (risks) is chronic exhaustion... So, when doing a physical activity, even a pleasurable physical activity, it's like, looking down the road, is this going to reduce my ability to make dinner for my kids or function, as a mom needs to, later on in the day? (P17, <50 years, non-breast cancer)

Along with these considerations, several participants accommodated busy appointment schedules and managed other life responsibilities, such as childcare and household tasks, often seen as *“challenging”* (P12, <50 years, breast cancer). For some participants, work-related responsibilities would *“get in the way sometimes”* of LPA plans (P14, <50 years, non-breast cancer). Participant 13 (>50 years, non-breast cancer) discussed needing to prioritize time for other responsibilities, such as *“applications for my retirement and pension”* and *“things that I want to do to lessen the burden on my family... (like) clearing things out of my apartment”*.

Theme 2: Being intentional with LPA: In order to safely participate in LPA without aggravating symptoms and increasing risks, the participants spoke about being “*intentional*” and finding “*balance*” and “*moderation*” on an ongoing basis. Participant 4 (>50 years, breast cancer) emphasized recognizing “*the importance of physical activity and daily physical activity for well-being*”. Several participants discussed “*planning the things you really want to do*” (P6, <50 years, breast cancer) and prioritizing their daily activities to integrate regular LPA. Some participants described intentionally choosing activities that “*bring joy*”.

So, I take joy from gardening, I take joy from being on the water. So really, being intentional about the leisure activities that I do. And I guess some of the other leisure activities that I do that don't bring me joy, they bring joy to my kids. So I'll do that. (P17, <50 years, non-breast cancer)

Participant 7 (<50 years, breast cancer) also explained they selected activities “*for pleasure instead of just because I'm supposed to exercise certain number of hours.*”

Due to the unpredictability and “*inconsistency in life after cancer*” (P8, >50 years, non-breast cancer), it was challenging for some participants to establish an ongoing balance with regards to LPA.

There's all these other new things that happen with cancer, that I'm still trying to figure out. And it's a juggle... I can't find the balance of when to stop (exercise) if I feel good when I'm actively doing it, but sometimes it takes me two or three days to recuperate, and that sucks. (P18, >50 years, non-breast cancer)

To exercise caution and moderation, Participant 8 (>50 years, non-breast cancer) explained having “*to actually make a lot of adjustments*”, such as substituting running with walking, replacing ski racing with leisure skiing, and discontinuing tennis. Several participants described being intentional and finding balance in LPA by decreasing the intensity and duration of activities, “*doing smaller bouts more frequently*” (P14, <50 years, non-breast cancer), making it “*part of the routine*” (P1, <50 years, breast

cancer), relying on assistance (e.g. electric bike), and recognizing the need to take breaks and sometimes “just not really do much” (P2, >50 years, breast cancer).

Theme 3: Health benefits of LPA: The participants acknowledged several health benefits with LPA, particularly to mitigate fatigue symptoms.

There is fatigue associated with treatment. But I really feel that the exercise actually helps with the fatigue. So it kind of balances out. (P4, >50 years, breast cancer)

Along with others, one participant explained yoga reduced treatment-related “aches and pains”, as well as helped them “sleep better”, “feel more nimble and flexible” and “get a better breath” (P7, <50 years, breast cancer). Effects of LPA on stabilizing weight and appetite were also described. For several participants, LPA helped with “making sure that you don't gain as much weight” (P2, >50 years, breast cancer), as weight gain was identified as a side effect associated with certain therapies for metastatic breast cancer. Meanwhile, a participant with a non-breast cancer diagnosis described how LPA helped stimulate appetite and maintain muscle mass.

I don't have a great appetite, because of my illness. So exercise increases my appetite. I'm battling to keep weight on, which can be quite common... A lot of times, our treatments are difficult on our bone mass and our muscles. So strengthening exercises like yoga and walking is fantastic. It really just keeps my muscle mass up there. (P8, >50 years, non-breast cancer)

This participant also spoke about how being active allowed them to continue living in their home.

I can tell you that if I don't increase my lung capacity and if I don't look after my heart, if I have to walk from the basement to the second floor, I'm winded. And my heart rate's up. So the benefits of the activity helps me live, helps me stay within our home. (P8, >50 years, non-breast cancer)

Similarly, others indicated the transfer of LPA to daily functional activities, such as carrying groceries, climbing stairs, and playing with kids. One participant discussed engaging in regular LPA and other daily activity in order “to stay as strong and healthy as possible” and decrease “burden on other people” (P19, >50 years, non-breast cancer).

In addition to these benefits, several participants felt that LPA improved their blood counts, treatment tolerance, and recovery from procedures and complications.

One thing that often shows up in my various tests is ‘patient tolerates procedure well’. So you bounce back faster, you recover faster. (P3, >50 years, breast cancer)

Another participant also spoke about treatment response and eligibility for future therapies.

My last CT came back ‘no evidence of disease’... And I think a lot of that is due to being young and physically active and healthy, other than the cancer. So I want to continue that. So that if, or when, I become resistant to (this treatment), I’ll be eligible for other therapies. Some of them, you need to be physically capable to withstand those. (P17, <50 years, non-breast cancer)

Finally, several participants engaged in LPA to improve their cancer outcomes, such as disease progression and survival; to “keep me stable within my illness” (P4, >50 years, breast cancer) and “to stick around as long as I can” (P15, >50 years, non-breast cancer).

Theme 4: Psychosocial meanings of LPA: Along with the health benefits described, the participants identified important psychosocial meanings of LPA. For several participants, being active evoked a “feeling of accomplishment” (P15, >50 years, non-breast cancer), along with “empowerment” and a “sense of control”, particularly due to the lack of control felt with advanced cancer disease (P8, >50 years, non-breast cancer). LPA participation also helped “bring back a bit of normalcy” (P5, <50 years, breast cancer) and “it kind of makes me forget that I’m sick” (P16, <50 years, non-breast cancer), “in the sense that it takes you away from your cancer diagnosis” (P15, >50 years, non-breast cancer). A few

participants described how LPA helped them achieve enjoyment in their lives and “*prioritize some fun*” (P1, <50 years, breast cancer). Engaging in PA was not particularly pleasurable and felt obligatory for some participants, but still provided a sense of accomplishment.

I was never a physically active person, So, to me, especially at this time, I mostly felt that I need to do physical activity... At times, I felt it maybe was a little bit exhausting but I felt I was doing something and, you know, I feel good that I participated, so that was good. Otherwise, it's mostly something I felt I needed to do rather than giving me a lot of pleasure. (P13, >50 years, non-breast cancer)

Several participants explained participation in LPA was “*a really important piece of feeling well... as kind of a mental health thing*” (P11, <50 years, breast cancer). Others described effects of mood elevation (P9, >50 years, breast cancer) and stress relief (P12, <50 years, breast cancer) when being physically active.

In contrast to feelings of accomplishment and mental wellness, there were also common experiences of loss and grief related to LPA.

You kind of grieve that loss. Like, I was a decent runner, for leisure, and over the years, I wasn't spending as much time running or investing in that. And I think now, in hindsight, when someone said, 'Wow, you're fast. You're coming in the top 10% of your age category', I'd say 'Oh whatever.' I was fast for my age at the time. And now I'm thinking, well, I can't even do that anymore. (P16, <50 years, non-breast cancer)

In another example, a participant described having to sell their bike and alpine skis and said “*when we have cancer, we always lose a lot of things*” (P20, >50 years, breast cancer).

In addition to meanings of accomplishment and loss, social connections were considered a key element of LPA participation for many participants. Opportunities to interact with family, friends and other people diagnosed with cancer through LPA were both important and beneficial. One participant

appreciated group-based LPA classes because *“sometimes it's nice to talk to someone who probably understands a little bit more about what you're going through”* (P2, >50 years, breast cancer). Another participant spoke about valuing connection within team sports and *“enjoying the dynamic of playing with other people”* (P6, <50 years, breast cancer). The interconnectedness of LPA and social relationships was described by a couple of participants.

The two things together are working to a point of providing harmony. Harmony that comes from being active, that gives me space to have better relationships, and having better relationships gives me more for this. (P1, <50 years, breast cancer)

Social interactions were also often identified as an important source of motivation for participating in LPA.

The social part totally motivates me... And so I would do all these physical activities not because I really wanted to go for a walk, but because I wanted to gab for an hour with my girlfriend. Or I wanted to go hiking with my friend and we would just go, talking and talking. And I love that. And so that was my motivator for moving half the time. (P7, <50 years, breast cancer)

Several participants explained having a spouse or friend accompany them for activities helped *“to keep you going”* (P14, <50 years, non-breast cancer). For a few participants, it was important to set examples for their young children by *“enjoying life”* (P1, <50 years, breast cancer) and *“living your best life”* (P17, <50 years, non-breast cancer) through participation in LPA.

While social relationships often facilitated LPA, a few participants expressed sadness and frustration about not being able to keep up with others, such as active family members.

I think, my hubby is very active. And so I think that helps me... But he's also very, very fit and doesn't want to me to slow him down too much. (P7, <50 years, breast cancer)

Participant 18 (>50 years, non-breast cancer) illustrated similar challenges by sharing a personal story where they felt unable to keep up with their spouse while biking and had difficulty justifying to the

spouse the need to enable the electric-assist option on their bike. Advice from other people living with cancer also sometimes undermined personal limitations and experiences and resulted in feelings of guilt for not engaging in adequate LPA.

I think that's very common in hearing, just get out for a walk and your life will be so much better. And maybe that isn't the case. Sometimes, the ability isn't necessarily there. And yet, the guilt is still being put on because they think they're saying something good for you or they're doing something great. And it's not necessarily great because then it just makes me feel like crap that I'm not able to do that. And the longer I sit in my house, the more guilty I feel that I should be out there doing this, as everyone says I should be doing. (P9, >50 years, breast cancer)

Theme 5: Seeking tailored support related to LPA: The participants felt tailored professional information and services were needed to “*support (quality of life) through physical activity*” (P4, >50 years, breast cancer) but noted important gaps in their cancer care experiences. Many participants highlighted the lack of acknowledgement and individualized support regarding LPA within standard cancer care.

I've gotten no advice, no restrictions, no limitations. Just, if you feel like doing it, do it. (P12, <50 years, breast cancer)

A traditional, medical focus in oncology care professionals and healthcare systems was often noted.

I think my oncologist was a person that maybe focused more on the medical aspects of it. He never talked to me about paying attention to your nutrition, to physical activity or anything like that. He just focused strictly on the chemo. (P13, >50 years, non-breast cancer)

Some participants attributed the lack of support to common assumptions about people with stage 4 cancer being “*close to death*” and “*a stigma of what a metastatic cancer patient can or can't do, in any part of their journey*” (P4, >50 years, breast cancer). Along with others, one participant also spoke about

unfair assumptions and explained that existing cancer exercise programs and research studies often “exclude metastatic patients”.

To make the assumption that people with metastatic disease are all sick or need to conserve their energy or shouldn't worry about these kinds of things, I think it's not fair. I think it's a faulty assumption. And I think more support needs to be there to encourage people with metastatic disease to exercise within the realms and the constraints of where they are in their treatment.

(P12, <50 years, breast cancer)

As it was not standard practice to receive professional support related to LPA, participants often requested information themselves, sought their own resources, consulted personal contacts, and relied on previous knowledge and experience. Some participants shared concerns about other individuals with cancer who did not have prior LPA experience (P15, >50 years, non-breast cancer) or did not actively seek support (P2, >50 years, breast cancer). Several participants described experiences in exercise classes that were not tailored for people with stage 4 cancer.

The class was offered to women with breast cancer. But the women that were going were survivors, some of them 20 years. So they were in a different category than me and I couldn't always keep up. I would have to sit down more. Or modify it. (P10, >50 years, breast cancer).

Many participants indicated “there should be more support” within cancer care related to LPA (P4, >50 years, breast cancer) and felt “that's a component that's missing” (P15, >50 years, non-breast cancer), particularly for people with stage 4 cancer. Some participants indicated their preference to receive initial advice about the safety and importance of activity from oncology care providers, particularly oncologists, ideally “three to four weeks (after diagnosis), or even the second visit with the oncologist” (P15, >50 years, non-breast cancer). A few participants preferred assistance from oncology team members (e.g., nurse, social worker) to navigate and access multidisciplinary support for LPA, nutrition, and other aspects of health. In particular, they desired consultations with specialized

professionals knowledgeable about PA and advanced cancer, such as a “*a physiotherapist or a personal trainer type of thing*” (P5, <50 years, breast cancer), for supervised, tailored guidance on LPA.

I think if it was a program, I would like it to be with people who are knowledgeable about cancer and the side effects of various treatments. And understanding how to build up your endurance. And to do it safely, but encouraging you to do more and to push yourself. (P12, <50 years, breast cancer)

A couple of participants described their experiences with physiotherapists who were cautious and limited in providing LPA recommendations and highlighted the need for a “*really well-trained person that has additional training or experience*” (P17, <50 years, non-breast cancer). The need for individualized support with adapting and progressing exercise programs safely was particularly emphasized.

When you are stage four, it's so different for every woman. I need to have individual training adapted to myself. And, to have someone who can teach me exercise and after that, we can change the program... We need to change and to progress. (P20, >50 years, breast cancer)

Along with professional LPA support integrated in cancer care, many participants desired access to community-based programs targeting LPA. Program preferences ranged from exercise programs with “*both cardio and strength, and some balance in them*” (P13, >50 years, non-breast cancer) to other activities, such as yoga, dance, and outdoor walking groups. Important considerations around accessibility included affordable cost, proximal locations with available parking, as well as online options. Several participants preferred the incorporation of in-person, group settings within LPA programs, with an opportunity for social interaction; “*in a setting, with other metastatic patients, who can motivate each other in just like a fun space, that's sort of social, but everyone's got the goal of moving and exercising in mind*” (P5, <50 years, breast cancer). Some participants explained their preference for accountability in LPA, through “*something scheduled and committed to somebody else...*”

or a group”, providing “a bit of motivation” and “a high commitment factor” (P10, >50 years, breast cancer). With respect to LPA resources, Participant 17 (<50 years, non-breast cancer) emphasized the need for support that was “culturally appropriate” and suggested collaborations with local community resources, such as “friendship centres, religious organizations, churches”, and academic institutions affiliated with teaching hospitals.

Discussion

The main findings of our qualitative study indicate the experiences of LPA for people with stage 4 cancer are diverse, fluid and linked to psychosocial meanings and health benefits. Participation in LPA frequently involves consideration of cancer-related symptoms, management of risks, and intentional planning and modification of activities. However, many patients do not feel well supported by existing supportive care and rehabilitation services. There is a need in advanced cancer care for LPA support, that is personalized, integrated, interprofessional and accessible.

The interpretive-description methodology permits the interpretation of new findings and linking to existing research knowledge to guide applications in clinical practice [37]. Our findings reveal important themes related to the perspectives and experiences of LPA in people with stage 4 cancer and help inform practical implications for rehabilitation. Firstly, the diversity and fluidity of LPA experiences for people with stage 4 cancer were highlighted. The participants recognized individual variations in personal goals and priorities, abilities, past experiences, as well as current preferences. The latter was illustrated by the variety of leisure activities that individuals found enjoyable, particularly mind-body exercises, outdoor activities, water activities, and recreational sports. Moreover, the participants also emphasized fluctuations in activity levels depending on cancer-related and personal factors. Due to different factors contributing to LPA participation, they indicated the need for a personalized approach

to support people with this challenging diagnosis. These results are consistent with findings described in previous qualitative studies with advanced cancer, recommending a patient-centered approach and tailored LPA recommendations according to past experience, preferences, functional ability and individual needs [17,19,30].

Expanding upon the individual experiences of LPA, many participants in our study spoke about specific considerations and activity modifications in order to safely engage in LPA. Regular consideration of cancer-related symptoms (e.g., fatigue, neuropathy) and potential risks (e.g., falls, fractures, overexertion) was needed to participate in LPA. Symptoms of fatigue, breathlessness, pain, insomnia, and nutritional concerns, are prevalent in people with advanced cancer [51,52]. Fatigue, in particular, as well as pain and shortness of breath, have been identified as important barriers to PA participation in this population [16,18,19,30]. Moreover, there are common issues of bone metastases, peripheral neuropathies, muscle weakness, decreased immune function, and lymphedema in this population [20,53,54]. These issues may be associated with further complications, such as falls, pathological fractures, cellulitis, and other infections. Similar to our study, other studies have identified apprehensions of physical injury and symptom exacerbation with PA [17,30]. The clinical presentation of different symptoms and concerns can be attributed to several factors associated with advanced cancer. Contributing factors may include local and metastatic tumour invasion of healthy tissue, previous and current treatment-related side effects, systemic inflammation and metabolic abnormalities, as well as co-morbidities [52,55,56]. Along with localized and metastatic cancer spread, all participants in our study had received past therapies and were on active treatment at the time of the interviews. Although some participants experienced other health conditions as well, these were not frequently cited as a barrier to PA. However, comorbidities have been identified as a barrier by individuals with advanced cancer who were generally older than our participants [30]. Our study findings highlight important

challenges associated with the clinical characteristics and treatments of stage 4 cancer, which can significantly impact participation in LPA.

Besides cancer-related symptoms and risks, additional considerations around busy appointment schedules and other demanding responsibilities, such as childcare and work activities, were also brought up in our study. Although these specific challenges have not been commonly reported in other similar studies, Mikkelsen et al. (2019) identified everyday life challenges as a barrier to PA in older people with advanced cancer, while Cheville et al. (2012) reported daily activities, such as housekeeping, cooking and yard work, constituted a form of exercise in participants with stage 3-4 lung cancer [19,30]. These research differences may also be related to the younger age and employment status of our participants (i.e., about half under the age of 50 and a quarter continuing to work). Thus, our results highlight some of the unique challenges experienced by younger adults diagnosed with cancer [57]. Moreover, as survival rates of stage 4 cancer improve, challenges related to employment and finances may become increasingly common [57,58]. Together, these findings further support the need for a personalized approach in rehabilitation to optimize safe, regular LPA participation in people with advanced cancer.

Practical implications of these findings suggest that individualized LPA guidance should be developed based on comprehensive, regular assessment of medical status, symptoms, risks, and other factors influencing LPA participation. For example, exercise prescriptions for people with bone metastases should be informed by a multidisciplinary assessment of bone lesions and risk for skeletal complications, and integrate components of close monitoring, positioning considerations and proper body mechanics [34]. In addition to optimizing safety, personalized rehabilitation strategies may be helpful to foster motivation, confidence, control and autonomy related to LPA in this population [17,30,59]. Furthermore, integrating targeted rehabilitation strategies besides LPA alone may be valuable to address different patient-reported concerns. Patient education on infection control and lymphedema risk-reduction practices may help manage additional cancer-related risks. Other

rehabilitation strategies for symptom management include pacing and energy conservation techniques, therapeutic exercises (e.g. balance, range of motion, stabilization, strengthening), breathing techniques, positioning strategies, acupuncture, lymphedema therapy, electro-physical modalities, and assistive devices [52]. Physiotherapy programs consisting of multiple interventions, including exercise, have been found to improve fatigue and other symptoms, as well as functional status in people with advanced cancer [60,61]. Thus, a multidimensional approach in rehabilitation may be useful to address the diverse challenges associated with advanced cancer and support safe participation in LPA.

The second theme in our findings revolved around intentionality, balance, and moderation within LPA. Through considerations of different personal and cancer-related factors, the participants described adopting several strategies to intentionally engage in safe, regular, and meaningful LPA. Many participants carefully planned their limited time and energy and prioritized activities that were important and enjoyable to them, including LPA. They also often modified their activity parameters (e.g., lower intensities and durations; small, regular bouts), omitted or replaced riskier activities with safer options, and utilized assistance or supportive equipment, in order to control their cancer-related symptoms and minimize their risks with LPA participation. While the concept of balance between activity and rest has been briefly explored in previous research [28], our study findings are unique in identifying patient-reported strategies to find intentional balance within LPA in people with stage 4 cancer. These findings may be related to many of our participants having extensive experience with LPA prior to diagnosis and figuring out how to continue LPA post-diagnosis. The majority of participants reported they did not receive sufficient support or guidance on LPA from health professionals. However, these patient-reported strategies are consistent with pacing and energy conservation techniques, risk management strategies, and exercise prescription principles that have been suggested as part of clinical guidelines and practice recommendations for people with cancer [9,34,62]. Identifying meaningful activities and educating patients about specific strategies to find intentional balance within LPA may be

empowering, particularly for those without previous knowledge and experience with LPA. Therefore, the strategies identified in our research and supported by published recommendations may be useful to inform patient education tools and tailored rehabilitation services aimed at promoting LPA in people with advanced cancer.

Another key theme in our study consisted of the health benefits associated with LPA engagement. In our participants, LPA contributed to several positive effects on symptoms of fatigue, energy, sleep quality, pain, and breathing, as well as outcomes of weight control, flexibility, and strength. Similar findings have been reported within previous quantitative research [13,15] and qualitative research [18,26–28,59] with the advanced cancer population. Furthermore, it is important to note the effects of LPA reported by our participants on functional independence, caregiver burden, and cancer-related outcomes, such as treatment tolerance and response. Although these outcomes have not been well explored in the literature, participants in other qualitative studies have also reported believing PA can help maintain functional independence [17,59], control cancer spread, and increase survival [28]. In a recent meta-analysis of 11 studies, higher levels of PA were associated with lower mortality in non-randomized trials with advanced cancer patients, but these results were not demonstrated within randomized controlled trials [63]. Our findings support previous research concerning the benefits of LPA on symptoms and physical function, but also highlight the need to further explore other clinical outcomes of interest, such as treatment response and overall survival. Also, evidence-based knowledge of the health benefits of PA can help increase awareness about the importance of LPA for people with advanced cancer, as well as inform clinical and educational initiatives targeting LPA in this population.

Along with health benefits, there were important psychosocial meanings of LPA for our participants. A sense of accomplishment was appreciated through LPA, accompanied by feelings of empowerment, control and normalcy. The concept of achievement with exercise has also been recognized in previous studies within hospice and palliative care settings [27,59]. In light of the

unpredictable nature of stage 4 cancer, LPA may offer a source of health-promoting behaviour that is positive, controllable and empowering. Moreover, it may consist of an activity that feels “normal” and provides distraction from the challenges of living with an incurable diagnosis. In addition to a sense of accomplishment, benefits of enjoyment, mental wellness, improved mood and stress relief through LPA were described by the participants in our study and within other studies with advanced cancer [18,26–28,59,64]. The benefits of exercise on psychological outcomes of anxiety and depressive symptoms have been well established in the general cancer [9] and, recently, the advanced cancer literature [14]. Similar to health benefits, this knowledge of positive psychological findings can also help guide initiatives to support LPA in this population.

In contrast to feelings of accomplishment and wellness, several participants also described personal experiences of loss, grief, and acceptance related to LPA. Loss also seemed to be an underlying concept to feelings of inadequacy, guilt, and frustration, that were sometimes experienced in social interactions with others. For example, many participants described generally positive experiences of engaging in LPA with their family and friends both prior to and following diagnosis. However, some expressed sadness and frustration at the inability to participate in certain activities to the same extent as before cancer diagnosis. Experiences of loss in LPA have also been previously described in the literature. Participants in two studies by Burke et al. (2020) and Turner et al. (2016) explained how engaging in PA could serve as a reminder of their overall health deterioration [17,59]. Loss and adaptation in leisure activity have also been explored in women experiencing chronic arm issues due to breast cancer, such as pain and lymphedema [65]. Interestingly, in the study by Belchamber (2009), group exercise helped replace a sense of physical loss experienced by participants [27]. The contrasting meanings of accomplishment and loss in LPA may have been particularly profound in our participants, due to their participation in activity prior to cancer diagnosis and the debilitating, lasting effects of incurable cancer. Our research highlights that psychosocial meanings of LPA may be simultaneously

positive and challenging for people living with this diagnosis. Moreover, these meanings may vary between individuals, as well as within individuals at different points in the disease trajectory, depending on cancer progression, treatment effects and other related factors. It is therefore important for rehabilitation professionals to be aware of personal, changing meanings of LPA, as well as to support patients with information and tools related to LPA that empower them as they navigate challenging experiences of advanced cancer. Additionally, some people may benefit from individualized guidance to determine their own abilities and limitations, as well as to communicate realistic expectations and need for support with others, such as loved ones.

Along with meanings of accomplishment and loss, social connections were a fundamental component of LPA for the participants in our study. Opportunities for social interactions were identified as both a source of motivation and a key benefit of LPA participation. The importance of the social aspect of PA has been previously described in several studies with advanced cancer [27,28,30,59]. Social connections through LPA may be particularly valuable for people facing incurable, life-threatening disease, in order to achieve “normal” activities with loved ones and to maintain supportive relationships. Family, friends and peers with cancer have been identified as an important source of social support, particularly emotional support, for people with advanced cancer [66]. Furthermore, perceived social support in this population has been linked to enhanced quality of life and stronger coping strategies [67,68]. Interactions with other people facing similar cancer experiences may also help combat feelings of social isolation reported in the advanced cancer population and foster a sense of belonging [31,58]. Moreover, social opportunities can provide motivation, commitment, and accountability, which may support LPA promotion [31]. Our findings also suggest it would be worthwhile to consider elements of socialization within individualized LPA recommendations and to incorporate group-based or peer support when designing LPA programs for people with stage 4 cancer. Group-based activities may help optimize combined effects of LPA participation and social support for this population.

The final theme of our study highlighted limitations in professional support related to LPA within cancer care and a need for tailored information and resources from health professionals. In particular, the participants preferred the delivery of personalized information about the safety and importance of LPA from oncologists or other health professionals, integrated in standard cancer care. They also desired referrals to specialized professionals and access to tailored programs, where they could obtain supervision and individualized LPA recommendations. In the study by Cheville et al. (2012), participants with stage 3-4 lung cancer reported confidence in PA advice received from oncologists, but similarly, few received any advice or guidance on this matter [19]. In a systematic review of 20 articles, Alderman et al. (2020) estimated 58.1% of health professionals discussed PA with their oncology patients in general, and 18.3% referred patients to exercise specialists or rehabilitation programs [69]. Our participants highlighted a particular need from specialized professionals for support on activity monitoring, modification, and progression. These findings identify important gaps within the survivorship experiences of cancer, particularly for those living with advanced cancer. Several qualitative studies with advanced cancer have indicated trained health professionals, particularly physiotherapists, can be helpful sources of guidance, motivation, and knowledge in PA [19,28,31]. Specialized rehabilitation and exercise professionals may be well-suited to fill supportive care gaps for people who face complex challenges due to stage 4 cancer, such as bone metastases [34].

This research supports the need to implement integrated, interprofessional care to support LPA in advanced cancer. Proposed cancer care models and clinical recommendations have similarly recommended the delivery of PA advice by oncology care providers within standard cancer care and the integration of specialized rehabilitation professionals for routine functional screening, PA supervision and tailored support, as well as other individualized rehabilitation strategies [33,34,70]. However, the role of tailored rehabilitation strategies addressing LPA and other aspects of function have not been well investigated and these warrant further research and clinical exploration, particularly in the advanced

cancer population. Additionally, better developed patient education materials, risk management strategies, and symptom management approaches are needed to support these patients from a rehabilitation perspective. Moreover, there is a need for increased education of health professionals concerning LPA, specifically to raise awareness about LPA in oncology care providers [70], as well as to improve specialized training for rehabilitation and exercise professionals [71,72]. Interprofessional collaboration may improve the quality of patient-centered care, but further work is needed to better implement such integrated models in the care of people with advanced cancer.

Along with integrated, interprofessional cancer care services, our findings suggest community- or hospital-based programs addressing LPA and other supportive care needs may be valuable. When designing LPA programs, an important consideration highlighted by our participants includes the incorporation of supervised, group settings. This preference further reinforces the need for professional support in LPA, to provide regular monitoring and guidance on safe activity participation and progression. Moreover, this preference highlights the importance of opportunities for social connections through LPA in this population. Accountability in LPA programs, through components of commitment to others (including professionals and peers), as well as structure (i.e. schedule), have also been emphasized in our research and others [30,31]. In addition, key considerations related to accessibility in LPA have been highlighted, in terms of affordability, suitable locations, online options, cultural appropriateness and integration within cancer care [30,31]. Accessibility may be particularly important given the complex health-related issues and daily life challenges (e.g., other responsibilities, finances, employment) experienced by people with advanced cancer. Finally, our findings demonstrate LPA besides aerobic and resistance exercise training are important and meaningful in this patient population and need to be further explored within research and clinical contexts. For example, mind-body activities, particularly yoga, were valued by our participants and these activities appear to be well tolerated and beneficial in the metastatic breast cancer population [73,74]. However, the safety and integration of

diverse leisure activities need to be examined within different cancer populations. Therefore, our findings indicate components of professional supervision, group settings, accountability, accessibility, and diversity are important to inform the design and delivery of LPA programs targeted to the advanced cancer population.

Study Limitations

At the participant level, one important limitation of our study is that many participants engaged in LPA both pre- and post-diagnosis of cancer. These individuals were more likely to be motivated to participate in LPA and have positive beliefs about LPA compared to those with lower activity levels. This finding could also explain why the participants identified barriers to LPA, but also often discussed strategies used to intentionally overcome these challenges. Thus, this unique perspective positively contributed to the development of our research findings. In addition, despite our efforts to recruit a diverse sample, the majority of participants identified as women and over half had primary diagnoses of breast cancer. The treatments, side effects and prognosis associated with different types of stage 4 cancer can vary, limiting the transferability of our research findings. However, our sample still included a few other cancer types, as well as participants of different ages and at varying times since diagnosis, providing valuable diversity within the perspectives shared through this work. Another study limitation is the high education and income levels of several participants. Socioeconomic status has been identified as a key determinant of LPA behaviour in the general adult population [75]. Moreover, information on racial and cultural backgrounds was not collected in this study. Cultural and socioeconomic factors can influence access to appropriate information and resources in people with cancer [76]. Finally, many participants were from urban areas and lived within the province of Ontario. Depending on location, there may have been variations in cancer care services offered to patients, affecting their survivorship

experiences. Thus, further work is needed to consider additional factors that can potentially impact participation in LPA in the advanced cancer population.

In terms of concepts explored within this research, a few participants described spiritual connections through LPA and other practices, such as mindfulness and meditation. Moreover, some participants mentioned other leisure activities, such as writing, baking, knitting, and photography, which may be appreciated by people with advanced cancer [77]. Other everyday life activities may also be important to provide a sense of structure and familiarity in these individuals [78]. These concepts were not examined in detail and may benefit from further exploration in future research.

Conclusion

Findings of this study indicate the experiences of LPA for people with stage 4 cancer are diverse and fluid and are strongly linked to psychosocial meanings and health benefits. Participation in LPA involves important cancer-related considerations and activity modifications. Many individuals with advanced cancer desire personalized and integrated support around LPA. Valuable strategies and diverse preferences related to LPA were identified in this study, which can help inform the development of tailored clinical resources for this population. Further clinical and research efforts are needed in rehabilitation to address the challenges faced by patients along the entire spectrum of the advanced cancer disease trajectory and to optimize safe, meaningful participation in LPA.

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Declarations

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CHAPTER 4: PHYSIOTHERAPIST MIXED-METHODS STUDY (MANUSCRIPT 3)

Relationship of Manuscript 3 to the Dissertation

This third manuscript describes the mixed-methods study involving physiotherapists working with advanced cancer (Study 3). There is a need to better comprehend the ability of rehabilitation professionals, including physiotherapists, to support LPA participation in people with advanced cancer. Thus, the objective of this study was to describe the clinical practices, knowledge, skills, and perspectives of Canadian oncology physiotherapists related to PA⁵ in people with advanced cancer. This mixed-methods study involved an online, cross-sectional survey with 62 physiotherapist participants, followed by qualitative individual interviews with 13 participants. The main findings highlighted the physiotherapists' knowledge of PA in the advanced cancer population, particularly with respect to considering important cancer-related concerns and adopting a patient-centered approach. Furthermore, the role of physiotherapists in supporting PA participation, functional activity, and symptom management for the advanced cancer population was emphasized.

Similar to the other components of my dissertation research, the underlying purpose of this study is to guide the development of supportive care strategies and thus, improve the cancer experiences of people living with advanced cancer. The scoping review (Study 1) recognized important research progress demonstrating benefits with exercise interventions for the advanced cancer population. In previous research and in our study with patient participants (Study 2), frequent challenges to participating in PA were reported and included cancer-related symptoms, risks of injury, and insufficient professional guidance and support. The role of physiotherapists in assisting people with

⁵ The overall focus of my dissertation research is leisure-time physical activity (LPA). In this mixed-methods study with the physiotherapists (Study 3), the survey questions were based on a previously developed survey examining views on physical activity (PA) and PA-related recommendations and concerns. The interview questions sought perspectives about LPA and exercise. Since the survey questions did not specify LPA, I have used the general term PA for the manuscript presented in this Chapter 4, except when LPA was specifically indicated.

advanced cancer has not been well explored within a Canadian context. This present study with Canadian physiotherapists highlights important considerations for physiotherapists involved with promoting PA in people with advanced cancer. Our findings also identify other supportive care areas where physiotherapists may be able to contribute in assisting this patient population. Finally, this research guides ongoing initiatives aimed at improving educational training opportunities for physiotherapists, as well as enhancing interprofessional collaboration in cancer care. Thus, this work further improves our understanding of Canadian physiotherapy practice in oncology and identifies important implications for rehabilitation practice and education.

In the next section of this chapter, I share the manuscript currently under review for publication in the *Physiotherapy Theory and Practice* journal. The manuscript has been prepared and formatted according to the guidelines of the journal.

Manuscript 3: Clinical Practices, Knowledge, Skills and Perspectives of Oncology
Physiotherapists Related to Physical Activity and Advanced Cancer: a Canadian Mixed-
Methods Study

Abstract

Background: Individuals with advanced cancer can benefit from physical activity (PA), but face barriers to PA participation. Physiotherapists may be well-positioned to support these patients.

Objective: Our objective was to describe the clinical practices, knowledge, skills and perspectives of oncology physiotherapists related to PA in people with advanced cancer.

Methods: In this mixed-methods study, we recruited Canadian physiotherapists with current or recent clinical experience with advanced cancer. Phase I consisted of an online, cross-sectional survey about views towards PA in advanced cancer and PA-related recommendations and concerns for two case scenarios. Phase II consisted of individual, semi-structured interviews about perspectives related to working with advanced cancer.

Results: Sixty-two physiotherapists participated in the survey, of which 13 participated in interviews. Most respondents (>85%) agreed or strongly agreed PA is important and safe for individuals with advanced cancer. Case responses highlighted cancer-related considerations (e.g. bone metastases), tailored PA recommendations and patient-centered, interprofessional care. Interview themes included: (1) recognizing PA within individually meaningful goals; (2) strategies to promote PA; (3) overarching

roles in functional optimization and symptom management; (4) generalized lack of awareness regarding physiotherapy.

Conclusion: Our findings indicate Canadian oncology physiotherapists describe knowledge of the safety and importance of PA, as well as key considerations in advanced cancer. Moreover, they highlight the importance of a patient-centered approach to support this population, particularly in facilitating safe and meaningful PA, as well as optimizing function and alleviating symptom burden. Further efforts are needed to investigate the development and integration of physiotherapy within cancer care.

Keywords: oncology, physical activity, exercise, palliative care

Introduction

In 2021, over 1.8 million Americans were estimated to be diagnosed with cancer, with over 240,000 annual cases presenting as distant-stage at diagnosis (Centers for Disease Control and Prevention, 2021; National Cancer Institute, 2021). While cancer therapy options continue to improve, research shows that individuals with different types of advanced cancer present with several cancer-related and treatment-related challenges. People with advanced cancer frequently report moderate to severe symptoms of fatigue, breathlessness, pain, and insomnia and some experience psychosocial concerns, such as anxiety, depressive symptoms, and isolation (Cardoso et al., 2016; Hummler et al., 2014; LeBlanc et al., 2015; Li et al., 2019; Mayrbäurl et al., 2016; Rojas-Concha et al., 2021; Sheean et al., 2015; Yee et al., 2014). Other challenges, such as declined aerobic fitness, reduced muscle strength, lymphedema, and neuropathies, are also prevalent in this population (Cheville et al., 2008; Hummler et al., 2014; Shallwani et al., 2016; Yee et al., 2014). In one study of women with metastatic breast cancer, over 90% of participants reported at least one physical impairment that could affect engagement with daily activities (Cheville et al., 2008). Several studies have demonstrated that individuals with advanced cancer experience issues with different aspects of functioning, such as self-care, mobility, household tasks, and leisure activities (Cardoso et al., 2016; Cheville et al., 2009; Di Lascio & Pagani, 2017; LeBlanc et al., 2015; Yee et al., 2014). Despite the advancement of cancer control and palliation treatments, survivors face significant effects that are detrimental to their quality of life and daily function (Hummler et al., 2014; LeBlanc et al., 2015; Mayrbäurl et al., 2016; Shallwani et al., 2016).

Supportive care strategies (Olver et al., 2020) may be helpful in mitigating some of the difficulties experienced by people with advanced cancer. However, many patients report challenges with accessing timely, relevant information and obtaining appropriate professional support, including physical rehabilitation and psychosocial services (Cardoso et al., 2016; Cheville et al., 2008; Lam et al.,

2014; Lewis et al., 2015; Wang et al., 2018). Further exploration is needed to develop and implement clinical strategies addressing diverse needs and improving clinical outcomes in the advanced cancer population throughout the continuum of cancer care (Lustberg et al., 2021).

Physical activity (PA), including exercise, is a growing area of interest within rehabilitation oncology (Campbell et al., 2019; Shallwani et al., 2021). Recent reviews and meta-analyses have demonstrated exercise is beneficial for people diagnosed with advanced cancer, particularly to enhance physical function and quality of life (Chen et al., 2020; Dittus et al., 2017; Heywood et al., 2018; Nadler et al., 2019). Barriers reported by these individuals to engaging in different types of PA include cancer-related symptoms (e.g. fatigue, weakness), fear of injury, challenges with accessibility (e.g. lack of appropriate facilities), as well as limited information and support from health professionals (Burke et al., 2020; Cheville et al., 2012; Frikkel et al., 2020; Sheill, Guinan, Neill, et al., 2018b). Physiotherapists may be well-positioned to address barriers and assist people with advanced cancer to participate in PA. Moreover, physiotherapy interventions and other rehabilitation services can be helpful to manage symptoms and improve functional status in this population (Bernabeu-Wittel et al., 2021; Pyszora et al., 2017). Previous studies have described PA-related views, concerns and education needs of Irish and Dutch physiotherapists working with advanced cancer (Sheill, Guinan, O Neill, et al., 2018; Ten Tusscher et al., 2020). However, little is currently known about physiotherapists' clinical practices and perspectives related to PA in individuals with advanced cancer, particularly within a Canadian context (Canestraro et al., 2013). Enhancing our understanding of this topic can contribute to advancing knowledge and addressing gaps in current Canadian physiotherapy practice in oncology. This information would be useful to guide the development of tailored clinical programming and resources for patients, to identify educational priorities for physiotherapists as well as to situate future research inquiries in cancer rehabilitation. The objective of our mixed-methods study was to describe the clinical

practices, knowledge, skills, and perspectives of Canadian oncology physiotherapists related to PA in individuals diagnosed with advanced cancer.

Materials and Methods

Study Design

We used an explanatory, sequential mixed-methods study design, which involves collecting qualitative data to supplement quantitative information (Creswell & Plano Clark, 2017a; Cummings et al., 2013). This research was informed by the interpretive-description approach, which supports the use of multiple data collection strategies to understand experience phenomena with relevant implications for practice-based disciplines, such as physiotherapy (Olsen et al., 2013; Thorne et al., 1997). Our project consisted of two phases: a web-based survey (phase I), followed by qualitative interviews (phase II). The survey component offered a broad, descriptive knowledge of current physiotherapy oncology practice within Canada, as well as physiotherapists' views towards PA in people with advanced cancer. The follow-up interviews provided additional information about the perspectives and experiences of physiotherapists related to working with people with advanced cancer. We obtained approval for this study from the University of Ottawa Research Ethics Board (H-07-20-5937).

Physiotherapist Participants

We invited physiotherapists meeting the following criteria to participate in the study: (a) licensed physiotherapists in Canada; (b) current or recent (within last five years) clinical experience with adults diagnosed with advanced cancer. We recruited participants primarily through the Canadian Physiotherapy Association (CPA) Oncology Division member email list, as well as by word-of-mouth and social media. Based on the Division membership (n=195), we targeted a conservative response rate of

20% (n=39) for the online survey, as our focus was a subgroup of physiotherapists with specific experience in advanced cancer (Cho et al., 2013). Following completion of the survey questionnaire, respondents were asked to provide their contact information if they wished to participate in follow-up interviews. We aimed to recruit 10 interview participants, as we considered this sample size would represent a diverse subset of participants and offer detailed qualitative information to supplement our survey findings (Creswell & Plano Clark, 2017b).

Phase I: Survey

The first study phase consisted of a cross-sectional, web-based survey. We adapted the survey questionnaire, with permission, from a previously developed survey used to examine the views of Irish physiotherapists towards PA in people with advanced cancer (Sheill, Guinan, O'Neill, et al., 2018). Our survey included anonymized closed- and open-ended questions on the following: (a) demographics, professional training, clinical experience, and practices (e.g., level of education, post-graduate training, clinical setting, patient population); (b) views towards PA in people with advanced cancer (7-point Likert scale); (c) PA-related recommendations and concerns for two clinical case scenarios (**Supplemental Material S1**). We included a final question requesting contact information from survey respondents interested in participating in follow-up interviews.

The survey was translated to French by a bilingual student volunteer. We developed the French version as an adjunct to the online English survey; however, no participant requested the French version. We pre-tested the English and French versions of the survey with one French-speaking, one English-speaking and two bilingual volunteer physiotherapists. The survey questions and layout were adapted according to feedback obtained during the pre-testing process (Cummings et al., 2013).

Survey responses were collected over a six-week period from October to November 2020. We shared the recruitment poster and survey link via email and social media posts three times during the study period. The survey was administered using the online SurveyMonkey program (SurveyMonkey Inc., San Mateo, California). Email and IP address tracking options were disabled and no identifying information was collected during the survey. A separate second survey was linked to the end page of the first survey for the final question requesting contact information. These responses were not connected to the first survey with the questionnaire to maintain anonymity.

Phase II: Interviews

The second phase consisted of qualitative individual, semi-structured interviews. Based on interpretive-description methodology (Thorne et al., 1997), we developed an interview guide with open-ended, exploratory questions about the following: (a) descriptive information on clinical setting and experience; (b) perspectives about leisure PA (Pettee Gabriel et al., 2012) and exercise in people with advanced cancer; and (c) general perspectives and experiences related to working with advanced cancer (***Supplemental Material S2***). We pilot tested the interview guide with one physiotherapist who had oncology experience and refined the questions following the interview.

The interviews occurred from January to February 2021. We shared the interview guide with participants prior to the interviews. The interviews were conducted by the primary researcher (SMS), who disclosed her role as a Ph.D. candidate in rehabilitation sciences and, if requested, her clinical experience as a physiotherapist in oncology (Thorne et al., 1997). The interviews occurred virtually using an online video-conferencing program (Zoom version 5.9.1) or over the phone, depending on participant preference. We recorded the interviews using built-in features of the video-conferencing program as well as an external voice recorder (Sony ICDPX370). Most interviews were transcribed independently by

the primary researcher with the aid of an automatic transcription program. Two interviews were transcribed by a research assistant and verified by the primary researcher.

Data Analysis

Response rates for the online survey and follow-up interviews were tracked. We performed descriptive analyses of the quantitative data for the participant characteristics and clinical practices, and the survey responses regarding the physiotherapists' views towards PA.

Guided by the interpretive-description approach, we inductively analyzed the qualitative data to generate common themes in the participants' responses and highlight practical implications from a physiotherapy perspective (Thorne et al., 1997). The data were coded using the qualitative analytical software program NVivo (QSR International, release version 1.6.1). To describe the physiotherapists' clinical knowledge and skills, the primary researcher reviewed the survey responses to the case scenarios, identified common PA-related considerations and strategies, and then coded the data line-by-line. Following iterative discussions with research team members, the data were categorized by topic and frequency and then descriptively summarized to develop general recommendations.

To further explore the physiotherapists' perspectives related to PA, the primary researcher reviewed the interview transcripts and generated a preliminary codebook. The codebook was reviewed with team members for verification and feedback. The primary researcher iteratively coded the interview data and analyzed the codes to identify meaningful patterns within the interview responses, noting general similarities and differences from the survey data (Creswell & Plano Clark, 2017a; Thorne et al., 1997). A reflective journal was kept during data collection and analysis, and analytical interpretations were discussed iteratively with the team.

Role of the Funding Source

The authors received no specific funding for this work.

Results

Survey Participants

Of 74 initial responses, 62 physiotherapists participated in the survey. Descriptive characteristics are provided in **Table 4.1**.

Table 4.1 Descriptive Characteristics of Respondents (N=62 Survey Responses)

Characteristic		
Age*, mean (sd)		43.2 (10.6)
Gender identity		
	Woman	55 (88.7%)
	Man	6 (9.7%)
	Don't wish to answer	1 (1.6%)
Region^ (Canadian Provinces)		
	Eastern Canada:	46 (74.2%)
	<i>Atlantic Provinces (NL, NS, PEI) / Central Canada (ON, QC)</i>	5 (8.1%) / 41 (66.1%)
	Western Canada:	16 (25.8%)
	<i>Prairie Provinces (AB, MB, SK) / West Coast (BC)</i>	9 (14.5%) / 7 (11.3%)
Highest level* of education		
	Diploma or college degree	1 (1.7%)
	Bachelor's degree	30 (50%)
	Master's degree	28 (46.7%)
	Doctorate or Ph.D. degree	1 (1.7%)
Entry-to-practice level of physiotherapy education		
	Diploma or college degree	1 (1.6%)
	Bachelor's degree	37 (59.7%)
	Master's degree	24 (38.7%)
Cancer-specific training		
	Yes	49 (79.0%)
	No	13 (21.0%)
Types of cancer-specific training or courses		
	Post-graduate courses (CPA)	23 (37.1%)
	Post-graduate courses (other organizations)	32 (51.6%)
	Lymphedema certification training	28 (45.2%)
	University courses (during physiotherapy training)	9 (14.5%)
	University courses / degree (post-graduate training)	4 (6.5%)
	Other#	10 (16.1%).
Years of clinical experience as physiotherapist, mean (sd)		
	General experience	18 (10.8)
	Cancer-specific experience	9.7 (7.5)
Current employment status		
	Working full-time as PT	45 (72.6%)
	Working part-time as PT	12 (19.4%)
	Not working as PT or other#	5 (8.1%)
Clinical setting of practice with patients with advanced cancer		
	Hospital in-patient	26 (41.9%)
	Hospital out-patient	15 (24.2%)
	Private practice	23 (37.1%)

Home care	9 (14.5%)
Rehabilitation in-patient / out-patient	2 (3.2%)
Community-based centre	2 (3.2%)
Other [#]	2 (3.2%)
Percentage of average caseload consisting of patients with cancer	
<50%	33 (53%)
At least 50%	29 (47%)
Types of patients with advanced cancer	
Breast	54 (87.1%)
Colorectal	38 (61.3%)
Gastrointestinal	33 (53.2%)
Gynecological	45 (72.6%)
Hematological	42 (67.7%)
Head and neck	34 (54.8%)
Lung	38 (61.3%)
Pancreatic	31 (50.0%)
Prostate	36 (58.1%)
Other	13 (21.0%)
Physiotherapy services provided to patients with advanced cancer	
Assessment	61 (98.4%)
PA / exercise prescription (individualized)	58 (93.6%)
Education (individualized)	53 (85.5%)
Mobility aids	41 (66.1%)
Lymphedema therapy	29 (46.8%)
Manual therapy	28 (45.2%)
Biophysical modalities	14 (22.6%)
Other	11 (17.7%)
Group education	8 (12.9%)
Group exercise sessions	7 (11.3%)
Total N	62

All results in n (%), unless otherwise indicated; PT: physiotherapist

*Missing data for age (n=3) and highest level of education (n=2)

[#]Other employment statuses: on leave, retired, teaching; other clinical settings: tele-health, cancer centre; other PT services: acupuncture, laser, chest physiotherapy; other cancer-specific training: CPA clinical specialty program, independent learning

[^]Source:

<https://www.canada.ca/en/immigration-refugees-citizenship/corporate/publications-manuals/discover-canada/read-online/canadas-regions.html>

Survey Findings

The physiotherapists' views towards PA in people with advanced cancer are presented (**Table 4.2**). The majority of respondents agreed or strongly agreed that PA is important (88.7%) and safe (85.5%) and that patients are capable of PA (79%). Many participants felt confident in their ability to prescribe PA (80.6%) and regularly prescribed PA (72.6%), but felt more information is needed on PA prescription (80.6%). Fewer participants agreed or strongly agreed that patients believe they should be active (42.6%) and follow PA advice (37.7%) or that family and friends encourage PA (27.4%). Just over half of the respondents agreed or strongly agreed that patients seek PA recommendations (50.8%) and that PA recommendations are well received by patients (60%).

Table 4.2 *Physiotherapists' Views Towards Physical Activity in People with Advanced cancer (N=62 Survey Responses)*

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree	Total N
a) In my opinion, PA is important for patients with advanced cancer.	31 (50.0%)	24 (38.7%)	5 (8.1%)	2 (3.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	62
b) In my opinion, PA is safe for patients with advanced cancer.	24 (38.7%)	29 (46.8%)	8 (12.9%)	1 (1.6%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	62
c) I feel patients with advanced cancer believe they should remain physically active.	12 (19.7%)	14 (23.0%)	20 (32.8%)	5 (8.2%)	8 (13.1%)	2 (3.3%)	0 (0.0%)	61
d) I feel patients with advanced cancer are capable of participating in PA.	21 (33.9%)	28 (45.2%)	11 (17.7%)	2 (3.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	62
e) I find providing PA recommendations to patients with advanced disease is usually well received.	8 (12.9%)	29 (46.8%)	16 (25.8%)	6 (9.7%)	3 (4.8%)	0 (0.0%)	0 (0.0%)	62
f) I feel patients with advanced cancer will follow the advice of PA recommendations given.	3 (4.9%)	20 (32.8%)	27 (44.3%)	6 (9.8%)	4 (6.6%)	1 (1.6%)	0 (0.0%)	61
g) I feel patients with advanced cancer come to me for PA recommendations.	6 (9.8%)	25 (41.1%)	11 (18.0%)	8 (13.1%)	4 (6.6%)	6 (9.8%)	1 (1.6%)	61
h) I am confident in my ability to prescribe PA to patients with advanced cancer.	16 (25.8%)	34 (54.8%)	9 (14.5%)	0 (0.0%)	1 (1.6%)	2 (3.2%)	0 (0.0%)	62
i) I regularly prescribe PA recommendations to patients with advanced cancer.	21 (33.9%)	24 (38.7%)	13 (21.0%)	2 (3.2%)	0 (0.0%)	2 (3.2%)	0 (0.0%)	62
j) I feel there is a need for more information on how to prescribe PA to patients with advanced cancer	27 (43.6%)	23 (37.1%)	8 (12.9%)	3 (4.8%)	1 (1.6%)	0 (0.0%)	0 (0.0%)	62
k) I find the families and friends of patients with advanced cancer encourage PA.	4 (6.5%)	13 (21.0%)	16 (25.8%)	15 (24.2%)	10 (16.1%)	3 (4.8%)	1 (1.6%)	62

PA: physical activity

Key considerations and strategies related to PA and advanced cancer were suggested by the participants in response to the case scenarios (**Table 4.3**). Summarized recommendations include: (1) recognizing cancer-related concerns (e.g., bone metastases, peripheral neuropathy, and fatigue) and other considerations, and providing patient education and activity modifications to encourage safe PA in people with advanced cancer; (2) tailoring PA recommendations to promote regular, appropriate, and meaningful PA; and (3) adopting an interprofessional, patient-centered approach in physiotherapy for people with advanced cancer.

Table 4.3 Physiotherapists' Considerations and Strategies Related to Physical Activity in People with Advanced Cancer (N=47/46* Survey

Responses)

PA-related considerations and strategies (# participants~)	Selected quotes from survey respondents
<p>Cancer-related concerns</p> <p>Bone metastases (n=42)</p> <ul style="list-style-type: none"> • Education on fracture risk • Monitoring for pain, red flags (e.g. spinal cord compression) • Body mechanics, modified positions and activities (e.g. mobility, leisure activities), adaptive / assistive devices <p>Peripheral neuropathies, balance concerns (n=38)</p> <ul style="list-style-type: none"> • Education on fall risk and risk management strategies (e.g. footwear, environment, mobility aids) • Modified activities and exercises • Balance training <p>Fatigue, low energy (n=34)</p> <ul style="list-style-type: none"> • Education, monitoring 	<p><i>I would discuss the importance of his body mechanics and possibly making some adaptation or using some tools to assist with his gardening. I would make sure he has a good understanding of his fracture risk and what to avoid. Education ++. Monitor pain control, bracing if needed (C1, response #7)</i></p> <p><i>Safety concerns re: torsional movements and risk of pathological fracturing, along with proper movement patterns to limit risk. Educate on how he can perform those activities that are important to him but perhaps differently so it is safer (C1, response #10)</i></p> <p><i>Education for symptoms to monitor including pain, weakness, changes to sensation, bowel or bladder (C1, response #38)</i></p> <p><i>Pay attention to keeping spine straight (in good alignment) while sitting getting in and out of bed (C1, response #43)</i></p> <p><i>Be aware that your balance and proprioception have likely changed since diagnosis and treatment of your cancer, use greater caution with gardening and golf to avoid falls and risk of fractures. (C1, response #4)</i></p> <p><i>Review floor recovery and balance concerns and prescribe therapy for both as needed. (C1, response #10)</i></p> <p><i>Environmental factors such as uneven ground for gardening and hilly paths for golfing which are falls risks factors (C1, response #26)</i></p> <p><i>Falls risk and skin breakdown/ulcer and infection due to peripheral neuropathies - seated or supine activities may be a good place to start as she is persistently fatigued and at risk for falls. She should be checking skin often with peripheral neuropathies, especially if any friction is involved with her exercises. (C2, response #12)</i></p> <p><i>Use proper foot wear and ensure safe exercises in terms of balance. Include balance training (C2, response #30)</i></p> <p><i>Her peripheral neuropathy could increase her risk of falling, so proper footwear and stable surfaces for any walking program (or doing so with another person, walking stick, etc) would be advised (C2, response #31)</i></p> <p><i>To listen to his body but to know that he may feel fatigue and that exercise can help with that (C1, response #9)</i></p> <p><i>Pace himself, might not feel effects right away and would rather be active comfortably rather than over do it and unable to do anything for a few days (C1, response #37)</i></p>

<ul style="list-style-type: none"> • Pacing and energy conservation techniques • Management strategies, including exercise 	<p><i>Fatigue - not to over do it, but to understand that exercising at a moderate level will help to combat fatigue, she must avoid extreme exercise (C2, response #4)</i></p> <p><i>Monitor fatigue to ensure that she is still able to participate in functional activities throughout her day (C2, response #16)</i></p>
<p>Lymphedema (n=28)</p> <ul style="list-style-type: none"> • Education on risk-reduction and management, monitoring • Skin care, infection control • Management strategies, including compression, exercise, referral to specialist 	<p><i>Be careful of exercise equipment used (no wrapping theraband around wrists) (C2, response #4)</i></p> <p><i>She may need to be watchful of some upper extremity activities with her UE lymphedema and warn her of signs/symptoms of worsening or infection. Educate re: wrapping/massage and who she may see in the community for assist as needed if she is not already followed. (C2, response #12)</i></p> <p><i>Be aware of arm and prevent any cuts/scrapes/trauma to arm to prevent infection with lymphedema (C2, response #14)</i></p> <p><i>Lymphedema-specific education as to how much/what types of activity can help/potentially aggravate a lymphedematous limb would certainly be covered. Lymphedema-specific parameters for arm strengthening and mobility would also be provided as part of our lymphedema education (to prevent a worsening of her currently stable lymphedema). (C2, response #31)</i></p> <p><i>Ensure she has a review of day and night time garments. Following this begin resisted ex. program while monitoring lymphedema. Ensure she has a clear understanding of risk reduction practices for lymphedema (C2, response #40)</i></p>
<p>Additional considerations</p> <ul style="list-style-type: none"> • Pain (n=15), risk of infection (n=5) • Co-morbidities (n=13), other treatment effects (n=6), • Activity tolerance (n=14) • Personal expectations, knowledge, motivation, adherence (n=14) 	<p><i>Decrease risk for infection with proper training and equipment (C1, response #10)</i></p> <p><i>No mention of risk of lymphedema for him but with gardening, talk about safety equipment to limit infections (gloves, etc) to decrease inflammatory responses and risk of infection if immune compromised based on adjuvant therapies (C1, response #10)</i></p> <p><i>I might be concerned of his level of expectation related to how much work or exercise he could tolerate (C1, response #34)</i></p> <p><i>I also would review her adjuvant therapies and risks involved in recovery then, eg. being careful with therapy post-radiation, especially in early stages of tissue healing. Other concerns with adjuvant therapies would be managing side effects and helping with recovery post-treatments (C2, response #10)</i></p> <p><i>Need to avoid worsening her pain (C2, response #28)</i></p> <p><i>I would be concerned that she has a history of being inactive. It may take more effort for her to embrace physical activity especially with her multiple cancer related side effects AND comorbidities (C2, response #34)</i></p> <p><i>Comorbidities: need to know what they are in the event they will impact physical activity. Poor patient understanding of how increased physical activity can help her... may be reluctant to start exercise, despite education (C2, response #41)</i></p>
<p>Recommendation 1: Individual cancer-related concerns and other considerations, patient education and activity modifications to encourage safe PA in people with advanced cancer</p>	

Maintaining regular, enjoyable activity (n=37)

- Focus on individual goals, enjoyable activities
- Recommendation to stay active, maintain regular activity

Continue to be active as it is something he enjoys (C1, response #24)
I would encourage him to maintain his current activities, especially if he is well accustomed to them, enjoys them and currently tolerates them well (C1, response #34)
I would align program to her specific goals rather than general physical activity (C2, response #5)
Focus on activities she enjoys most. (C2, response #6)
To try to put some time aside everyday to do a form of physical activity (make it like an appt you can't miss). Even if this is a short walk. (C2, response #9)

Exercise prescription (n=37)

- Specific prescriptions (FITT parameters, MET activity levels)
- Modes: aerobic, resistance, flexibility
- Therapeutic exercises (e.g. balance, core, hydrotherapy)
- ROM exercises
- Walking as activity
- Yoga, Tai Chi, relaxation exercises

To start off with mild-moderate exercise every day and work his way up to more moderate-vigorous activity for 150mins/week (walking, swimming, cycling) (C1, response #9)
Brisk walking daily (C1, response #26)
Prescribe stretching and strengthening ex. based on initial assessment and goals. Include aerobic program (C1, response #40)
To work on rehab exercises to strengthen his core (C1, response #30)
Prescribe an initial low level cardiovascular, begin with an isometric training program to evaluate exercise tolerance and aim to develop a resistance training program to prepare him for his chosen activities (C1, response #46)
Pool therapy may be a perfect activity to reduce weight on feet as well as treat lymphedema (C2, response #8)
Balance and agility exercises (C2, response #25)
Gentle active ROM ex for all extremities in sitting and standing with support (C2, response #26)
Start with light walking 5-10 minutes on even ground, increasing time to her tolerance, aim for 150 minutes moderate intensity per week (C2, response #25)
Gradually start to increase whole body, especially cardio exercise - 90 mins/week at her "moderate" (C2, response #28)
Aim for min of 90 min per week of mod ex and 2 x week resistance ex (C2, response #30)
I would recommend a gentle and progressive routine of strengthening, cardiovascular exercise and stretching with an emphasis on activities she enjoys (C2, response #38)
Specific FITT of exs depends on her goals (e.g. to improve energy, strength, heart health, etc.) (C2, response #41)
Gentle yoga for cancer recovery might be an option as well (C2, response #44)

Slow, progressive activity (n=33)

Gradual progression of activities in small increments while monitoring symptoms (C1, response #45)

<ul style="list-style-type: none"> • Starting with slow / gentle activity (e.g. ROM exercise, walking) • Short, frequent bouts of PA • Gradual progression 	<p><i>Start slowly with gentle ROM exercises of the whole body, after 1 week add weight to resistance of ROM. Start walking ie to street and back then to corner and back and slowly increase distance walking as tolerated (C2, response #2)</i></p> <p><i>She could try a progressive walking program or swimming pool exes or adapted yoga class or any light to moderate activity that she has interest in, with respect to fatigue, increasing distance and or intensity progressively if well tolerated (C2, response #15)</i></p> <p><i>Separate sessions of exercises during the day 10 mins each at least 3 times/day (C2, response #27)</i></p> <p><i>I would encourage her to begin with small but frequent periods of 'movement' (active ROM, walking, breath work) and increase her activities with increased tolerance to movement (C2, response #34)</i></p> <p><i>Importance of GRADUATED exercise (i.e. start slowly and with low levels of intensity)... would create a program with her that follows these rules... (C2, response #41)</i></p>
<p>Education on PA (n=24)</p> <ul style="list-style-type: none"> • Education on safety and benefits of PA, risks of inactivity • Evidence-based information 	<p><i>Provide education on safe way to engage in physical activity. Balancing safety and quality of life (C1, response #29)</i></p> <p><i>Reassure her that physical activity will not spread her cancer further but will increase her ability to function more and do her ADL's (C2, response #8)</i></p> <p><i>I would provide the most recent evidence on exercise and quality of life, activity tolerance and fatigue in patients with breast cancer to ensure her that not only is this safe, but quite beneficial (C2, response #12)</i></p> <p><i>The evidence is clear that regular exercise may help 1) combat fatigue 2) manage and prevent exacerbation of lymphedema and 3) help improve tolerance of the neuropathies she is experiencing. They may also better help manage her multiple comorbidities (C2, response #34)</i></p> <p><i>First I would tell her about the value of physical activity even in advanced cancers and tell her that it can greatly improve the range of things she would like to do, maintain her independence in self care, possibly reduce her fatigue levels and improve her quality of life despite the neuropathies, lymphedema, and other medical issues. (C2, response #46)</i></p>
<p>Focus on function (n=14)</p> <ul style="list-style-type: none"> • Functional goals and activities (e.g. mobility, activities of daily living) • Functional exercises 	<p><i>Functional ex such as squats, heel raises, chair push ups (C1, response #26)</i></p> <p><i>Ensure ex. compliment function and goals (C1, response #40)</i></p> <p><i>As she has not previously been physically active. I would initially have her concentrate on exercises to increase her functional activity level (C2, response #42)</i></p> <p><i>Individualized exercise program to bring her ability to perform daily ADLs safely and then gradually progress to more functional goals to stay independent as long as possible (C2, response #45)</i></p>
<p>Other considerations (n=19)</p> <ul style="list-style-type: none"> • Monitoring strategies 	<p><i>As a physio I would track blood pressure and HR in sessions, to help the patient understand RPE and self guided exercise (C1, response #32)</i></p>

- Supervised, group settings *Gradually increase activity and use a log to record post activity adverse symptoms. (Case #2, response #6)*
- Motivational strategies *Group programming might be more suitable for client (C2, response #7)*
Make small measurable goals and treat yourself once you achieve these. To not be hard on herself when she has on "off day".
To participate in a group class for cancer patients to meet people and see that it is ok to exercise. This will also keep her accountable... Keep a journal to log her exercise so that she can stay motivated (C2, response #9)
A portable SpO2 monitor may help her monitor her heart rate and SpO2 levels and her body's response to activity over time or on days when she is particularly fatigued so that she can adjust reps or time accordingly (C2, response #12)
Supervised exercise and close monitoring would be essential... I would also recommend that she do her activities in the company of a family member or friend to maintain her motivation levels (C2, response #46)

Recommendation 2: Tailored activity recommendations to promote regular, appropriate and meaningful PA in people with advanced cancer

- Interprofessional, patient-centered approach (n=20)**
- Interprofessional collaboration *Liaise with his MD re what is allowed / precautions with any chemo, blood count issues. (C1, response #1)*
Speak with oncologist and get ortho opinion on WB status of limbs (C1, response #14)
 - Medical investigation (e.g. imaging, oncology / orthopedic consult, review blood counts, information on co-morbidities) *Be benefits and risks in collaboration with interdisciplinary team including the client himself (C1, response #29)*
There are many factors to consider - the specificity of his comorbidities, degree of metastasis and current functional level (C1, response #34)
Perhaps collaborate with OT re: pacing calendar and scheduling tasks (C2, response #10)
Assure blood work, medical clearance, fever, BP and HR tracking (C2, response #32)
 - Risk assessment and functional screening *What are her goals/ objectives? (C2, response #43)*
 - Patient-centered approach

Recommendation 3: Interprofessional, patient-centered approach in physiotherapy for people with advanced cancer

ADL: activities of daily living; BP: blood pressure; C1: case scenario #1; C2: case scenario #2; ex: exercise; FITT: frequency, intensity, time, type;

HR: heart rate; MD: Doctor of Medicine; MET: metabolic equivalent of task; min: minute; OT: occupational therapist; PA: physical activity; ROM:

range of motion; SpO2: oxygen saturation; WB: weight-bearing

*n=47 survey responses to first case scenario, n=46 survey responses to second case scenario

~Refers to number of participants mentioning a particular consideration or strategy in their survey responses to the case scenario questions

Interview Participants

Of 22 survey respondents who provided contact information, 13 participated in the interviews (including one pilot). Eight participants (62%) were based in Eastern Canada and five (38%) in Western Canada. Overall clinical experience ranged from five to 40 years and cancer-specific experience from four to 25 years.

Interview Findings

Four common themes were noted within the physiotherapists' perspectives on PA in people with advanced cancer: (1) recognizing PA within individually meaningful goals; (2) physiotherapy strategies to promote appropriate PA; (3) overarching roles of physiotherapy in functional optimization and symptom management; and (4) generalized lack of awareness regarding role of physiotherapy (Table 4.4).

Theme 1: Recognizing PA within individually meaningful goals

Expanding on the survey responses, the interview participants highlighted adopting a patient-centered approach with people diagnosed with advanced cancer to explore “*what the person's own goals are*” (Participant 9) and understand where PA fit in. Participant 1 also emphasized working with patients “*one-on-one, to really understand what their sense of physical activity is*”.

From the physiotherapists' perspectives, PA participation was “*important for their mental and also physical health*” (Participant 10). Participant 5 spoke about how some people with advanced cancer “*can have a lot of meaningful participation in activities*” and that leisure PA can contribute to a “*big increase in their quality of life*”.

Theme 2: Physiotherapy strategies to promote appropriate PA

Congruent with the survey responses, several interview participants described different physiotherapy strategies to encourage appropriate PA in this population. Educating patients about cancer-related issues, such as bone metastases, fatigue, and breathlessness, and appropriate risk management strategies was necessary to ensure safe participation in PA.

The education part is a big thing with our palliative patients, especially considering things like bone mets (metastases) and risks of injury ... trying to direct them to something more suitable and less risky. (Participant 8)

For example, Participant 4 described therapeutic and risk management strategies to support PA in people experiencing shortness of breath.

We worked a great deal on breathing... If they were walking, we said, 'Listen, we have to be sure that you have a place to sit. You have to pre-scope out where are you going to go and where are you going to sit, so that you can have a good rest while you're going. And you also need to have an emergency plan here. Ideally, you go with someone... And if not, you have to have a cell phone...' (Participant 4)

Participant 5 felt *“even the education about leisure activities and what the expectations can be, might help a lot.”* The participants highlighted tailoring PA recommendations according to individual preferences and enjoyment, *“by asking what is meaningful to the patient”* (Participant 2) and *“encouraging them to move in an activity that is pleasurable to them”* (Participant 7).

Theme 3: Overarching roles of physiotherapy in functional optimization and symptom management

Several participants connected PA in patients with advanced cancer to the overarching roles of physiotherapy in enhancing function and alleviating symptoms. Exercise prescription was often described to optimize daily activities and functional independence. Participant 9 spoke about the role of physiotherapists as a support *“with the right exercises for keeping them independent.”*

Participant 7 also highlighted PA as *“a modality, in terms of managing and controlling side effects... I mean, the research is supporting exercise and activity as having such an impact, in terms of limiting and changing symptoms, so I think there's a huge role that can play in people's experience, whether it be fatigue, whether it be energy, whether it be movement or pain reduction.”*

Theme 4: Generalized lack of awareness regarding role of physiotherapy

Concerning patient perspectives, the interview participants felt people with advanced cancer *“absolutely value”* (Participant 9) physiotherapy and that PA *“is very important to them”* (Participant 12). However, several participants expressed common frustrations about the generalized lack of awareness regarding the role of physiotherapy in the care of people with advanced cancer, among health professionals, patients, and caregivers. This limited awareness was believed to be particularly prevalent among oncology care providers, making it challenging for patients to be informed and access appropriate physiotherapy services.

I think (patients) are very appreciative. Some might not realize, or be aware of what benefit physiotherapy would have for them, which is, I think, partly because the whole health care system may not realize what physiotherapy can have to offer. And so they don't refer. (Participant 11)

Participant 7 also highlighted the under-recognized role of physiotherapy for *“preventive work”*.

Regarding this topic, Participant 4 described rehabilitation oncology as *“one of the fields in physical therapy that particularly needs development”*. Perceived factors contributing to this under-development included the common lack of awareness among health professionals and patients, a healthcare system which is *“increasingly in silos”* (Participant 12), along with limited information resources and training opportunities for physiotherapists and physiotherapy students.

How can patients know to ask for this type of care if they don't know it exists? How can clinicians, being oncologists, nurses, whoever, refer if they don't know it exists? And how can physios practice if they don't feel necessarily supported? (Participant 6)

Table 4.4 Themes and Exemplary Quotes to Illustrate Physiotherapists' Perspectives Related to Physical Activity in People with Advanced Cancer

(N=13 Interview Participants)

Theme	Exemplary Quotes (Participant Details*)
<p>Theme 1. Recognizing PA within individually meaningful goals</p>	
<p>a) Adopting a patient-centered approach to explore individual goals related to PA</p>	<p><i>You have to ask what the person's own goals are. If they never went skiing before and it's not of big interest to them, then that would be something you consider. But if someone really enjoys gardening and wants to get out and, even though they're essentially dying, they want to get out and enjoy their garden again, then that is what you make your goal, you know, is to be patient-centered. So, yeah, I think leisure activities are very important. Maybe the person wants to just go for walks with their loved one. And if you can help them get to that, I think that's important. Maybe someone wants to work on their vehicle. Maybe they're wanting to do some mechanical work or shopwork or something. If that's what they want to do, you can help them get to that. So I think it's all about the patient's own goals.</i> (Participant 9, ≥20 years experience, out-patient cancer centre / private clinic)</p> <p><i>I think you have to go to the patient one-on-one to really understand what their sense of physical activity is and then go around it.</i> (Participant 1, <20 years experience, in-patient hospital / out-patient hospital / private clinic)</p>
<p>b) Recognizing PA as meaningful for some people with advanced cancer</p>	<p><i>Advanced cancer, it covers so many people that there is going to be some people that can have a lot of meaningful participation in activities... I absolutely think that it should be part of any goal-setting that a physio does with somebody with advanced cancer regardless of, I think almost regardless of, the actual situation that the patient's in. Because one way or another, either you can help them get back to those things or educate them about it or look at other ways to do things. It's absolutely important...</i></p> <p><i>In my personal opinion, I would say, (leisure physical activity) is something we should be thinking of one hundred percent of the time. And when I go back to a lot of those people, like I mentioned, their quality of life was undoubtedly improved. A lot of times, those were people that thought they could never do these leisure activities again. And if we were able to find a way to get them to participate in those again, despite their symptoms and despite everything... that seemed to be one of the main factors for the individuals that I saw that experienced that big increase in their quality of life.</i> (Participant 5, <20 years experience, out-patient cancer centre)</p> <p><i>I think patients in general, you know you have that diagnosis of cancer, well they want normalcy as much as possible, you know. The cancer experience is anything but. And so, you know, we know how important it (physical activity) is for people's mental health, and also their physical</i></p>

health, their management of pain, and the management of some of the side effects of chemotherapy or radiation. To do things that make their heart, you know, their heart feel good. From a mental health, and a physical perspective. So, I don't find that there's very many patients that I have that are like, I just want to lie in bed and do nothing. (Participant 10, ≥20 years experience, private clinic / home care)

Theme 2. Physiotherapy strategies to promote appropriate PA

a) Education on cancer-related concerns, expectations and risk management related to PA *The education part is a big thing with our palliative patients, especially considering things like bone mets and risks of injury, so that's a big part of our focus with the advanced cancer... There's a lot of time spent in education, getting out our skeleton, talking about what things are safe and what things they should consider as more risky activities. And then trying to, you know, not saying you can't do this, but trying to direct them to something more suitable and less risky. (Participant 8, ≥20 years experience, out-patient hospital)*

If there are bone mets or other things to be considered, fatigue or cardiovascular or shortness of breath. We worked a great deal on breathing for these advanced cancer patients... And if they were walking, we said, 'Listen, we have to be sure that you have a place to sit. You have to pre-scope out where are you going to go and where are you going to sit, so that you can have a good rest while you're going. And you also need to have an emergency plan here. Ideally, you go with someone, you're accompanied. And if not, you have to have a cell phone...' (Participant 4, ≥20 years experience, out-patient hospital)

I think a lot of patients themselves, underestimate their ability and some patients, to be honest, overestimate their ability... to get back to those things. It's good to have some professional guidance... I have some patients that have tried so hard and wanted so much to do these leisure activities and then they get very frustrated... They try to do it and they are failing without understanding why. So I think that even the education about leisure activities and what the expectations can be, might help a lot. (Participant 5, <20 years experience, out-patient cancer centre)

b) Tailoring PA recommendations according to individual preference and enjoyment *It's really, anything goes. There are those patients who just really want to walk, and talk. And there are those who prefer to have like an exercise program with, let's say, 12 reps or x or y. So, there are really those two parts that you only get by asking what is meaningful to the patient. So, those who have more experience training, sometimes they will value more the exercise program. Those who have maybe less experience training, during their lives, well they prefer sometimes what is more 'functional training'. (Participant 2, <20 years experience, in-patient hospital)*

I encourage people to move as much as they are physically able to and I try to make it as positive as possible. And definitely choosing activities that they enjoy. I think that's the most important thing, is encouraging them to move in an activity that is pleasurable to them. (Participant 7, <20 years experience, private clinic / home care)

Theme 3. Overarching roles of physiotherapy in functional optimization and symptom management

a) Optimizing participation in daily activities, functional independence *There's much that we can do for, not only activities of daily living, but analyzing what they would like to do in a given day, and seeing how we can match exercises to gain that greater independence which is so important for them... So, we weren't doing stretching exercises or our usual calisthenics or manual therapy or usual orthopedic approaches. It really was very exercise-based and very functional, functionally-based types of programs. Based very much on what they wish to do, and what we wish them to be able to do. So if they had a home, mowing a lawn, or going to do groceries or driving. (Participant 4, ≥20 years experience, out-patient hospital)*

So I think our role is to, to be that sort of support, you know, as a physiotherapist, with the right exercises for keeping them independent, and so forth. (Participant 9, ≥20 years experience, out-patient cancer centre / private clinic)

b) Managing symptoms related to advanced cancer and treatments *I definitely talk about activity being a modality, in terms of managing and controlling side effects... I mean, the research is supporting exercise and activity as having such an impact, in terms of limiting and changing symptoms, so I think there's a huge role that can play in people's experience, whether it be fatigue, whether it be energy, whether it be movement or pain reduction. I think exercise is really important. (Participant 7, <20 years experience, private clinic / home care)*

We know how important it (physical activity) is for... their management of pain, and the management of some of the side effects of chemotherapy or radiation... (Participant 10, ≥20 years experience, private clinic / home care)

We don't just deal with physical activity. There's different areas, pain management, general recommendations, other tips that we can give them, even fatigue management, you know, edema control. Teach them, or give them tools to empower them. (Participant 1, <20 years experience, in-patient hospital / out-patient hospital / private clinic)

Theme 4. Generalized lack of awareness regarding physiotherapy

a) Believing patients with advanced cancer *I think once they see me, they value it highly. Sometimes they may think, 'Well I'm too sick to have physio' or 'I'm too sick to exercise' or whatever it is. And so they sometimes, I think maybe, are a little bit resistant. If they've been referred or their family member wants them to go to physio or whatever, they might be a bit resistant. But I think, once I see them, once I assess them, once I start giving them the exercises they need and*

<p>appreciate and value physiotherapy</p>	<p><i>helping them to, you know, be a little more independent, or move a bit better or function better, whatever it is, they absolutely value what I provide.</i> (Participant 9, ≥20 years experience, out-patient cancer centre / private clinic)</p>
	<p><i>Certainly where I live too, they really don't have many choices or many resources. So it's kind of nice that when they land in your lap, they're appreciative and, 'Oh my goodness this is helpful' or, you know, 'I didn't know this existed' or, you know, something like that.</i> (Participant 3, ≥20 years experience, private clinic / home care)</p>
<p>b) Experiencing frustrations about lack of awareness regarding physiotherapy for people with advanced cancer</p>	<p><i>I think (patients) are very appreciative. Some might not realize, or be aware of what benefit physiotherapy would have for them, which is, I think, partly because the whole health care system may not realize what physiotherapy can have to offer. And so they don't refer.</i> (Participant 11, ≥20 years experience, out-patient hospital)</p>
	<p><i>I think the other challenge is very limited acknowledgement that cancer rehab exists, within the greater medical field. So, (patients) are spending a lot of time with their palliative care team or their oncology team or whoever's sort of running their care, and often physio is never even crossed in their minds about, 'Hey, I know who could help you with quality of life'...</i></p>
	<p><i>How can patients know to ask for this type of care if they don't know it exists? How can clinicians, being oncologists, nurses, whoever, refer if they don't know it exists? And how can physios practice if they don't feel necessarily supported?</i> (Participant 6, <20 years experience, private clinic)</p>
	<p><i>It was super frustrating. (A patient) asked the medical team if there's anybody who could help them. And they just throw their hands up and say, 'We don't know'. They don't know that there's access to people like us who do this kind of work. So people are kind of stuck going out and trying to find their own treatment option.... And that's the biggest thing that I hear often is, 'We wish we had known help was available sooner'. That's really hard to hear. And really frustrating because the amount of preventive work that could be done is huge... So, I just wish there was more awareness and, a lot more knowledge out there across the board for just the general community and the medical community.</i> (Participant 7, <20 years experience, private clinic / home care)</p>
<p>c) Recognizing other factors contributing to under-development of physiotherapy in oncology</p>	<p><i>Then you also have a certain frustrations with the overall way our healthcare system is increasingly in silos, regardless of what they say about wanting to try and not be in silos. I think because things become more and more, complicated and technical, from the physician point of view, around how, you know, the drugs, the treatment options, it's a lot more complex than it used to be. That makes it harder to not be in silos, I guess.</i> (Participant 12, ≥20 years experience, in-patient hospital)</p>
	<p><i>You've also got doctors afraid to refer to us. You know, I think the mentality of physio, I think a lot of people have a concept that it's, you know, for the healthy. And for the mobile. But I think every cancer patient, be it stage one through four, should have access to a physiotherapist...</i></p>

So it's getting your mind changed... We haven't had success in getting (physio) students, because they think cancer and they're scared. I think students need to be exposed. I think we can offer a lot to palliative care as physios, improving their quality of life... It's really important that we mentor physios in oncology, and not have them be afraid of palliative... I think our profession has a long way to go. (Participant 13, ≥20 years experience, private clinic / home care)

And physiotherapists, I just obviously believe that we all need this oncology experience. But I do think it is particularly one of the fields in physical therapy that needs development. (Participant 4, ≥20 years experience, out-patient hospital)

*Participant details include overall years of clinical experience and clinical settings; limited information provided to preserve anonymity of

interview participants

Discussion

The main findings of our study indicate that Canadian oncology physiotherapists describe knowledge of the importance, safety, and benefits of PA, as well as of key cancer-related considerations (e.g., bone metastases) in people with advanced cancer. Moreover, they highlight the importance of personalized, patient-centered, and interprofessional care to support these individuals in terms of safe and meaningful participation in PA. Physiotherapists may be well-positioned to promote PA, as well as to optimize function and alleviate symptom burden in this population. Our findings highlight a potentially valuable, but under-recognized contribution of physiotherapy in supporting people with advanced cancer across the care continuum.

Our survey yielded a response rate that was higher than originally anticipated in the study design. The respondents indicated a wide range of experience levels, as well as diverse clinical settings and patient populations, contributing to a comprehensive understanding of perspectives and practices. Despite reported limitations in information and training opportunities, particularly within entry-to-practice education (Dunphy & McNeely, 2022), many physiotherapists in our study pursued additional post-graduate training to advance their knowledge and practical skills in oncology. These observations highlight the interest of both novice and experienced Canadian physiotherapists in this clinical area, as well as their commitment to contribute to the advancement of research and practice.

Key findings of our study focused on the positive perspectives of physiotherapists related to the safety and importance of PA in people with advanced cancer, as well as the role of physiotherapy in supporting PA promotion. Most survey participants felt highly confident in their ability to prescribe PA for this patient population and reported they regularly prescribed PA. Within their responses to the case scenarios, several respondents described familiarity with evidence-based knowledge of the safety of PA and benefits on function, quality of life, and fatigue, as well as exercise prescription and progression for cancer survivors (Campbell et al., 2019, 2022; Segal et al., 2017). These results are similar to those found

by Sheill et al. (2018) in their survey (Sheill, Guinan, O Neill, et al., 2018). In addition, our survey and interview participants frequently described applying skills of collecting additional information, communicating and collaborating with health professionals, and adapting clinical practices according to individual considerations (National Physiotherapy Advisory Group, 2019; Ontario Council of University Programs in Rehabilitation Sciences, 2019). In particular, recognizing cancer-related concerns, such as bone metastases, peripheral neuropathies, fatigue, and lymphedema, and other considerations, such as activity tolerance, were deemed necessary to support safe PA. Congruent with recent exercise and rehabilitation recommendations in oncology (Campbell et al., 2019, 2022; Maltser et al., 2017; Wolin et al., 2012), the survey respondents described medical consultation, symptom assessment, functional screening, patient education, as well as risk management and therapeutic strategies, to address these issues. Concerns due to advanced disease, particularly bone metastases and associated fracture risks, have been previously reported in studies with non-Canadian physiotherapists (Sheill, Guinan, O Neill, et al., 2018; Ten Tusscher et al., 2020). In addition to managing safety concerns, our survey and interview participants emphasized tailoring PA recommendations according to patients' individual expectations, diverse preferences, and personal enjoyment (Ten Tusscher et al., 2020). Other important PA-related considerations reported by our physiotherapist participants for this population included activity monitoring, supervised or group settings, gradual progression, as well as motivational strategies. These considerations and strategies are also in line with current exercise guidelines for cancer survivors (Campbell et al., 2019; Segal et al., 2017).

Through these different considerations, our study participants highlighted adopting a patient-centered approach for PA promotion, a concept which was especially emphasized within the interviews. The importance of a patient-centered approach has been previously recognized in related areas of physiotherapy practice, including oncology rehabilitation and palliative care (Brennan et al., 2022; McLeod & Norman, 2020; Olsson Möller et al., 2018). In particular, it was critical for our participants to

understand individual, meaningful goals and priorities in their patients and to determine where PA fit in. Our results indicate aligning rehabilitation objectives with individual considerations and patient-centered goals is of particular relevance for physiotherapists working with individuals facing incurable disease and extends to different aspects of intervention delivery, including PA-related recommendations.

Previous research has demonstrated physiotherapists can effectively increase PA in non-cancer populations, although PA promotion is not regularly implemented in clinical practice (Freene et al., 2017; Kunstler et al., 2018; A. Lowe et al., 2017; Rethorn et al., 2021a). Our research adds to the growing body of literature recognizing the need to advance the role and impact of physiotherapists in PA promotion (Kunstler et al., 2019; A. Lowe et al., 2018; Rethorn et al., 2021b). For individuals with advanced cancer, there remain gaps in the literature on evidence-based PA guidelines (Campbell et al., 2019; Shallwani et al., 2019) and information and training needs in physiotherapists have been identified within our research and other studies (Brennan et al., 2022; Sheill, Guinan, O Neill, et al., 2018; Ten Tusscher et al., 2020). Fortunately, there is increasing evidence on the effectiveness of structured exercise programs in advanced cancer (Chen et al., 2020; Nadler et al., 2019; Shallwani et al., 2021). In addition, recent work has focused on developing exercise recommendations for people with bone metastases (Campbell et al., 2022; Weller et al., 2021). Our findings suggest that physiotherapists describe the clinical knowledge, skills and confidence to promote PA in advanced cancer and support current recommendations indicating that specialized physiotherapists may be well-suited for this role (Campbell et al., 2022). As the research on this topic continues to expand, physiotherapists can potentially play an important role in applying evidence-based recommendations and enhancing safe, meaningful PA participation in individuals with advanced cancer.

In addition to supporting PA participation, several participants highlighted the key overarching roles of physiotherapy in optimizing function and quality of life in people with advanced cancer. PA and

exercise were often described to achieve patient-centered goals related to enhancing functional independence and alleviating symptoms, such as fatigue, pain, and breathlessness. In a U.K. survey, 68% of physiotherapists indicated recommending exercise for the management of cancer-related fatigue, particularly in those with advanced disease (Donnelly et al., 2010). Moreover, previous studies have demonstrated physiotherapy-led programs, consisting of exercise and other interventions, effectively improved functional status and symptom burden in these individuals (Bernabeu-Wittel et al., 2021; Pyszora et al., 2017). Within interdisciplinary programs for people with advanced cancer, physiotherapists have also contributed to significant improvements in functional outcomes (Chasen et al., 2013). These findings indicate that physiotherapy-led, multidimensional interventions, including PA programs, can produce various clinical benefits for this patient population.

Given the challenges associated with advanced cancer and the positive effects of PA and physiotherapy interventions, it is crucial to further examine how to improve the availability and quality of oncology rehabilitation programming. While our participants reported feeling knowledgeable and confident about their diverse roles with the advanced cancer population, there was a common frustration among many physiotherapists. This sentiment was related to the generalized lack of awareness regarding the role of physiotherapy and tailored rehabilitation strategies, including PA, to help these individuals. Similar to previous research, our survey responses indicated that the physiotherapists perceived challenges among patients with recognizing, seeking and following PA advice, as well as with families encouraging PA (Sheill, Guinan, O Neill, et al., 2018). However, the interview participants expanded on this topic and provided clarifications. They felt people with advanced cancer valued PA and physiotherapy, in general, but many were not aware of and could not access timely, appropriate rehabilitation services. They attributed this mainly to the lack of awareness and recognition of physiotherapy in oncology, particularly within the medical community. From the perspectives of people with advanced cancer, previous studies have identified barriers related to PA

participation, including cancer-related symptoms, fear of injury, inaccessibility, and limited support from health professionals (Burke et al., 2020; Cheville et al., 2012; Frikkel et al., 2020; Sheill, Guinan, Neill, et al., 2018b). Despite several challenges, patients with incurable disease have reported feeling capable and interested in PA and believing it could improve their symptoms and function (Burke et al., 2020; S. S. Lowe et al., 2010). In one study, people with advanced lung cancer revealed their preference to receive PA information from cancer care providers (Cheville et al., 2012). While oncology professionals have acknowledged the importance of PA for people with advanced cancer, many reported low confidence in prescribing PA and indicated the need for more information (Adams et al., 2021; Sheill, Guinan, Neill, et al., 2018a). Together, these findings suggest people with advanced cancer may be interested in PA and could benefit from tailored information from health professionals, but there may be challenges with accessing proper guidance and PA resources. Physiotherapists can potentially support oncology care teams, but many feel their role is not well recognized within the medical community.

To address these gaps, the ACSM's Exercise Is Medicine initiative has proposed incorporating routine PA assessment and advice within clinical care, with referral to rehabilitation professionals in cases where further assessment or exercise supervision are deemed necessary (Schmitz et al., 2019). The results of our study also suggest physiotherapists value interprofessional collaboration and may be well-positioned to support PA participation in people facing cancer-related challenges. However, our participants' perspectives and other research reports suggest the general role of physiotherapy is not well recognized or integrated in standard oncology practice, particularly within a Canadian context (Canestraro et al., 2013; Dunphy & McNeely, 2022). Factors further contributing to this lack of integration may include segmentations in the health care system, perceptions about physiotherapists' skills and training, as well as limited information resources and training opportunities in oncology for physiotherapists (Barnes et al., 2020; Donnelly et al., 2010; Dunphy & McNeely, 2022; Nelson et al., 2012; Sheill, Guinan, O Neill, et al., 2018; Ten Tusscher et al., 2020). Collectively, these findings indicate

the urgent need for continued education and advocacy on the benefits of PA and the role of physiotherapy in the care of people with advanced cancer. Moreover, improved availability and standardization of oncology content within Canadian physiotherapy education, and thus increased professional capacity, are needed to enhance accessible, high-quality physiotherapy services for people with cancer (Dunphy & McNeely, 2022; Ten Tusscher et al., 2020).

Integrating physiotherapists may enhance the quality of supportive cancer care and improve the well-being of people across the cancer experience. Recently, Barnes et al. (2020) proposed a model depicting the clinical integration of physiotherapy in cancer care. Key elements of this model comprise: (1) the inclusion of physiotherapists within oncology care teams and clinic environments; (2) prospective, routine screening of function throughout the cancer continuum; and (3) tailored rehabilitation interventions to address cancer-related functional impairments (Barnes et al., 2020). This model suggests a valuable framework for clinical practice that can be adapted to different oncology populations. Further research is needed to examine the impact of functional screening and tailored physiotherapy strategies and the implementation of such models in practice, particularly for people with advanced cancer.

Limitations of our study include a lower representation of participants from outside Eastern Canada, particularly the Northern region. Our recruitment strategy focused on members of the CPA Oncology Division, which may not represent all Canadian physiotherapists working with advanced cancer. Moreover, the physiotherapists who volunteered to participate in our survey and interviews may have been more motivated and confident in their skills with advanced cancer, compared to other physiotherapists. However, our participants were diverse in terms of experience levels and clinical settings and provided a valuable, extensive understanding of current Canadian physiotherapy practice with this population. Limitations of the survey include missing responses, as well as its limited scope in examining views related to PA. Additionally, as this study was descriptive in nature, no formal

assessment of the physiotherapists' clinical knowledge and skills was performed. However, adopting a mixed-methods design with follow-up qualitative interviews allowed us to understand PA-related perspectives in greater depth. For example, the interview participants elaborated on the connections of PA with overarching goals of functional optimization and symptom management. Due to our focus on PA, it was not possible to explore other aspects of the physiotherapists' perspectives and experiences related to advanced cancer. Important topics beyond the scope of our research question, such as emotional connections with patients, were described and warrant exploration in future research. Moreover, other meaningful activities and the role of occupational therapy have not been well researched in this population (la Cour, Johannessen, et al., 2009).

Conclusion

Our findings suggest Canadian oncology physiotherapists recognize the importance and benefits of PA, as well as key cancer-related considerations to support people with advanced cancer in terms of safe and meaningful participation in PA. Through a patient-centered approach, they describe important strategies to promote PA, such as considering individual goals and preferences, educating patients, tailoring PA recommendations, and collaborating with health professionals. Our mixed-methods study highlights a potentially valuable, but under-recognized contribution of Canadian oncology physiotherapists in assisting patients with PA participation, functional optimization, and symptom management. Further development and integration of physiotherapy within different clinical contexts may enhance the quality of supportive care for the advanced cancer population.

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Supplemental Material S1

Survey: Canadian Physiotherapists Working with Advanced Cancer

Advanced cancer has been defined as “*cancer that has spread to other places in the body and usually cannot be cured or controlled with treatment*” (National Cancer Institute, 2007).

1. Do you have any recent or current clinical experience with adults diagnosed with advanced cancer?
 - Yes, I currently work with adults with advanced cancer.
 - Yes, I have recent experience (within the last 5 years) with adults with advanced cancer, but no longer work with them right now.
 - No

2. I consent to participate in this survey.
 - Yes
 - No

3. How many years of clinical experience do you have in general as a physiotherapist?

4. How many years of clinical experience do you have working with patients with cancer?

5. What is your current employment status?
 - Working full-time as a physiotherapist
 - Working part-time as a physiotherapist
 - Not currently working as a physiotherapist (e.g. on leave, retired)
 - Other (please specify)

6. What percentage of your average caseload consists of patients with cancer?
(If you are not currently working, the remaining questions on this page apply to when you were recently working with this population.)
 - More than 50%
 - 50% or less
 - Other (please specify)

7. In what clinical setting(s) do you specifically see patients with advanced cancer?
Please check all that apply.
 - Hospital in-patient
 - Hospital out-patient
 - Home care
 - Private practice
 - Hospice / palliative care

- Rehabilitation in-patient
- Rehabilitation out-patient
- Community-based centre
- Other (please specify)

8. What type(s) of physiotherapy services do you provide to patients with advanced cancer?

Please check all that apply.

- Physiotherapy assessment
- Individualized education / counseling
- Group education classes
- Mobility aids / assistive devices
- Physical activity / exercise prescription
- Group exercise sessions
- Manual therapy techniques
- Lymphedema treatment techniques (e.g. compression, manual lymphatic drainage)
- Biophysical modalities (e.g. Ultrasound, TENS)
- Other (please specify)

9. What type(s) of patients with advanced cancer do you work with?

Please check all that apply.

- Breast cancer
- Colorectal cancer
- Gastrointestinal cancer
- Gynecological cancer (e.g. endometrial, cervical, ovarian)
- Hematological cancer (e.g. lymphoma, leukemia)
- Head and neck cancer
- Lung cancer
- Pancreatic cancer
- Prostate cancer
- Other (please specify)

10. In what province / territory do you primarily practice physiotherapy?

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut

- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon

11. What is your highest level of education, in general?

- Diploma / college degree
- Bachelor's degree
- Master's degree
- Doctorate / PhD degree
- Other (please specify)

12. What is your entry-to-practice level of physiotherapy education? (i.e. what degree did you obtain in order to practice physiotherapy?)

- Diploma / college degree
- Bachelor's degree
- Professional Master's degree
- Clinical doctorate degree
- Other (please specify)

13. Have you taken any training or courses on working with cancer patients (not specifically advanced cancer)?

- No
- Yes

14. If you answered yes to the previous question, what type of cancer-specific training or courses have you taken?

Please check all that apply.

- Post-graduate courses offered through the Canadian Physiotherapy Association (CPA)
- Post-graduate courses offered by other associations or institutions
- Clinical specialty program (CPA)
- Lymphedema therapy certification
- University courses (during physiotherapy training)
- University courses / degree (post-graduate training)
- Other (please specify)

15. What is your gender identity?

Gender identity is your sense of self, for example, your sense of being a man, a woman, both or neither. It may be different from your physical sex and includes the options below.

- Woman

- Man
- Transgender
- I do not wish to answer
- You don't have an option that applies to me. I identify as (please specify):

16. What is your current age?

17. Please select the response which best matches your opinion for each statement.

(7-point Likert scale: *strongly disagree, disagree, somewhat disagree, neither agree nor disagree, somewhat agree, agree, strongly agree*)

- In my opinion, physical activity is important for patients with advanced cancer.
- In my opinion, physical activity is safe for patients with advanced cancer.
- I feel patients with advanced cancer believe they should remain physically active.
- I feel patients with advanced cancer are capable of participating in physical activity.
- I find providing physical activity recommendations to patients with advanced disease is usually well received.
- I feel patients with advanced cancer will follow the advice of physical activity recommendations given.
- I feel patients with advanced cancer come to me for physical activity recommendations.
- I am confident in my ability to prescribe physical activity to patients with advanced cancer.
- I regularly prescribe physical activity recommendations to patients with advanced cancer.
- I feel there is a need for more information on how to prescribe physical activity to patients with advanced cancer.
- I find the families and friends of patients with advanced cancer encourage physical activity.

18. Case Description #1:

Martin is 86 years old with widespread axial metastases secondary to prostate cancer. He has few comorbidities and has been active all his life. During his consultation, he mentions to you that he plans on remaining active and continuing activities, which include manual labor in the garden and playing golf every day.

Please answer the following two questions concerning case description #1.

- What recommendations would you give to Martin in relation to physical activity?
- Please highlight any concerns you have related to physical activity for Martin.

19. Case Description #2:

Sally is 64 years old and has stage IV breast cancer with persistent fatigue, stable arm lymphedema and peripheral neuropathies in her legs. She reports being inactive pre- and post-cancer diagnosis and has multiple comorbidities. She feels that her cancer diagnosis and side effects further limit her physical activity.

Please answer the following two questions concerning case description #2.

- What recommendations would you give to Sally in relation to physical activity?
- Please highlight any concerns you have related to physical activity for Sally.

Supplemental Material S2

Interview Guide: Canadian Physiotherapists Working with Advanced Cancer

The objective of this study is to describe the clinical practices, perspectives and experiences of Canadian oncology physiotherapists related to people diagnosed with advanced cancer.

Advanced cancer has been defined as “*cancer that is unlikely to be cured or controlled with treatment*”. (NCI, 2007)

Interview Guide (Sample Questions)

- How many years of clinical experience do you have as a physiotherapist? Can you describe the clinical setting you work in?
- How did you gain the knowledge and skills to work with people diagnosed with advanced cancer? Do you feel you have a good foundation of knowledge in this area?
- What do you feel is our role as physiotherapists working with the advanced cancer population?
- How do you think people with advanced cancer feel about leisure physical activity and exercise? About physiotherapy, in general?
- Can you share your general thoughts and feelings about working with the advanced cancer population? What are some of the challenges? What are some of the positive aspects?

CHAPTER 5: INTEGRATED DISCUSSION

The overall purpose of my dissertation research is to explore LPA in people with advanced cancer.⁶ To achieve this goal, I completed three studies: (1) a scoping review of the literature on the topic; (2) a qualitative interpretive-description study with adults diagnosed with stage 4 cancer about their perspectives and experiences of LPA; and (3) a mixed-methods study with oncology physiotherapists to understand their clinical practices and perspectives. This research may help inform the development and integration of targeted LPA resources within supportive cancer care, particularly from a rehabilitation perspective. Moreover, it may guide educational initiatives targeting health professional and patient knowledge, as well as inform future research inquiries in this area.

In this final chapter, I first provide a concise summary of the findings from each study associated with this dissertation research in **Table 5.1** and then expand on the findings following the table. Next, I integrate the information from the respective studies and discuss common themes noted within the research findings, along with their implications for clinical practice in supportive cancer care and rehabilitation oncology. Following this, I described key educational and research implications of this work. Finally, I share the strengths and limitations of my research, and conclude my dissertation with a summary of the discussion.

⁶ Although this research has been described within the context of my dissertation, there were several collaborators who provided significant contributions to this work. In accordance with the University of Ottawa thesis guidelines, I outline the contribution of the collaborators involved in my research within **Appendix F**.

Table 5.1 Summary of Dissertation Findings

Overall purpose of dissertation: To explore LPA in people with advanced cancer, through the perspectives of adults diagnosed with stage 4 cancer and oncology physiotherapists in Canada					
	Study 1: Scoping review (Chapter 2)	Study 2: Patient interpretive-description study (Chapter 3)	Study 3: Physiotherapist mixed-methods study (Chapter 4)		
Objectives	To map the research and understand key concepts from the literature about LPA in people with advanced cancer	To explore the perspectives and experiences of LPA in individuals with stage 4 cancer	To describe the clinical practices, knowledge, skills, and perspectives of oncology PTs related to PA in people with advanced cancer		
Methods	Scoping review of 92 articles exploring LPA in people with advanced cancer (scoping methodology)	Qualitative, individual interviews with 20 Canadian adults diagnosed with stage 4 cancer (interpretive-descriptive methodology)	Explanatory, sequential mixed-methods design: (a) cross-sectional survey with 62 Canadian PTs; (b) qualitative, individual interviews with 13 PTs (interpretive-descriptive methodology)		
Results / Themes	<u>Scoping review findings:</u>	<u>Interview themes / sub-themes related to LPA:</u>			
	<ul style="list-style-type: none"> - Most studies were published in the last decade (80%) and used quantitative methods (77%) - Many study populations included mixed (40%), breast (21%) or lung (17%) cancers - Stages 3-4 or metastatic disease were frequently indicated to describe study populations (77%) - Several studies (68%) described LPA programs or interventions; of these, 78% involved structured aerobic / resistance exercise, while 16% explored other LPA types 	1. Diverse, fluid experiences	- Diverse, changing experiences	<ul style="list-style-type: none"> - Most PT respondents (>85%) agreed or strongly agreed PA is important and safe for individuals with advanced cancer - Case responses highlighted cancer-related considerations (e.g., bone metastases), tailored PA recommendations and patient-centered, interprofessional care 	
		2. Being intentional	- Intentionally planning and prioritizing activities		- Finding balance through activity modifications
		3. Health benefits	- Symptoms and physical function		- Health outcomes
		4. Psychosocial meanings	- Accomplishment vs. loss		- Social connections
5. Seeking tailored support		- Lack of professional support	- Need for tailored support		
		<u>Survey findings:</u>			
		<ul style="list-style-type: none"> 1. Recognizing PA within individually meaningful goals 2. Strategies to promote PA 3. Overarching roles in functional optimization and symptom management 4. Generalized lack of awareness regarding physiotherapy 			

			- Other preferences (e.g., group-based settings, accessibility)	
Findings and Implications	<ul style="list-style-type: none"> - There is a recent surge in research exploring LPA in advanced cancer - Most studies examine exercise interventions with traditional quantitative methods - Less is known about patient experiences and perceptions towards LPA, and about other leisure activities (e.g., Tai Chi, dance, sports) - Further research is needed to address current gaps in the literature 	<ul style="list-style-type: none"> - Experiences of LPA are diverse, fluid and connected to psychosocial meanings and health benefits - LPA participation involves important cancer-related considerations and intentional planning and modifications - To facilitate LPA, patients desire professional support, that is integrated, interprofessional, accessible and tailored to individual needs and preferences - Further efforts are needed in cancer care to address challenges faced by people with stage 4 cancer and to optimize safe, meaningful participation in LPA 		<ul style="list-style-type: none"> - Canadian oncology PTs describe knowledge of the safety and importance of PA and of key considerations in advanced cancer - A patient-centered, interprofessional approach and tailored recommendations are important to facilitate safe, meaningful PA in people with advanced cancer - PTs may also play a valuable role in optimizing function and alleviating symptom burden in this population - Further efforts are needed to enhance the development and integration of physiotherapy within cancer care

LPA: leisure-time physical activity; PA: physical activity; PT: physiotherapist

Summary of Findings

In this section, I present the key findings of each study conducted as part of this dissertation work. The overall objective of my research is to explore LPA in people with advanced cancer, through the perspectives of individuals with stage 4 cancer and oncology physiotherapists with clinical experience in advanced cancer. My dissertation research consisted of a scoping review (Study 1), a qualitative interpretive-description study with adults diagnosed with stage 4 cancer (Study 2), and a mixed-methods study with oncology physiotherapists (Study 3).

Scoping Review (Study 1)

There is increasing awareness of the benefits of exercise and PA for individuals following diagnosis of cancer. Prior to conducting research with participants, there was a need for an updated, comprehensive review of the literature specifically exploring LPA in people with advanced cancer. This step was necessary in order to help establish an understanding of existing research knowledge in this area, to detect gaps in the literature, and to further elucidate how to define the key concepts under study, including LPA and advanced cancer. Therefore, through the scoping review (Study 1), I aimed to map the current body of literature and to understand key concepts from the research about LPA in people with advanced cancer.

The scoping review of 92 articles highlighted a rapid increase in research over the last decade focused on the topic of LPA in the advanced cancer population. These studies have mainly adopted quantitative methods to examine exercise interventions in these individuals. This information has contributed to noteworthy research developments in this area, demonstrating the safety, feasibility, and several clinical benefits of exercise in people with advanced cancer. This work has been focused primarily on individuals diagnosed with advanced breast or lung cancer, of female gender, and of older ages. Although there has been substantial growth in the literature on this topic, I identified several

important research gaps in this review. In particular, few studies have explored patient perspectives and experiences related to LPA. Moreover, leisure activities besides aerobic and resistance exercise training programs have not been well studied in this population. Finally, there exist population-related gaps in the literature and further efforts are needed to consider diverse representations of advanced cancer in the research on this topic. Thus, the scoping review provides an extensive overview of the literature and guides the development of future research inquiries exploring LPA in advanced cancer.

Patient Interpretive-Description Study (Study 2)

As demonstrated by the scoping review (Study 1), further research is needed to better understand perceptions, facilitators, barriers, and preferences of LPA in people living with advanced cancer. Increased knowledge of patient perspectives can help inform the creation and integration of supportive care resources targeting LPA in this population. To address these gaps in knowledge, the objective of the patient study (Study 2) was to explore the perspectives and experiences of LPA in a diverse group of individuals with stage 4 cancer. To fulfill this research objective, I conducted a qualitative interpretive-description study, which consisted of individual, semi-structured interviews with 20 Canadian adults diagnosed with stage 4 cancer.

The main findings of this study highlighted the diversity and fluidity of experiences with LPA in the stage 4 cancer population. In the participants living with advanced, incurable cancer, engaging in LPA involved important considerations of cancer-related symptoms and risks, along with deliberate planning and modification of activities. Being intentional was an important element of finding meaningful and acceptable balance within different types of LPA for these individuals. Moreover, there were important psychosocial meanings and health benefits associated with LPA participation. In particular, psychosocial meanings of LPA revolved around experiences of accomplishment, loss and grief, as well as opportunities for social connections. Health benefits associated with LPA included improved cancer-

related symptoms, physical well-being, functional activity, and cancer-related outcomes. However, the participants with stage 4 cancer also reported unmet needs related to professional support for LPA within oncology care services. Specific preferences around LPA support included personalized advice offered within standard cancer care, guidance from specialized rehabilitation and exercise professionals, elements of group or peer support, diversity in leisure activity types, and access to community-based programs tailored to this population. These study findings describe unique aspects of LPA participation for the advanced cancer population and highlight important implications for supportive care and rehabilitation initiatives in oncology.

Physiotherapist Mixed-Methods Study (Study 3)

Along with gaps in understanding patient perspectives, little is known on the ability of physiotherapists to support LPA in the advanced cancer population, particularly within a Canadian context. Further comprehension of this topic can help support the integration of clinical rehabilitation strategies in cancer care and enhance educational initiatives for health professionals and trainees in the physiotherapy profession. Thus, in the mixed-methods study (Study 3), I aimed to describe the clinical practices, knowledge, skills, and perspectives of Canadian oncology physiotherapists related to PA in people diagnosed with advanced cancer. This study consisted of an online, cross-sectional survey with 62 physiotherapists, following by individual, qualitative interviews with 13 physiotherapists.

The findings of this study indicated a positive recognition among Canadian oncology physiotherapists regarding the safety, importance, and benefits of PA in people with advanced cancer. Through the clinical case scenarios provided in the survey, the participants described detailed considerations of cancer-related concerns (e.g., bone metastases, peripheral neuropathies, fatigue, and lymphedema), of individualized PA recommendations, and of a patient-centered, interprofessional approach to care. Important themes from the interviews included understanding individually meaningful

activity goals in patients and adopting additional tailored strategies to optimize PA participation. Along with PA promotion, the predominant roles of physiotherapists in supporting functional independence and symptom management were highlighted. Finally, there were frustrations voiced concerning the limited awareness of the benefits of PA and of the role of physiotherapy in advanced cancer, along with poor access to rehabilitation services to assist the advanced cancer population. Therefore, these findings are helpful to understand the knowledge and perspectives of Canadian oncology physiotherapists working in this clinical area. This information highlights specific aspects of advanced cancer care to which physiotherapists may contribute, namely PA support, functional optimization, and symptom management. Moreover, this study helps identify educational and outreach priorities to improve the training and integration of physiotherapists into clinical care for this patient population.

Integrated Discussion and Practical Implications

Overview of Integrated Discussion

Having summarized the main findings of each study, I now integrate the findings from the different components of this dissertation research. In this section, I highlight several common central themes concerning LPA in people with advanced cancer, as well as unique contributions of the respective research studies in my work. The first four themes describe new integrated understandings of perspectives and experiences related to LPA in people with advanced cancer. The remaining four themes focus on relevant practical implications of this work for the development of supportive care and rehabilitation resources in oncology. As the approach of my dissertation research is focused on generating experiential knowledge and determining relevant practical implications (Creswell & Plano Clark, 2017; Thorne, 2016), the themes discussed within this section have been directly informed by the findings of my research.

Complexities of Advanced Cancer

One central theme of my research findings consists of the complexities of living with advanced cancer, which deeply impact experiences of LPA. The heterogeneity of the advanced cancer population was noted in the research included in the scoping review. Despite research gaps in the body of literature, this heterogeneity was demonstrated by variability within the participant characteristics, such as cancer types, stages, expected life expectancies, and clinical settings (e.g., home-based, palliative care, hospice care). Moreover, the broad range of concerns and considerations related to stage 4 cancer, its treatments, as well as other daily life responsibilities, was illustrated by the patient participants. In several examples, the participants discussed how cancer-related issues, such as fatigue and peripheral neuropathies, impacted their daily physical activities. Moreover, socio-environmental factors, such as family and work responsibilities, necessitated careful planning and prioritization of different activities, including LPA. Through the survey case responses, the physiotherapist participants also focused on the management of diverse cancer-related issues, including bone metastases and lymphedema. In the interviews with the physiotherapists, other rehabilitation needs were also identified to be of concern in this population. These needs included functional challenges and symptoms, such as pain and breathlessness. Thus, my dissertation findings shed light on the range and complexity of concerns experienced by people with advanced cancer. To further expand on these challenges, the patient participants in my research explained that fluctuations in clinical presentations were quite common due to disease progression and treatment effects. My findings are consistent with other research identifying different, varying issues experienced by the advanced cancer population and indicating that these concerns can often be an ongoing barrier to PA (Cheville et al., 2012; Frikkel et al., 2020; Sheill, Guinan, Neill, et al., 2018a). Therefore, the findings of this dissertation research help characterize the distinct complexities of living with advanced cancer and their consequential impact on

LPA experiences for these individuals. Consideration of these diverse concerns can help guide the development of clinical initiatives focused on LPA in this population.

Intention and Meaning Within LPA

In light of the complexities and unpredictability associated with advanced cancer, another important theme was noted around finding intention and meaning within LPA participation. Being intentional and establishing balance were particularly important for the patient participants, in order to prioritize activities that were meaningful to them. A fundamental aspect of physiotherapy practice also revolved around identifying personal goals and priorities in patients, related to LPA and other functional activity. In the same vein, there was a recognition of the diversity of leisure activities that were important and enjoyable in this population. The patient participants identified a wide range of leisure activities they participated in. Examples of preferred LPA consisted of outdoor activities (including winter and water-based activities), mind-body exercise (e.g., yoga, QiGong), and recreational sports. The scoping review identified studies demonstrating positive benefits with exercise interventions, but highlighted important gaps in the literature on other types of LPA. My research findings further support the notion that identifying individually meaningful goals and recognizing diverse activity preferences are paramount when exploring LPA in the advanced cancer population (Burke et al., 2020; McLeod & Norman, 2020). This recognition could assist patients to become intentional and prioritize activities of importance while appreciating meaningful enjoyment within their chosen activities (la Cour, Johannessen, et al., 2009).

In terms of finding meaning within LPA, many of the health benefits previously identified in the literature were also recognized through the three studies conducted as part of this dissertation work. The research studies included in the scoping review mainly examined exercise interventions and reported favourable effects on several clinical outcomes, particularly physical function and quality of life

(Chen et al., 2020; Nadler et al., 2019). Similarly, the patient participants described the positive aspects of LPA participation for improvement of fatigue, sleep, pain, physical function, and mental health. Important purposes of LPA for some patient participants in my research also involved maintaining functional independence and decreasing caregiver burden. These varied benefits on symptoms, physical performance, and functional activity were likewise acknowledged by the physiotherapist participants. Although cancer-related and treatment-related outcomes have not been well explored in the advanced cancer literature (Takemura et al., 2021), improving treatment eligibility and response, and increasing survival consisted of other reasons the patient participants engaged in LPA. Thus, the findings of my dissertation research collectively highlight important health meanings of LPA for the advanced cancer population, particularly in terms of symptom control, physical well-being, functional independence, and cancer-related outcomes.

Along with these health benefits, I also discovered that there were profound psychosocial meanings of LPA, emphasized mainly by the patient participants in my research. Feelings of achievement, normalcy, empowerment, and control were often experienced in relation to LPA engagement. The concept of accomplishment through exercise activity was also evident and has been explored in other qualitative work with the advanced cancer population (Belchamber, 2009; Turner et al., 2016). This sense of achievement may be particularly intense for these individuals, due to the opposing experiences of living with unpredictable, incurable stage 4 cancer and of participating in a health behaviour that is controllable and positive. Moreover, LPA may also serve as a “*normal*” and distracting activity for this population. Another important and related meaning of LPA participation was its interconnectedness with the social dimensions of patients’ lives. The patient participants indicated elements of social support and motivation, through LPA participation with family, friends, and other people with cancer. Opportunities for socialization may facilitate emotional support, promote the use of coping strategies, further enhance feelings of normalcy, and provide a sense of belonging (Applebaum et

al., 2014; Paltiel et al., 2009; Rutkowski et al., 2018; Zabalegui et al., 2013). Moreover, social connections may enhance accountability and commitment in LPA, and consequently, help promote LPA behaviour (Paltiel et al., 2009). The above-mentioned benefits of LPA on psychosocial function have been supported by other qualitative and quantitative research with this population (Belchamber, 2009; Gulde et al., 2011; Heywood et al., 2018; Mikkelsen et al., 2019; Paltiel et al., 2009; Turner et al., 2016). This indicates there are important psychosocial meanings associated with LPA participation that warrant attention in people diagnosed with advanced cancer.

While the meanings of LPA were generally positive for the patient participants in my research, there were also challenging emotions of grief and loss related to activity. Similarly, these experiences may have been especially profound in the participants, due to the unpredictable and progressive nature of stage 4 cancer and their regular engagement in LPA prior to and following diagnosis. My findings complement other work recognizing experiences of loss with PA engagement in this population (Burke et al., 2020; Turner et al., 2016). The physiotherapists emphasized inquiring about individually meaningful priorities and activity preferences in their clients, while considering the complexities of advanced cancer. They also recognized the quality of life and mental health benefits of LPA. However, there was limited acknowledgement by the physiotherapists of these particular psychosocial meanings (e.g., accomplishment, loss) in relation to LPA. Thus, the findings from this research support previous evidence of the clinical benefits of LPA in this patient population, but also identify distinct meanings of LPA for people with stage 4 cancer. This knowledge can inform educational and clinical strategies to optimize LPA in individuals with advanced cancer, as well as to improve relevant knowledge in health professionals working with this population.

LPA Promotion Strategies

As noted in this section so far, there are important considerations related to cancer-related challenges, personal priorities, and meaningful activity in people with advanced cancer. Through these considerations, various strategies were identified within my research to promote safe and meaningful LPA in this patient population. From the perspectives of the patient participants, these included strategies of planning daily activities and intentionally prioritizing enjoyable LPA. Moreover, due to the presence of cancer-related symptoms and risks, they frequently incorporated activity modifications, such as changing specific activities or positions, adjusting activity parameters, using assistive equipment, and including regular breaks or rest periods. For example, there was a participant who modified their exercise positioning and technique due to feeling discomfort in their hip at the location of a bone metastasis. Several participants discussed decreasing their activity intensity or duration to avoid overexerting themselves during LPA and potentially exacerbating their symptoms of fatigue. Another participant used an electric-assist bike for this same reason. A final example is a participant who described experiencing peripheral neuropathies in the feet and using specific footwear to facilitate their outdoor walking activity.

In addition, there were other strategies identified by the patient participants to increase motivation and help promote LPA. These tactics included making leisure activity part of the daily routine, participating in activities with other people, as well as seeking professional information, resources, and support. Previous literature has explored barriers of LPA participation in the advanced cancer population (Burke et al., 2020; Cheville et al., 2012; Frikkel et al., 2020; Sheill, Guinan, Neill, et al., 2018a), but my research is unique in clearly identifying patient-reported strategies to overcome challenges and optimize LPA participation. The nature of these findings may have been attributed to the regularity of LPA participation in many of the patient participants. Although this may be a limitation of this research, this particular perspective provides useful information on applicable ways to support LPA in this population.

From the perspectives of the physiotherapist participants, there were similar strategies identified to address cancer-related concerns and other factors influencing LPA. Patient education and risk management techniques were key to address concerns of bone metastases, peripheral neuropathies, and lymphedema. For example, in the survey, there was a case scenario of a patient who had axial metastases due to stage 4 prostate cancer. To address this case, the physiotherapists described strategies to educate the patient about fracture risk and to monitor pain. Moreover, the survey participants explained specific body mechanics and positioning modifications (e.g., proper spine alignment, avoidance of torsional movements) for daily activities, such as bed transfers and leisure activities of gardening and golf. Likewise, for another case scenario of a patient with peripheral neuropathies, the survey responses included considerations to reduce the risks of falls, skin breakdown, and associated complications. Examples of specific strategies that were suggested by the physiotherapists include proper footwear, environmental safety, assistive devices, and skin checks. To address concerns of fatigue in the case scenarios, recommendations consisted of regular monitoring of fatigue and activity levels, as well as pacing and energy conservation techniques. Personal factors of activity expectations, motivation and adherence were also addressed through individualized patient education and tailored LPA recommendations. Overall, these findings indicate congruence between the patient and physiotherapist participants in terms of strategies adopted to promote safe LPA, in the presence of cancer-related symptoms and risks.

In addition to education and risk management approaches though, the physiotherapist participants also described specific therapeutic strategies to directly manage cancer-related symptoms and concerns, and subsequently, improve LPA participation. For example, balance training exercises were recommended to improve safety and mobility in the presence of peripheral neuropathies, and strategies suggested for lymphedema management included compression therapy and manual lymphatic drainage. It is important to note that within the physiotherapist interviews, there was also an

emphasis on the overarching roles of physiotherapy in optimizing functional independence and assisting with symptom management. Other research has demonstrated benefits with physiotherapy interventions in people with advanced cancer, in terms of functional status and symptom status (Bernabeu-Wittel et al., 2021; Pyszora et al., 2017). Thus, my research identifies areas of rehabilitation, within and beyond LPA promotion, where physiotherapists can potentially contribute in supporting the advanced cancer population.

The patient and professional participants in my dissertation research reported similar strategies to facilitate LPA in people with advanced cancer. The common identification of strategies may have been attributed to their familiarity and knowledge in this area. Along with lived experiences of stage 4 cancer, many of the patient participants also had personal experiences of engaging in LPA both pre- and post-diagnosis. Similarly, several physiotherapist participants had acquired specialized knowledge and skills in oncology, through post-graduate training and clinical experience. Therefore, my research findings highlight specific strategies that can be implemented in practice to help optimize safe, appropriate LPA in people with advanced cancer. Similar exercise and supportive care recommendations have been previously published to guide the management of symptoms and promotion of LPA participation in people with cancer (Berger et al., 2015; Campbell et al., 2019, 2022; Maltser et al., 2017; Segal et al., 2017; Wolin et al., 2012). The strategies identified through my research may be useful to inform tailored educational materials and rehabilitation interventions targeting LPA in the advanced cancer population, particularly for those individuals without prior knowledge and experience with LPA. In addition, my findings suggest oncology physiotherapists may possess specialized knowledge and skills that could be useful to manage other challenges experienced by people with advanced cancer. Thus, this work also helps delineate the specific roles of physiotherapists in the clinical care of people with advanced cancer.

Gaps in Professional Support

In this discussion so far, I have explored the complex challenges of advanced cancer, the diverse meanings of LPA for individuals affected by this condition, as well as particular strategies to promote LPA in this population. Similar to my research findings, individuals with advanced cancer in other studies have indicated interest in PA participation (Burke et al., 2020; S. S. Lowe et al., 2010), but face several challenges to achieving this type of activity. From a clinical perspective, the findings of my research highlight several gaps in professional support related to LPA within cancer care. The majority of patient participants with advanced cancer did not feel they received adequate guidance or information about LPA from professionals involved in the management of their cancer (e.g., oncologists, oncology nurses). In addition, many lamented the lack of referrals to any specialized professionals (e.g., physiotherapists, personal trainers) or access to tailored programs to support their LPA. The physiotherapist participants also reported frustrations at the limited awareness, particularly among oncology care providers, concerning the benefits of LPA for people with advanced cancer and the role of physiotherapy in supporting these individuals. My findings are congruent with other research findings showing there are limitations in PA guidance and referrals from oncology care professionals to appropriate rehabilitation and exercise supports (G. Alderman et al., 2020; Cheville et al., 2012; Hardcastle et al., 2018). From the perspectives of the patient participants in my research, an important factor believed to be contributing to these supportive care gaps include common assumptions about the prognosis of advanced cancer and about the ability and willingness of patients to engage in LPA. The patient and physiotherapist participants also highlighted a traditional bio-medical focus within oncology care as well as a fragmented health care system as additional reasons for these gaps. Thus, my research findings identify important limitations in cancer care services addressing LPA within oncology practice.

In addition to challenges within oncology care systems, there were also concerns about the availability and skills of rehabilitation professionals and exercise specialists to support the advanced

cancer population. The patient participants in my research identified difficulties with finding qualified professionals who could appropriately guide them in their LPA programs. Similarly, the physiotherapists felt many patients with advanced cancer could not access appropriate physiotherapy services to support their care. Suggested reasons for this gap included the generalized lack of recognition discussed earlier in this section, as well inadequate human and financial resources⁷ to support rehabilitation initiatives in oncology. Other research has also highlighted similar concerns regarding the “*undertreatment*” of people with advanced cancer. For example, in one study, only 20-30% of physical impairments in people with metastatic breast cancer were appropriately treated with rehabilitation interventions (Cheville et al., 2008). These findings suggest there exist limitations in the availability of, and in patient access to, suitable oncology rehabilitation services.

On a similar note, there were other relevant findings in my research with respect to the skills of rehabilitation and exercise professionals working with the cancer population. A few patient participants described experiences of physiotherapy sessions and instructor-led exercise classes that were not adequately tailored to their needs. From the perspectives of physiotherapists, the majority of the participants in my research reported feeling confident in their ability to prescribe PA and regularly prescribing PA to patients with advanced cancer. However, there were also challenges identified with accessing updated information and specialized training opportunities in oncology for physiotherapy students and practicing clinicians. Similar concerns have been noted about the availability and standardization of cancer-specific instruction in physiotherapy education and subsequently, the quality of physiotherapy services in oncology (Dunphy & McNeely, 2022; Sheill, Guinan, O Neill, et al., 2018; Ten Tusscher et al., 2020). Therefore, this research identifies resource limitations in the capacity of different

⁷ This point was briefly mentioned within the manuscripts presented in Chapters 3 and 4, but there were other data to support this concern. These findings may be explored further in other future work.

professionals, including physiotherapists, to adequately support LPA and other supportive care needs in the advanced cancer population.

Finally, along with access to specialized professionals, gaps within current cancer programs addressing LPA were also identified. The patient participants described experiences of being excluded from cancer exercise and research programs, or participating in community-based LPA programs that were not appropriately tailored for them. As noted in other research as well, there were also concerns regarding the accessibility of LPA programs, particularly in terms of location and cost (Mikkelsen et al., 2019; Paltiel et al., 2009). In their work exploring PA in a hospice care setting, Burke et al. (2020) identified similar challenges in access to appropriate PA programs, with respect to transportation and specialized equipment, as well as a lack of policy-level support to sustain funding and resources for integrated PA delivery. Thus, these findings assist the recognition of important gaps in professional cancer care services addressing LPA for people with advanced cancer. Moreover, my research indicates a particular need for cancer resources and supports that are accessible, interprofessional, and collaborative in nature.

Patient-Centered Approach

Earlier in this section, I discussed several important themes highlighted in my dissertation research exploring LPA in people with advanced cancer. In particular, there are diverse complexities associated with diagnosis of advanced cancer and considerations of personal goals, intention, and meaning within the context of LPA participation. Tailored strategies to promote LPA in the advanced cancer population have also been described. These considerations circle back to a key element concerning the clinical care of people with advanced cancer. A patient-centered approach to LPA is an important central theme emphasized throughout this dissertation research. The patient participants in my research recognized the need for “*personalized*” LPA support to address gaps in cancer care and

discouraged the adoption of a “*one-size-fits-all*” solution. They identified several factors that could influence LPA participation, including fluctuations in cancer status, treatment side effects, past experiences, diverse activity preferences, and socio-environmental factors. Similarly, the physiotherapist participants acknowledged the importance of tailoring PA guidance according to individually meaningful goals and cancer-related factors when working with this patient population. Other relevant research has also encouraged this personalized approach to LPA, through the consideration of personal factors and functional ability (Burke et al., 2020; Cheville et al., 2012; Mikkelsen et al., 2019). Collectively, these findings suggest the need for comprehensive assessments of factors impacting LPA in patients, as well as clear communication between patients and health professionals to establish patient-centered goals and priorities related to LPA.

Along with a personalized approach to LPA, findings from both of my dissertation studies with participants highlight the need for interdisciplinary services in order to address the range of diverse issues experienced by individuals living with advanced cancer. Other challenges that are common in this patient population include pain, nutritional issues, and psychological concerns (Henson et al., 2020). The patient and physiotherapist participants in my research indicated the need for different types of professional support, such as nutritional interventions and occupational therapy strategies. Thus, these findings further justify individualized supportive care that considers the following components: (a) comprehensive, regular assessment of cancer and treatment status, clinical presentation and concerns, along with individual and contextual factors; (b) open communication with patients and families regarding personal goals, priorities, expectations, and needs; (c) interprofessional collaboration and support; and (d) tailored supportive care interventions (Hui et al., 2021; Lacey et al., 2019; Olver et al., 2020). Through these considerations, an oncology care model that is patient-centered and interprofessional would serve as an optimal clinical framework to facilitate safe, meaningful LPA participation in the advanced cancer population.

A patient-centered approach consists of *“providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions”* (Committee on Quality of Health Care in America & Institute of Medicine, 2001). This is important and relevant to my research because of the focus on tailoring LPA support to individual needs and preferences, as well as identifying LPA priorities and clinical outcomes that are meaningful to patients. However, it is important to note the recent shift towards the promotion of person-centered care, which further highlights *“social, mental, emotional, and spiritual needs, as well as individuals’ strengths, weaknesses, preferences, and values”* (Lines et al., 2015). There are several commonalities between the concepts of patient-centered and person-centered care, with respect to empathy, communication, individual and family involvement, as well as holistic and coordinated care (Håkansson Eklund et al., 2019; Lines et al., 2015). The findings of my research support the need to further integrate these components into the clinical care of people with advanced cancer. As person-centered care focuses on the whole person and their diverse needs, this approach may be especially valuable for people experiencing chronic health conditions, such as cancer (Kumar & Chattu, 2018). There remain challenges with defining and differentiating the two approaches. For example, there appears to be a particular emphasis on function in research adopting a patient-centered approach, while person-centered research often focuses on meaningfulness (Håkansson Eklund et al., 2019). However, both approaches represent a necessary shift away from a traditional bio-medical perspective and towards care that addresses different needs and preferences in individuals. Patient-clinician communication, shared decision-making, and care coordination have been identified as essential components of patient-centered, high-quality cancer care (Levit et al., 2013; Nekhlyudov et al., 2014). My research justifies the need to incorporate these elements when designing LPA and other supportive care resources for individuals with advanced cancer. That said, future work may examine how to clearly outline a person-centered approach and explore its integration into advanced cancer care.

Role of Oncology Care Providers

To further enhance patient-centered, interprofessional, and coordinated care, it is necessary to delineate the roles of different professionals involved in supporting the advanced cancer population. Oncology care providers, particularly oncologists, are considered the focal point of cancer diagnostic and treatment support within the healthcare system. Oncologists are also often viewed by patients with advanced cancer as the professionals responsible for coordinating different aspects of cancer care (Mayer et al., 2015). With respect to LPA, the patient and physiotherapist participants in my research highlighted the role of the oncologist as a key source of information and guidance. This has also been identified in similar research with individuals diagnosed with advanced lung cancer (Cheville et al., 2012). In my study with patient participants, there was a desire for information from oncology care providers about LPA, nutrition, and other aspects of health, following initial diagnosis of advanced cancer. Moreover, oncology team members, such as nurses or social workers, were considered well-positioned to assist patients in navigating the healthcare system and accessing different types of interdisciplinary care, including LPA support. Such perspectives are also supported by literature which advocates for more robust cancer care teams, characterized by interprofessional communication and collaboration, as well as patient-centered communication and assistance for patient navigation (Mayer et al., 2015; Pedersen & Hack, 2010). Therefore, my findings reinforce the essential roles of oncology care providers in offering LPA information and facilitating referrals to different types of professional support, in order to address diverse supportive care needs in the advanced cancer population.

With respect to professional support for LPA, specific preferences that were identified in my research include individual consultations with specialized rehabilitation and exercise professionals, as well as tailored LPA programs for the advanced cancer population. The implications of these findings further indicate the importance of interprofessional collaboration and integrated care models to

incorporate regular LPA support within standard cancer care (Dennett et al., 2017). The American College of Sports Medicine's Exercise Is Medicine Initiative has been proposed to facilitate the integrated delivery of exercise information to people following diagnosis of cancer (Schmitz et al., 2019). Two components of this model include routine assessment and guidance related to exercise by oncology care providers, as well as referrals to specialized rehabilitation professionals for further individualized support. This model may be particularly valuable to implement in the care of people with advanced cancer, who face varying cancer-related challenges, but can also gain several health benefits from regular participation in LPA. Therefore, my dissertation findings endorse the application of such models to promote exercise and other types of LPA in standard oncology practice and support their inclusion of individuals living with advanced cancer.

Role of Physiotherapists

In the previous section, I clarified the roles of oncology care providers in providing LPA guidance and assisting with patient navigation. My research also helps outline the role of rehabilitation professionals, particularly physiotherapists, in the care of people with advanced cancer.⁸ As described earlier, the patient participants desired access to rehabilitation and exercise professionals, who had specialized training in working with the advanced cancer population. Some suggested examples included physiotherapists, personal trainers, as well as yoga instructors. Moreover, important elements of professional LPA support identified in my research include integration within standard cancer care services and offered at regular intervals during the fluctuating trajectory of advanced cancer. There was a particular emphasis on professional cancer-specific guidance for safe modifications and appropriate progression in LPA. Participants in other studies have also acknowledged the value of PA guidance and

⁸ This point is to acknowledge that while my research focuses on physiotherapists, there are different rehabilitation professionals who can be involved in and contribute to the care of people with advanced cancer. The practical implications of my work may extend to other rehabilitation professions as well.

support from qualified health professionals, such as physiotherapists or nurses (Cheville et al., 2012; Paltiel et al., 2009). In the work by Gulde et al. (2011), patients with cancer in palliative home care settings highlighted the roles of physiotherapists as “*tutor*” and “*motivator*”, with respect to promoting appropriate PA. Thus, these findings collectively indicate that patients with advanced cancer would likely appreciate and benefit from professional LPA support offered by specialized physiotherapists or other health professionals.

From the perspectives of the physiotherapist participants, there was a shared recognition of the lack of appropriate supportive care for the advanced cancer population, a population that was particularly “*under-serviced*” with respect to physiotherapy. The oncology physiotherapists also desired standardized, integrated, and routine access to physiotherapy services for individuals living with advanced cancer. They generally believed PA was safe and important for these patients and felt confident in their ability to prescribe PA. The physiotherapists also described knowledge of key considerations to promote PA, such as addressing cancer-related issues (e.g., bone metastases, peripheral neuropathies, fatigue, lymphedema), considering personal factors, collaborating with other health professionals, and tailoring PA recommendations. Such considerations are in line with current guidance to facilitate exercise participation in the cancer population (Campbell et al., 2019, 2022; Maltser et al., 2017; Segal et al., 2017; Wolin et al., 2012). These published recommendations also suggest elements of medical clearance and pre-exercise assessment, adapted exercise programming, and professional supervision. My findings support current recommendations indicating that specialized physiotherapists may be particularly well-suited to guide safe exercise in individuals experiencing challenges due to advanced cancer, such as bone metastases (Campbell et al., 2022). Furthermore, my research highlights a necessary focus in physiotherapy on goals and activities that are meaningful to patients. This concept was particularly important to the patient participants as well, and something they wished was considered further within their cancer care experiences. This research identifies parallels

between the care preferences of individuals with advanced cancer and the values and approaches of physiotherapists towards patient care in oncology. Together, these findings indicate that trained physiotherapists, as well as other rehabilitation and exercise professionals, may play a valued role in recognizing patient-centered goals and facilitating safe, meaningful PA in people with advanced cancer.

In addition to LPA promotion, the physiotherapist participants in my research identified important overarching roles of physiotherapy in the care of people with advanced cancer. One key aspect of physiotherapy practice was optimizing functional activity and independence in this patient population. Examples of physiotherapy goals described by the participants included facilitating daily activities, preserving mobility, and supporting caregivers. Moreover, several physiotherapists also discussed the management of symptoms, such as pain, fatigue, breathlessness, and edema, in the advanced cancer population. They reported the use of techniques and modalities common in physiotherapy practice, including positioning, breathing techniques, compression garments, massage, acupuncture, and therapeutic exercise, in order to alleviate symptom burden in these individuals. These findings complement other research showing potential benefits with different rehabilitation strategies to ameliorate symptom concerns and functional status in this population (Berger et al., 2015; Bernabeu-Wittel et al., 2021; Chapman et al., 2022; Gupta et al., 2021; Henson et al., 2020; Hökkä et al., 2014; Pyszora et al., 2017; Shallwani & Towers, 2018; Swarm et al., 2019). Moreover, my research supports the model proposed by Barnes et al. (2020) outlining the integration of physiotherapists within cancer care. The predominant roles of physiotherapists in this model include prospective, regular functional screening, along with tailored rehabilitation and exercise strategies, particularly to manage functional concerns (Barnes et al., 2020). Therefore, my findings further highlight the potential roles of rehabilitation professionals, particularly physiotherapists, in promoting LPA, optimizing functional capacity, and managing symptoms in the advanced cancer population.

Interestingly, the possible contributions of physiotherapy and other targeted rehabilitation interventions in addressing functional concerns and alleviating symptoms were not well recognized by the patient participants in my research. This may be attributed to the noted lack of integration of rehabilitation professionals within cancer care. Moreover, both the patient and physiotherapist participants highlighted limitations in the cancer-specific skills and training of physiotherapists. Together, these findings suggest there are varying levels of oncology training and comfort in physiotherapists working with the cancer population in different clinical settings. Thus, my findings distinguish important roles of rehabilitation professionals in supporting the advanced cancer population, but also justify the need for further work to improve the training of physiotherapists and to enhance their integration into the care of people with advanced cancer.

LPA Programs and Resources

Along with access to specialized rehabilitation and exercise professionals, there was an identified need for tailored LPA programs and resources, integrated within standard cancer care as well as within accessible community-based settings. This information is based primarily on the findings with patient participants. Important elements of such programs that were identified include professional supervision and guidance, appropriate modifications for cancer-related concerns, as well as respect for diverse activity preferences. These findings are congruent with previous research that suggests the need for programs and resources that are adapted for the advanced cancer population, as well as individualized supports developed according to patient preferences and enjoyment (Burke et al., 2020; Cheville et al., 2012; Mikkelsen et al., 2019). In addition to tailored and diverse activities, the inclusion of group settings was emphasized to provide opportunities for social connections. My research findings complement the findings of other studies, indicating the importance of social connections in LPA as particularly meaningful for the advanced cancer population (Belchamber, 2009; Gulde et al., 2011;

Mikkelsen et al., 2019; Paltiel et al., 2009; Turner et al., 2016). As described earlier, social interactions can help facilitate social support, particularly emotional support, as well as foster motivation and accountability within LPA. Therefore, these findings indicate the need to specifically integrate elements of tailored professional support and group-based options in LPA resources designed for the advanced cancer population.

Along with these components, my research highlights that there are other important considerations related to accessibility in LPA programs. Firstly, the affordability of such resources was emphasized by the participants in my research. Financial challenges have been found to be common in people with advanced cancer, likely attributed to changes in employment as well as the costs associated with cancer for patients and families (Cardoso et al., 2016; Longo et al., 2021). My findings suggest the costs of LPA programs need to be considered to minimize additional financial burden on individuals with advanced cancer. Secondly, the availability of LPA services in appropriate hospital-based or community-based locations was suggested in my research and in other research as well (Mikkelsen et al., 2019; Paltiel et al., 2009). Considerations related to location include transport and parking options, access to proper equipment and space, as well as the above-mentioned integration of professional support. While in-person, group-based settings were preferred, the participants in my research recognized the need for flexibility in the delivery of LPA programs, for example, by offering online options. Thus, relevant practical implications of my work include the identification of different considerations that can help inform the design of LPA programs for the advanced cancer population.

Finally, another notable consideration related to the design of LPA resources that was brought up in my research was cultural appropriateness. Cultural and socioeconomic factors can deeply impact access to cancer-related information and support in individuals diagnosed with cancer (Surbone & Halpern, 2016). In my research, one participant with stage 4 cancer highlighted the need for culturally appropriate LPA programs, and recommended partnerships with community resources, such as

Indigenous friendship centres and religious organizations. Through their work with Inuit cancer survivors and family members, Enuaraq et al. (2021) have identified important components of culturally safe cancer survivorship programs. These include access to traditional practices (e.g., crafting, land-based activities, spiritual practices), clear communication (e.g., language and non-verbal cues, Indigenous-based resources, patient navigator, health professional awareness), and family involvement (family-centered care) (Enuaraq et al., 2021). Besides Indigenous groups, other cultural communities have also been found to have distinct needs related to information and support in their cancer care (Bedi & Devins, 2016; Haynes-Maslow et al., 2016; R. A. Jones et al., 2011; Kwok & White, 2014). Within the context of my work, these findings indicate the need to consider cultural factors in leisure activities and enhance the accessibility and suitability of LPA support for people of different backgrounds. Further work is warranted to explore how to design and deliver LPA resources that are culturally appropriate and safe within supportive cancer care. Together, these research findings can help inform practical considerations and support the recognition of research priorities, in order to enhance the development of appropriate supportive care strategies for the advanced cancer population.

Summary of Integrated Discussion

In this discussion section, I highlight key findings of my dissertation research and recognize important practical implications of this work. To summarize, LPA participation in people with advanced cancer involves considerations of the diverse complexities associated with this health conditions, as well as of personal meanings of LPA. Through this research, I identify useful strategies reported by individuals with stage 4 cancer and by oncology physiotherapists to facilitate safe, meaningful LPA participation in this population. However, my work detects important gaps in professional support for LPA in people living with advanced cancer and guides clinical initiatives to improve supportive cancer care resources.

To address these limitations in clinical practice, a patient-centered, interprofessional, and integrated approach can facilitate the delivery of LPA support for the advanced cancer population. In particular, oncology care providers can play a valuable role in providing LPA information following cancer diagnosis and referring to specialized professionals and programs for tailored support. Trained rehabilitation professionals, particularly physiotherapists, can assist patients with advanced cancer through offering tailored LPA recommendations, as well as through optimizing functional independence and managing symptoms. In addition, accessible community-based LPA programs and resources can fill in gaps to improve the cancer care experiences of this patient population. Thus, there are important practical implications of my dissertation research in informing the development and integration of LPA resources within supportive cancer care, particularly from a rehabilitation perspective. In the next section, I describe the implications of this research for future educational and research initiatives in the areas of supportive cancer care and rehabilitation oncology.

Educational and Research Implications

Educational Implications

As described in the previous section, there are important gaps in professional support related to LPA for the advanced cancer population. One factor identified to be contributing to these gaps consists of the limited recognition of oncology care providers concerning the safety and benefits of LPA for the advanced cancer population. Moreover, this limited awareness extends to knowledge about the role of rehabilitation professionals to support this population. Both the patient and physiotherapist participants in my research believed this poor recognition hinders patient access to appropriate support for LPA and other supportive care needs (Dennett et al., 2017). To address these gaps, Schmitz et al. (2019) have suggested that *“educational programs are needed to ensure that medical, surgical, and radiation oncologists; oncology nurse practitioners; nurses; and all other members of the cancer care team are*

cognizant of the value of exercise for their patients before, during, and after active cancer therapies.”

Strategies are greatly needed to increase knowledge in oncology care providers about the safety and effectiveness of exercise, as well as about screening and referral processes (Schmitz et al., 2021). My research further highlights the need to educate oncology care providers on the importance of LPA specifically for people with advanced cancer, as well as key considerations that are unique to this population. Moreover, educational initiatives are necessary to enhance interprofessional collaboration, in order to improve the quality of integrated cancer care for patients and their families.

In addition to knowledge gaps in oncology care providers, there have been information and training needs identified in physiotherapists through my research and other research. Specific areas in oncology where physiotherapists require educational support include clinical assessment (e.g., physical examination, exercise testing), interprofessional collaboration, PA prescription, and physiotherapy management of diverse cancer-related issues, such as bone metastases and lymphedema (Dennett et al., 2021; Dunphy & McNeely, 2022; Sheill, Guinan, O Neill, et al., 2018; Ten Tusscher et al., 2020). As noted in my research as well, information and training needs have been identified in both physiotherapy students and practitioners alike (Dunphy & McNeely, 2022; Schmitz et al., 2021). These needs may be attributed to overall limitations in cancer-specific training opportunities, as well as variability in oncology content within physiotherapy entry-to-practice educational programs (Dunphy & McNeely, 2022). These findings further justify current initiatives aimed at improving specialized knowledge in rehabilitation and exercise specialists to work with the cancer population (Campbell et al., 2022; Dennett et al., 2022; Schmitz et al., 2021). Educational tools that integrate evidence-based and expert knowledge, and are accessible (e.g., through e-learning) can be useful to improve oncology training for these professionals, including physiotherapists (Dennett et al., 2022; Schmitz et al., 2021). Furthermore, targeted efforts are needed to enhance the availability, quality, and standardized delivery of such resources. These initiatives may help increase the capacity of qualified rehabilitation professionals and support the ability

of physiotherapists within different clinical settings to work safely with people with cancer. My research indicates specialized knowledge in physiotherapists is particularly important to manage the diverse, complex needs of the advanced cancer population. Improving the availability and readiness of physiotherapists can help *“ensure that accessing high-quality, oncology-specific physical therapy becomes the standard of care for all patients with a diagnosis of cancer”* (Dunphy & McNeely, 2022). Therefore, my dissertation research supports the development of educational strategies targeting knowledge gaps and training needs in oncology care providers and rehabilitation professionals, particularly physiotherapists.

Along with enhancing knowledge in health professionals, there is also a need for better developed patient education tools incorporating LPA information, as well as standardized delivery of these resources within oncology practice. As noted in my findings from the scoping review, current educational materials for people with advanced cancer are limited in providing appropriate, updated information on safe activity and exercise (Canadian Cancer Society, 2017; ESMO Palliative Care Working Group, 2011; National Cancer Institute, 2020). Patient education resources offered through the use of online portals may facilitate the routine, integrated delivery of LPA information by oncology care providers in clinical practice (Schmitz et al., 2019). Such initiatives could facilitate the widespread dissemination of resources to people with advanced cancer and potentially prompt clinical discussions for information and referrals that are more personalized in nature. Further efforts are needed to support the development and implementation of patient education materials addressing LPA and to promote their routine use within standard cancer care.

Research Implications

In addition to educational priorities, there are several research implications identified through my work. From a population perspective, I aimed to include a diverse sample of participants with stage 4

cancer. The patient participants in my research had different types of cancer diagnoses, ranged from recently diagnosis to long-term, and represented diverse age groups. Other population-related research gaps that still need to be addressed include studies with individuals with primary diagnoses besides breast and lung cancer, male participants, as well as people that are less physically active. In addition, there remains a need to further explore other leisure activities, besides exercise programs, in the advanced cancer population. My research demonstrates people with advanced cancer value and appreciate different types of LPA, such as mind-body activities (e.g., yoga, QiGong), dance, outdoor activities, as well as recreational sports. Further research is needed to explore the safety, feasibility, and experiences of such activities, particularly in people facing complex challenges due to advanced cancer. Moreover, my findings highlight distinct issues experienced by these individuals, such as functional problems, burdensome symptoms, and complex psychosocial challenges. Thus, it would be valuable to direct further work towards exploring and understanding diverse rehabilitation needs in this population. In addition, research is needed to examine the impact of LPA and other rehabilitation strategies on outcomes that are important, but not well studied in people with advanced cancer. Examples of such outcomes include functional independence, treatment outcomes (e.g., tolerance, response), and cancer-related outcomes (e.g., progression, survival). Such research would shed light on the range of concerns experienced by people with advanced cancer, as well as help understand potentially beneficial rehabilitation approaches for this patient population.

Along with these research implications, there is a need to further explore the integration of LPA guidance and rehabilitation support within cancer care models. For example, the model proposed by Barnes et al. (2020) describes the integration of physiotherapists in routine screening of functional mobility, in offering exercise supervision and support, and in providing other targeted rehabilitation interventions, as needed. My research offers additional insight on the specific roles of oncology care providers and rehabilitation professionals in clinical oncology practice with people diagnosed with

advanced cancer. However, little is currently known on the value of implementing such models for the advanced cancer population, particularly for outcomes such as patient experience and health care utilization. Moreover, research is needed to develop and examine educational initiatives aimed at increasing knowledge related to LPA in oncology care professionals and improving the clinical knowledge and skills of physiotherapists. Therefore, there are key research and educational implications of my dissertation work that can clearly guide future initiatives in this area. In the next section, I further highlight the strengths and limitations of my dissertation work.

Strengths, Limitations, and Future Directions

In this section, I describe the strengths and limitations of my research, as well as suggest future directions. Specific limitations of the three individual studies have been described earlier within Chapters 2, 3, and 4 of this dissertation. Here, I focus on the general strengths and limitations of my overall research approach and methodological decisions.

One particular strength is the overarching pragmatic paradigm informing my dissertation work. This view has contributed to the identification of diverse research objectives and the adoption of a practical, action-oriented approach within this research. Moreover, pragmatism has permitted the use of different methodologies, including interpretive-description and mixed-methods, as well as the inclusion of multiple data sources and data collection methods to explore the topic of interest. Through varied approaches and perspectives, these methodological strategies have resulted in valuable aspects of breadth and depth within the knowledge obtained through this work. However, limitations of this approach include the challenges of managing large amounts of data and achieving an optimal balance of comprehensiveness and detail within the analytic interpretations, in order to appropriately address the original research objectives. For example, the 92 articles identified in the scoping review provided a broad, comprehensive overview of the current research exploring LPA in people with advanced cancer.

However, the quantity and heterogeneity of the included articles made it challenging to analyze information from the studies in greater depth. Similarly, the interviews with the oncology physiotherapists offered detailed information on their general perspectives and experiences of working with advanced cancer. As the emphasis of my research is related to LPA in people with advanced cancer, the analysis of the physiotherapists' interview transcripts was limited to data pertinent to the initial research objective. Thus, a pragmatic paradigm helped achieve a simultaneously broad and detailed understanding of my research topic, but required careful deliberation and navigation during the processes of data management and analysis.

Another related advantage of this approach is that other information collected through the studies in my dissertation work can support future research inquiries. For example, the scoping review methods and findings may serve as the foundational framework for a subsequent meta-synthesis of qualitative research exploring LPA in people with advanced cancer. In addition, contextual information on the impact of the COVID-19 pandemic on patient experiences of LPA was not explored within this dissertation, but may be examined in detail to address future research questions specifically on this topic. Similarly, other aspects of physiotherapy practice with the advanced cancer population, beyond PA and exercise, may be further investigated in subsequent work. Therefore, this research can provide the groundwork for designing and implementing future research efforts focused on advanced cancer in the areas of supportive cancer care and rehabilitation oncology.

Additional strengths and limitations of my dissertation research revolve around the challenges with defining key concepts. An important element of this research is the explicit focus on LPA, which is the leisure domain of PA. As there is often ambiguity between the terms PA, LPA, and exercise, it was necessary to clearly define these terms and to intentionally establish the focus on LPA throughout this work, including the three individual studies. The criteria for the scoping review and the questions designed for the interviews with the patient and physiotherapist participants were deliberately clear in

their emphasis on LPA. This effort was valuable in providing clarity on the subject matter and identifying important considerations related to this topic. For example, the scoping review findings further justified the decision to explore LPA, due to the lack of research noted on leisure activities besides exercise. The specific emphasis on LPA was also instrumental in helping the patient participants identify the diversity of activities they engaged in and enjoyed, as well as elaborate on the meanings of LPA for them. For the physiotherapists, the concept of LPA inspired relevant comments related to understanding meaningful goals in their patients with advanced cancer. These observations support the need for clear identification of PA-related concepts that are explored within research studies.

One exception to this deliberate effort of focusing on LPA in my research consisted of the survey that was conducted with the physiotherapist participants. The survey questions were obtained from a survey previously developed for use with Irish physiotherapists (Sheill, Guinan, O'Neill, et al., 2018). Through these survey questions, I collected information about the views of physiotherapists towards PA and their PA-related recommendations and concerns for two clinical case scenarios with advanced cancer. The majority of considerations that were identified by the participants in this research were actually based on PA that was leisure in nature (e.g., exercise, golf, gardening). That said, as the survey questions referred to PA, and not LPA, I could not make any definitive conclusions about LPA within the analysis of the survey data. However, in the follow-up interviews with the physiotherapists, I was able to clarify these points and gain knowledge about their perspectives specifically related to LPA and exercise. Thus, these deliberations further justify the need to clearly distinguish the different types of PA and to explore these categories in greater depth within research contexts. Moreover, mixed-methods approaches in PA research can help supplement and clarify quantitative findings through the collection of detailed qualitative information.

It is important to note that there are also limitations to applying a research focus on LPA. Other types of activity, such as household or occupation, may be of particular importance for the advanced

cancer population (la Cour, Johannessen, et al., 2009). As noted in the study by Chevillat et al. (2012) with stage 3-4 lung cancer patients, daily life activities can also be viewed as a form of exercise for some individuals. In my research with participants with stage 4 cancer, other life activities were explored as a challenge to LPA participation, and as a consideration when finding intention and balance related to LPA. However, the narrow focus of my interview questions may have limited the experiences and perspectives that were shared through this work. Therefore, it might be worthwhile to further explore LPA within the context of daily life activities and associated priorities.

Similarly, advanced cancer is a particularly broad term that has been challenging to define within research and clinical contexts. During the scoping review, I adopted a very broad description of advanced cancer, in order to extensively scope the literature relevant to my topic of interest. The review findings further highlighted the heterogeneity of this patient population and contributed to my recognition of important differences in the clinical presentations and expected prognoses between various cancer types and stages (Canadian Cancer Statistics Advisory Committee, 2018). Therefore, it was necessary to be more precise in defining advanced cancer for my research study with patient participants. This reflection resulted in the decision to include people with stage 4 / metastatic cancer in the study with patient participants, even though non-metastatic cancers can be advanced as well (Haun et al., 2017). The criterion of stage 4 cancer still resulted in a wide-ranging description of advanced cancer for this research, which has its own advantages and disadvantages. The main advantage is a diversity in the study participants, which represents variations within the advanced cancer population and permits the understanding of shared commonalities and individual differences in such a diverse population. For example, since I included stage 4 breast and non-breast cancer diagnoses, I learned important information about the impact of LPA on appetite and weight. In people with breast cancer, LPA contributed to counteracting the effects of weight gain, which is common with treatment for metastatic breast cancer. Meanwhile, in a participant with a non-breast cancer diagnosis experiencing

loss of appetite, it supported the stimulation of appetite and contributed to stabilization of muscle mass and weight. However, the disadvantage of applying a broad definition of advanced cancer is further related to its heterogeneity and the difficulty in capturing all the variations that may exist within such a diverse population. Thus, these reflections highlight the need for continued identification of well-defined participant criteria and characteristics in research with advanced cancer. Moreover, there remains a need to target research initiatives in under-represented subgroups within this population, in order to comprehend the full range of experiences of advanced cancer.

To further expand on representations of advanced cancer, there are additional considerations related to the study populations included in my research. One strength includes a diverse sample of participants with stage 4 cancer, particularly in terms of cancer type, time since diagnosis, and age. These elements were important to address the population-related gaps noted in my scoping review. However, the majority of the patient participants identified as female and over half had diagnoses of breast cancer, potentially limiting the transferability of the research findings to people of other genders and with non-breast cancer types. Another potential limitation of my research is related to cultural and socioeconomic factors. Income and education levels were relatively high in the patient participants, which may have influenced their engagement in LPA behaviour (O'Donoghue et al., 2018). Moreover, I did not collect information on race and cultural background. Given that cultural and socioeconomic factors can impact access to cancer-related information and support (Surbone & Halpern, 2016), it is important to deliberately consider these elements and ensure future research efforts are more inclusive of participants representing under-represented socioeconomic and cultural subgroups.

Another consideration related to the diversity of the patient participants is the finding that many participants were engaging in regular LPA prior to and following diagnosis of stage 4 cancer. This trend consisted of a potential limitation in the perspectives explored within this research, as these participants may have had more positive views and experiences of LPA than those who were less active.

However, as mentioned within the integrated discussion, it is also important to note these participants had lived experiences of advanced cancer and shared practical and applicable strategies to promote LPA in this population. Thus, this information can be particularly valuable in guiding clinical and educational initiatives in this area.

Similarly, the physiotherapists in my research were volunteer participants recruited primarily from the Canadian Physiotherapy Association Oncology Division mailing list. Although there was a wide range of experience levels, these physiotherapists likely represented professionals with detailed knowledge of cancer-specific considerations, and those particularly committed to improving clinical practice and research in the area of oncology. Therefore, the findings from this research may not represent the knowledge, skills, and perspectives of physiotherapists in general, or even of oncology physiotherapists with less specialized training and clinical experience. However, like the patient participants, there was particularly useful information offered through these perspectives on the key roles of physiotherapy in advanced cancer care, which helps inform the practical implications of this research.

To summarize, in this section, I highlight several strengths and limitations of my dissertation work, mainly around adopting a pragmatic view, focusing on LPA, and representing advanced cancer. These reflections can be helpful in informing subsequent research inquiries and guiding methodological considerations in the design of future research. In the next and final section of this chapter, I provide a conclusion for my dissertation research with a particular focus on the overall findings and key implications of my dissertation work.

Conclusion

As survival rates of advanced cancer continue to increase, there is a crucial need to improve the cancer care experiences of individuals living with this challenging diagnosis. There is growing awareness

of the benefits of exercise and other types of LPA for people with cancer, including advanced cancer. The overall purpose of my dissertation research is to explore LPA in people with advanced cancer, particularly from the perspectives of individuals with stage 4 cancer and oncology physiotherapists with clinical experience in advanced cancer. Through a scoping review, I provided a comprehensive overview of the literature and identified distinct research gaps. In a qualitative study with Canadian adults with stage 4 cancer, I described elements of diversity, fluidity, and intentionality within experiences of LPA. Moreover, there are important health benefits and psychosocial meanings associated with LPA participation, and tailored professional support related to LPA may be valuable for these individuals. Finally, in a mixed-methods study with Canadian oncology physiotherapists, there was a recognition of the safety and benefits of PA for the advanced cancer population, as well as key considerations to promote safe, meaningful PA. The roles of physiotherapy in LPA support, functional optimization, and symptom management within the context of oncology care were also highlighted. Thus, my dissertation work generates new research knowledge on the distinct LPA experiences and supportive care needs of people with stage 4 cancer, as well as the clinical knowledge, skills, and potential contributions of oncology physiotherapists working with advanced cancer. These findings can help inform the development and integration of tailored supportive care resources targeting LPA in the advanced cancer population, particularly from a rehabilitation perspective.

Implications of this research support the recognition of cancer-related complexities and distinct meanings of LPA in advanced cancer. Moreover, this work highlights specific clinical recommendations and strategies which may be useful to facilitate LPA participation in people living with this health condition. In order to address gaps in supportive cancer care, clinical initiatives targeting LPA should consider elements of patient-centered care, interprofessional collaboration, integrated models, as well as accessibility. Furthermore, educational priorities include addressing information and training needs in

oncology care providers and physiotherapists, so that these health professionals can better support safe, appropriate LPA participation in the advanced cancer population.

Finally, these dissertation findings are helpful to guide future research efforts. In people with advanced cancer, additional research is needed to address population-related gaps, explore diverse leisure activities of interest, and examine other rehabilitation needs. Moreover, further development and evaluation of educational strategies, LPA resources and programs, as well as integrated care models can support the translation of research findings to clinical practice. Therefore, the findings of my dissertation research offer valuable insight about patient and professional perspectives of LPA in people with advanced cancer. This work can support future efforts aimed at enhancing supportive care experiences for individuals living with advanced cancer.

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APPENDICES

Appendix A: Scoping Review Protocol

Appendix B: Additional Definitions and Descriptions

Appendix C: Recruitment Materials

Appendix D: Data Collection Tools

Appendix E: Ethical Approval and Consent Forms

Appendix F: Contribution of Collaborators

Appendix A: Scoping Review Protocol

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Leisure physical activity in people with advanced cancer: a scoping review protocol

ABSTRACT

Background: With the increasing survival rates associated with advanced cancer, more people are living with the substantial effects of this health condition and its treatments. Despite reported difficulties in daily activities and potential benefits with leisure physical activity (PA), there is limited knowledge on participation in leisure PA in people with advanced cancer.

Objective: The objective of our scoping review is to examine and map the literature on leisure PA in people with advanced cancer. Specifically, we wish to: a) examine the extent, range and nature of literature on leisure PA in people with advanced cancer; b) report on how leisure PA has been explored in the identified body of literature and; c) report on the use and definitions of terms to describe the advanced cancer population in the identified body of literature.

Methods: The following steps will be taken to perform a scoping review on leisure PA in people with advanced cancer. A peer-reviewed literature search of 11 electronic databases and supplementary material will be conducted. Two reviewers will independently scan titles and abstracts and subsequently review full texts to determine eligibility according to the article selection criteria. Relevant data will be extracted from the included studies by two reviewers. A narrative summary of the findings will be presented with a descriptive analysis of the evidence base and a thematic analysis of content-specific information.

Conclusion: This scoping review will provide a comprehensive understanding of the current literature on leisure PA in people with advanced cancer and will identify gaps in knowledge on this topic to guide future research inquiries.

Keywords: neoplasms; palliative care; leisure activities; exercise; rehabilitation

BACKGROUND

Advanced cancer

In the US, it is estimated that 1.7 million people were diagnosed with cancer in 2017 and the lifetime risk of developing cancer is around 38.5% [1]. The National Cancer Institute has defined advanced cancer as *“cancer that has spread to other places in the body and usually cannot be cured or controlled with treatment”* [2]. Advanced cancer may be categorized as locally advanced (stage 3) or metastatic (stage 4) [3]. Challenges with measuring the prevalence of advanced cancer have been recognized, primarily due to difficulties with tracking cases of early-stage cancer who develop disease recurrence or progression [1, 4]. Recent estimated figures report that while 15,000 women were expected to be diagnosed with metastatic breast cancer in the US in 2017, there is a prevalence of more than 150,000 women currently living with the disease [1, 4].

Progress in therapy options and efficacy has contributed to significant improvements in survival rates for the cancer population, including cases of advanced cancer.[5] However, despite the improvement of cancer control and palliative treatments, people living with advanced cancer face a myriad of physical and psychosocial challenges, which may impact their quality of life and functional well-being [6, 7, 8, 9, 10, 11]. Research findings support the notion that unmet information [12, 13, 14, 15] and supportive care [6, 15, 16, 17] needs are common in this population.

Rehabilitation and physical activity

Cancer rehabilitation has been defined as *“coordinated, interprofessional care designed to enable people to maximize physical, social and psychological function within the limits imposed by the disease and treatment effects and engage in personally valued activities within their social contexts”*[18]. While the effects of cancer and its treatments on functioning have been recognized at different phases

of the disease trajectory, there is limited knowledge on the specific role of rehabilitation for individuals living with advanced cancer [19, 20, 21, 22]. However, physical activity (PA), particularly exercise, has recently gained increasing interest in the advanced cancer population, both as an aspect of physical functioning and a rehabilitation intervention strategy [22, 23, 24].

According to Pettee Gabriel et al. (2012), PA is defined as *“the behavior that involves human movement, resulting in physiological attributes including increased energy expenditure and improved physical fitness”* [25]. Four domains of PA behaviour consist of: 1) leisure (including exercise); 2) occupation; 3) household, domestic, self-care; and 4) transport. Leisure-time PA has been described by Howley (2001) as *“the activities one participates in during free time, based on personal interests and needs. These activities include formal exercise programs as well as walking, hiking, gardening, sport, dance, etc”* [26]. Quantifying PA behaviour may involve direct observation or self report to obtain information on the frequency, intensity, duration and type of activities performed, while the characteristics of human movement may be examined through the use of direct assessment instruments, such as activity monitors [25].

Leisure PA in advanced cancer

In several studies, people with advanced cancer have reported limitations with daily activities, including self-care, household activities and leisure PA participation [11, 15, 27, 28, 29]. Some of the important consequences of advanced cancer on functioning and quality of life may be amenable to targeted physical rehabilitation strategies [30, 31, 32]. Previous literature reviews on this topic have examined intervention studies and focused mainly on structured physical exercise [23, 24, 33, 34, 35, 36, 37, 38]. These reviews have reported a scarcity of high-quality evidence, but have suggested potential benefits with exercise in the advanced cancer population for various outcomes, such as physical function and quality of life.

There are several limitations in the current level of research on leisure PA in people living with advanced cancer. As previous systematic reviews have been restricted to intervention studies, these reviews have not captured related topics of relevance, such as activity preferences, facilitators and barriers or actual experiences of people with advanced cancer engaging in PA. Moreover, as noted in reviews of other cancer populations, participation in leisure activities besides structured exercise alone, such as yoga or dance, may be meaningful and potentially effective as a rehabilitation strategy to optimize outcomes [39, 40]. Given the rapidly growing body of evidence on PA in cancer [41, 42], there is an urgent need for an updated and comprehensive understanding of the scope of literature on this topic and the identification of specific gaps in the evidence base to guide future research inquiries.

Rationale

With the increasing survival rates associated with advanced cancer, more people are living with the substantial effects of this health condition and its treatments. To our knowledge, no review has comprehensively examined the literature on leisure PA in people with advanced cancer; specifically how this health condition and its treatments may impact leisure PA and how participation in leisure PA may be experienced and affect outcomes in this population. Additional complexities in this field of research include the challenges with defining and reporting on key concepts, such as advanced cancer and leisure PA. Scoping review methodology permits a broad, extensive review of the literature and may be particularly valuable to employ in understudied or complex research areas [43, 44]. The main objective of our scoping review is to examine and map the literature on leisure PA in people with advanced cancer. Specifically, we wish to: a) examine the extent, range and nature of literature on leisure PA in people with advanced cancer; b) report on how leisure PA has been explored in the identified body of literature and; c) report on the use and definitions of terms to describe the advanced cancer population in the identified body of literature.

METHODS

Our scoping review will follow the steps outlined in the methodological framework developed by Arksey and O'Malley (2005) [43] and the PRISMA-P (Preferred reporting items for systematic review and meta-analysis protocols) 2015 checklist [45] with the consideration of recent recommendations, such as the use of a deliberate approach for the literature search, study selection, data extraction and data charting procedures [44, 46, 47, 48, 49, 50].

Search strategy

The literature search strategy has been developed in consultation of the National Library of Medicine Medical Subject Headings (MeSH) resource [51], the 2011 Compendium of Physical Activities [52] and previous reviews on relevant topics [26, 53, 54, 55]. In addition, we collaborated with an interdisciplinary research team, including a librarian specialized in the health sciences [44, 46].

The first step of the literature search will involve searching for peer-reviewed scientific journal publications within the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1940-current); Cochrane Database of Systematic Reviews (CDSR) (2005-current); Database of Abstracts of Reviews of Effects (DARE) (1st quarter 2016); Cochrane Central Register of Controlled Trials (CENTRAL) (2018); Excerpta Medica Database (EMBASE) (1947-current); Medical Literature Analysis and Retrieval System Online (MEDLINE) (1946-current); Physiotherapy Evidence Database (PEDro) (1999-current); Psychological Abstracts (PsycINFO) (1806-current); US National Library of Medicine Database (PubMed) (1966-current); National Rehabilitation Information Center Database (REHABDATA) (2002-current); and Sports Medicine Database (SPORTDiscus) (1892-current). The search

strategy for MEDLINE has been provided in Appendix I. The EndNote X7.8 software (Clarivate Analytics, PA, USA) will be used to export and manage citations from different data sources.

Upon completion of the database search, the second step will involve a search of supplementary material, including systematically scanning the reference lists of all included articles as well as any additionally identified literature reviews of relevance. Based on our consultation with the librarian, we will focus the grey literature search within the publication databases of the following cancer organizations: Canadian Cancer Society (Canada), National Cancer Institute, American Cancer Society (USA), National Cancer Research Institute (UK), European Cancer Organisation, European Society for Medical Oncology (Europe), and Cancer Australia (Australia). These organizations represent key international research and patient-oriented associations, which may publish additional literature of relevance in the area of advanced cancer. Finally, to ensure the comprehensiveness of our literature search, we will run a citation analysis on articles included in the review using the Web of Science and Scopus databases.

Study selection

Relevant studies will be selected based on the inclusion criteria (**Table 1**) developed through the initial study design and the pilot testing exercise described below. Briefly, in PICO format, studies including adults diagnosed with advanced cancer (population) and exploring any aspect of leisure PA (intervention or exposure) will be selected for the review. No limitations with respect to comparators or specific outcomes will be applied. Original primary research studies with any study design and any methodology (quantitative, qualitative or mixed) will be included. Studies may include people at any phase of the disease trajectory post-diagnosis of advanced cancer (e.g. newly diagnosed, during treatment, end of life) and within any clinical setting (e.g. home-based, community-based, hospital-based, hospice care).

Upon running the literature searches, duplicates will be removed in the EndNote software and the remaining citations will be exported into the Covidence online software (Veritas Health Innovation Ltd ACN 600 366 274) for scanning. Two reviewers will independently scan titles and abstracts and subsequently review full texts to determine eligibility. A list of studies excluded during full text scanning and reasons for exclusion will be provided as an appendix. An iterative search process involving initial trial exercises, scanning articles in blocks (e.g. blocks of 50) as well as ongoing discussion and consultation between research team members will permit the clarification of discrepancies and the post-hoc refinement of inclusion criteria [44]. In cases of disagreement, consensus will be achieved through discussion or consultation with a third reviewer, as needed [47].

Although not formally part of scoping methodology, it has been proposed that setting quality criteria may be considered at this stage [46], while others have maintained that a scoping review should be inclusive towards all available literature [47]. No quality criteria will be set at this stage of our review to maintain a broad, comprehensive approach and ensure all relevant literature is examined.

- **Pilot testing of study selection procedures:** In February 2018, the research team performed a pilot testing exercise to test the literature search strategy and proposed study selection criteria. Two reviewers scanned a sample of 114 citations exported from the CINAHL database search. The first 10 titles and abstracts were reviewed together in the Microsoft Excel software (version 14.7.7) and decisions on inclusion or exclusion were determined concurrently. Following this, the remaining titles and abstracts were scanned independently in two blocks of 40 and 64. After each block, results were compared between reviewers. Consequently, one researcher reviewed the full texts of 31 articles identified during the abstract scan. The full text review and discussions with senior research team members resulted in 17 articles being included in the review. This process confirmed the feasibility of conducting the scoping review, allowed the

refinement of the selection criteria and proposed the development of data extraction and management strategies to organize information of relevance.

Table 1. Article selection criteria

Participants	The review will include studies with human adults aged ≥ 18 years who have been diagnosed with advanced cancer (e.g. locally advanced, stage 3, metastatic, stage 4, incurable, palliative). Studies on animals, human children or adolescents, or adults that have been diagnosed with early-stage cancer or non-cancer diagnoses (e.g. other health conditions, cancer prevention) will be excluded. Studies with mixed populations where people with advanced cancer have been analyzed as a separate subgroup for the concept of leisure PA will be included.
Concept	Studies examining post-cancer diagnosis leisure PA (e.g. exercise, leisure walking, sports, gardening, hiking, bowling, yoga, tai chi, qi gong, dance) will be included. Leisure PA may be considered as a main study outcome (for quantitative research), as a focus of inquiry or emerging theme (for qualitative research) or as a principal component of a study intervention. Studies examining pre-diagnosis PA or other domains of PA (e.g. household / self-care, occupation, transport) as described by the model by Pettee Gabriel et al. (2012) [25] will be excluded from this review. Studies combining multiple domains of PA to determine a total / global level of PA, but not reporting exclusively on leisure PA, will be excluded.
Context	This review will include studies of people at any phase of the disease trajectory post-diagnosis of advanced cancer (e.g. newly diagnosed, during treatment, end of life) and within any clinical setting (e.g. home-based, community-based, hospital-based, hospice care).
Types of studies	Original primary research studies with any study design and any methodology (quantitative, qualitative or mixed) will be included in the review. Literature reviews, editorials, commentaries, letters, research protocols, conference abstracts, dissertations, book chapters and books will be excluded. Only English articles with available full texts will be included.

Data extraction

Draft forms for data extraction have been developed based on the identified objectives and pilot testing exercise (**Appendix II**). These forms will be pre-tested and modified by research team members following completion of the study selection process. Relevant data will be recorded from each included article by two trained reviewers and verified by a third reviewer. Data that will be extracted include study characteristics (e.g. year, country, discipline), study type and design, methodology, population characteristics (e.g. diagnosis, stage, treatment phase), relevance of leisure PA, details on outcomes, interventions and comparators (if any) and key findings. Specific information will be recorded related to

the article descriptions of the advanced cancer population and of leisure PA. Group consultation exercises and opportunities for discussion and refinement will be considered during the data extraction process as needed [44, 46, 47].

Data analysis

A narrative summary of the findings will be presented with a descriptive analysis of the evidence base and a thematic analysis of content-specific information. While there is actually no formal quality assessment or synthesis of the findings in scoping methodology, such practices have been advocated.[44, 46, 48] Quality appraisal of included studies and synthesis of the findings will depend on the volume and heterogeneity of studies retrieved. Categorical frameworks to organize and analyze the research findings may be based on variables, such as role of leisure PA (e.g. as outcome or area of inquiry vs. as part of intervention or strategy) or population characteristics (e.g. diagnosis, phase of disease trajectory).

CONCLUSION

The proposed scoping review will provide a broad understanding of the current literature on leisure PA in adults diagnosed with advanced cancer. Limitations of this review include the focus on advanced cancer according to identified criteria and the examination of solely the leisure domain of PA. Another limitation of the study selection criteria is the omission of quality criteria and the inclusion of different study designs and types, resulting in a potential risk of bias in our review findings. The likely heterogeneity of included studies will limit our ability to assess the quality of the literature and synthesize findings. However, as indicated in scoping review methodology in cases of understudied or complex research areas, this broad, comprehensive approach will fulfill the objectives of examining and

mapping all published literature on this topic. Moreover, our scoping review will assist in developing focused, refined questions for future research inquiries.

Conflict of Interest

The authors have no conflicts to disclose.

Appendix I. MEDLINE search strategy

1. ((advance* or metasta* or stage 3 or stage III or stage 4 or stage IV or incurable or nonresectable or non-resectable or unresectable or inoperable or nonoperable or non-operable or end stage or end-stage or late stage or late-stage) adj3 (cancer* or neoplas* or carcinom* or adenocarcinom* or malignan* or tumor* or tumour* or oncolog* or cyst*)).tw.
2. exp Palliative Care/
3. (end* adj2 life).tw.
4. (last year of life or LYOL).tw.
5. palliat*.tw.
6. exp Terminally Ill/
7. hospice*.tw.
8. 2 or 3 or 4 or 5 or 6 or 7
9. exp Neoplasms/
10. (cancer* or neoplas* or carcinom* or adenocarcinom* or malignan* or tumor* or tumour* or oncolog* or cyst*).tw.
11. 9 OR 10
12. 8 AND 11
13. 1 OR 12
14. (physical* adj2 activ*).tw.
15. exp Exercise/
16. exp Exercise Therapy/
17. exercis*.tw.
18. exp Leisure Activities/
19. (leisur* adj2 activit*).tw.
20. recreation*.tw.
21. ((aerobic or cardiovascular or interval) adj2 training).tw.
22. (walking or running or jogging or cycling or bicycl* or swimming or danc*).tw.
23. ((strength* or resistance) adj2 training).tw.
24. (weightlifting or weight lifting or weight training).tw.
25. (stretch* or yoga or pilates or tai ji or tai chi or qi gong or qigong or martial art*).tw.
26. sports/ or baseball/ or basketball/ or bicycling/ or boxing/ or football/ or golf/ or gymnastics/ or hockey/ or martial arts/ or mountaineering/ or racquet sports/ or running/ or skating/ or snow sports/ or soccer/ or swimming/ or "track and field"/ or volleyball/ or weight lifting/ or wrestling/
27. (sport* or baseball or basketball or boxing or football of golf* or gymnastics or hockey or mountaineering or tennis or squash or soccer or (track and field) or volleyball or wrestling).tw.
28. (bowling or hiking or skiing or skating or snowboarding or rollerblading* or gardening).tw.
29. (active video gam* or wii or kinect or playstation move).tw.
30. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
31. 13 AND 30

Appendix II. Draft* data extraction forms

**Forms to be pre-tested and modified as needed following completion of study selection*

1. Data extraction form #1: Description of included studies

Study characteristics:			
Year of publication:			
Country of study:			
Discipline(s) of authors:			
Study type:			
Methodology:	<input type="checkbox"/> Quantitative <input type="checkbox"/> Qualitative <input type="checkbox"/> Mixed		
Study design (quantitative):	<input type="checkbox"/> Observational (cross-sectional) <input type="checkbox"/> Observational (longitudinal) <input type="checkbox"/> RCT <input type="checkbox"/> Case-control study <input type="checkbox"/> Single-group pre-post intervention <input type="checkbox"/> Case study		
Study design (qualitative):	<input type="checkbox"/> Ethnography <input type="checkbox"/> Phenomenology <input type="checkbox"/> Grounded theory <input type="checkbox"/> Descriptive <input type="checkbox"/> interpretive <input type="checkbox"/> Narrative <input type="checkbox"/> Case study <input type="checkbox"/> Other		
Population characteristics			
Number of participants:			
Age:		<input type="checkbox"/> mean <input type="checkbox"/> median <input type="checkbox"/> stdev <input type="checkbox"/> range	
Gender:		<input type="checkbox"/> n <input type="checkbox"/> % <input type="checkbox"/> n <input type="checkbox"/> %	
Cancer diagnosis:		<input type="checkbox"/> n <input type="checkbox"/> % <input type="checkbox"/> n <input type="checkbox"/> % <input type="checkbox"/> n <input type="checkbox"/> % <input type="checkbox"/> n <input type="checkbox"/> %	
Stage:		<input type="checkbox"/> n <input type="checkbox"/> % <input type="checkbox"/> n <input type="checkbox"/> % <input type="checkbox"/> n <input type="checkbox"/> % <input type="checkbox"/> n <input type="checkbox"/> %	
Phase of disease trajectory (e.g. newly diagnosed, during treatment, end of life):			
Treatment status:	<input type="checkbox"/> On active treatment <input type="checkbox"/> Off-treatment		
Treatment type:	<input type="checkbox"/> Chemotherapy <input type="checkbox"/> Radiotherapy <input type="checkbox"/> Other		
Location:	<input type="checkbox"/> Home-based <input type="checkbox"/> Community-based <input type="checkbox"/> Hospital-based <input type="checkbox"/> Hospice care <input type="checkbox"/> Other		
Study outcomes (if any)			
	<i>Construct</i>	<i>Method of assessment</i>	<i>Specific tools</i>

Measurement time points:		
Categories / themes		
Intervention characteristics (if any)		
	<i>Intervention / strategy</i>	<i>Control intervention / strategy</i>
Type of intervention / strategy:	<input type="checkbox"/> Uni-dimensional <input type="checkbox"/> Multi-dimensional <input type="checkbox"/> Clinical program <input type="checkbox"/> Other	<input type="checkbox"/> Wait-list <input type="checkbox"/> Uni-dimensional <input type="checkbox"/> Multi-dimensional <input type="checkbox"/> Clinical program <input type="checkbox"/> Other
Components of intervention:	<input type="checkbox"/> Structured PA <input type="checkbox"/> Behavioural <input type="checkbox"/> Educational <input type="checkbox"/> Other	<input type="checkbox"/> Structured PA <input type="checkbox"/> Behavioural <input type="checkbox"/> Educational <input type="checkbox"/> Other
Intervention details (e.g. aerobic, resistance, flexibility, yoga, Tai-chi, etc.):		
Location:	<input type="checkbox"/> Hospital <input type="checkbox"/> Community <input type="checkbox"/> Home <input type="checkbox"/> Hospice care	<input type="checkbox"/> Hospital <input type="checkbox"/> Community <input type="checkbox"/> Home <input type="checkbox"/> Hospice care
Supervision:	<input type="checkbox"/> No <input type="checkbox"/> Yes: _____ (professional type)	<input type="checkbox"/> No <input type="checkbox"/> Yes: _____ (professional type)
Frequency:		
Intensity:		
Duration:		
Main results		
Key findings related to leisure PA		

2. Data extraction form #2: Concept of leisure PA

Use of framework / definition to conceptualize PA:	
Identification of leisure domain:	
Assessment method (if any):	<input type="checkbox"/> Self-report <input type="checkbox"/> Interviewer-administered <input type="checkbox"/> Direct assessment <input type="checkbox"/> Other
Specific tool (if any) (e.g. questionnaire, interview, activity tracker):	
Other domains / aspects of physical activity examined:	<input type="checkbox"/> Occupation <input type="checkbox"/> Household / Self-care <input type="checkbox"/> Transport <input type="checkbox"/> Total / Global <input type="checkbox"/> Sedentary <input type="checkbox"/> Sleep <input type="checkbox"/> Other

3. Data extraction form #3: Description and criteria for advanced cancer population

Specific terms used to describe population:	
Description / definition of advanced cancer:	
Criteria used for population:	<input type="checkbox"/> Stage (____) <input type="checkbox"/> Metastatic <input type="checkbox"/> Life expectancy (____) <input type="checkbox"/> Incurable <input type="checkbox"/> Palliative <input type="checkbox"/> Other
Other notes:	

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Appendix B: Additional Definitions and Descriptions

Term	Definition / Description
Physiotherapy	<p><i>“a primary care, autonomous, client-focused health profession dedicated to improving quality of life by:</i></p> <ul style="list-style-type: none"> • <i>Promoting optimal mobility, physical activity and overall health and wellness;</i> • <i>Preventing disease, injury, and disability;</i> • <i>Managing acute and chronic conditions, activity limitations, and participation restrictions;</i> • <i>Improving and maintaining optimal functional independence and physical performance;</i> • <i>Rehabilitating injury and the effects of disease or disability with therapeutic exercise programs and other interventions; and</i> • <i>Educating and planning maintenance and support programs to prevent re-occurrence, re-injury or functional decline.”</i> (Canadian Physiotherapy Association, 2012) <p>https://physiotherapy.ca/sites/default/files/site_documents/dopen-en.pdf</p>
Physiotherapists	<p><i>“Description of physiotherapy practice: Physiotherapists are primary health care practitioners who consult and collaborate with clients and others to provide quality client-centred services. Physiotherapists contribute to keeping people productive throughout their lives by maximizing function and improving quality of life. Through evidence-informed practice, physiotherapists prevent, assess, and treat the impact that injury, pain, disease, and/or disorders have on clients’ movement, function, and health status. Physiotherapists practise both independently and as part of interprofessional teams along the health system continuum from primary to tertiary care.”</i> (National Physiotherapy Advisory Group, 2019)</p> <p>https://physiotherapy.ca/sites/default/files/competency_profile_final_en.pdf</p>
Rehabilitation	<p><i>“a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments”</i> (World Health Organization, 2011)</p> <p>https://www.who.int/news-room/fact-sheets/detail/rehabilitation</p> <p><i>“Rehabilitation addresses the impact of a health condition on a person’s everyday life by optimizing their functioning and reducing their experience of disability. Rehabilitation expands the focus of health beyond preventative and curative care to ensure people with a health condition can remain as independent as possible and participate in education, work and meaningful life roles. Anyone may need rehabilitation at some point in their lives, whether they have experienced an injury, disease, illness, or because their functioning has declined with age.”</i> (World Health Organization, 2022)</p> <p>https://www.who.int/health-topics/rehabilitation#tab=tab_1</p>
Supportive care	<p><i>“The prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care. Enhancing rehabilitation, secondary cancer</i></p>

	<p><i>prevention, survivorship and end of life care are integral to Supportive Care.” (Rittenberg et al., 2010)</i></p> <p><i>“Care given to improve the quality of life of people who have an illness or disease by preventing or treating, as early as possible, the symptoms of the disease and the side effects caused by treatment of the disease. Supportive care includes physical, psychological, social, and spiritual support for patients and their families. There are many types of supportive care. Examples include pain management, nutritional support, counseling, exercise, music therapy, meditation, and palliative care. Supportive care may be given with other treatments from the time of diagnosis until the end of life” (National Cancer Institute, 2022)</i></p> <p>https://www.cancer.gov/publications/dictionaries/cancer-terms/def/supportive-care</p>
<p>Physiotherapy knowledge</p>	<p><i>“The theoretical knowledge required for physiotherapy practice. Physiotherapy knowledge shapes, & is shaped by the profession’s constantly evolving scope of practice. Although an individual’s knowledge base will be shaped by the demands & context of their practice, physiotherapists must demonstrate how their knowledge & understanding relates to physiotherapy & their individual scope of practice.” (Chartered Society of Physiotherapy, 2020)</i></p> <p>https://www.csp.org.uk/system/files/documents/2020-05/CSP%20Physiotherapy%20Framework%20May%202020.pdf</p>
<p>Physiotherapy practice skills</p>	<p><i>“The practical (psycho-motor) skills used by the physiotherapy workforce. In order to apply physiotherapy-specific practice skills, physiotherapy values & knowledge are required. Without physiotherapy values & knowledge, physiotherapy-specific practice skills of exercise & movement, manual therapy, electro-physical modalities & other physical approaches become nothing more than a physical technique. The physiotherapy workforce also uses practical skills/techniques such as First Aid or Manual Handling that are shared with other groups of staff that work in the health & wellbeing economy. As with physiotherapy knowledge, an individual’s skill-base will evolve according to their experiences & context of practice, but practitioners must demonstrate how their skills relate to physiotherapy & their personal scope of practice.” (Chartered Society of Physiotherapy, 2020)</i></p> <p>https://www.csp.org.uk/system/files/documents/2020-05/CSP%20Physiotherapy%20Framework%20May%202020.pdf</p>
<p>Generic behaviours, knowledge & skills</p>	<p><i>“As well as its physiotherapy values, knowledge & practice skills, the physiotherapy workforce also requires generic knowledge & skills. These are behaviours, knowledge & skills used by all practitioners working in the health & wellbeing economy. The physiotherapy workforce uses these sets of generic behaviours, knowledge & skills to apply its physiotherapy values, knowledge & practice skills to maximise individuals’ potential – through its clinical, educational, leadership & research practice. This element is subdivided: behaviours, knowledge & skills for interaction; & behaviours, knowledge & skills for problem-solving & decision-making.” (Chartered Society of Physiotherapy, 2020)</i></p>

<https://www.csp.org.uk/system/files/documents/2020-05/CSP%20Physiotherapy%20Framework%20May%202020.pdf>

Generic behaviour, knowledge and skills required by physiotherapists for interaction include “*communicating, helping others learn and develop, managing self and others, promoting integration and teamwork, putting the person at the centre of practice, respecting and promoting diversity.*” (Chartered Society of Physiotherapy, 2020)

Generic behaviour, knowledge and skills required for problem-solving and decision-making include “*ensuring quality, improving and developing services, lifelong learning, practice decision making, researching and evaluating practice, using evidence to lead practice.*” (Chartered Society of Physiotherapy, 2020)

Appendix C: Recruitment Materials

Messages for Participant Recruitment: Patient Interpretive-Description Study (Study 2)

1. Example of message to patient support groups and pages on social media:

Hi, my name is Shirin Shallwani and I am a Ph.D. candidate at the University of Ottawa School of Rehabilitation Sciences under the supervision of Dr. Roanne Thomas and Dr. Judy King. My research project involves interviewing Canadians diagnosed with stage 4 / metastatic cancer about leisure physical activity. I was wondering if it would be possible to share information about my research study through your Facebook group / page. If you have any questions or concerns, please don't hesitate to let me know. Thank you so much for your consideration.

2. Example of e-mail to local cancer centres:

To whom it may concern,

My name is Shirin Shallwani and I am a Ph.D. candidate at the University of Ottawa School of Rehabilitation Sciences under the supervision of Dr. Roanne Thomas and Dr. Judy King.

As part of my PhD research, I am currently interviewing Canadians diagnosed with different types of stage 4 cancer to better understand their perspectives and experiences related to leisure physical activity. I was wondering if you would be willing to share information about my study with any of your clients who may be interested. This study has been approved by the University of Ottawa Research Ethics Board and all information obtained during the interviews will remain anonymous. I have attached my recruitment poster. If you have any questions or concerns, please don't hesitate to let me know. Thank you so much for your consideration.

*Kind regards,
Shirin*

*Shirin Shallwani, PT, PhD candidate
University of Ottawa School of Rehabilitation Sciences*

Leisure Activity in Canadians Living with Advanced Cancer (The LACAC Study)



We are a team of researchers at the University of Ottawa currently seeking **Canadian adults with advanced / stage 4 cancer** for our study. We want to interview you to learn about your thoughts and experiences related to leisure physical activity.

We are looking for participants meeting the following criteria:

- Diagnosis of advanced (stage 4 / metastatic) cancer
- Solid tumour cancer at any stage of treatment
- Adults aged ≥ 18 years
- English-speaking
- Living in Canada

The study will involve one interview lasting about 30-45 minutes. Interviews will take place online via videoconferencing (e.g. Zoom).

If you are interested in participating or have any questions, please contact us at [REDACTED]

Participants will be selected on a first come, first served basis. The ethical aspects of the study have been approved by the University of Ottawa Research Ethics Board.

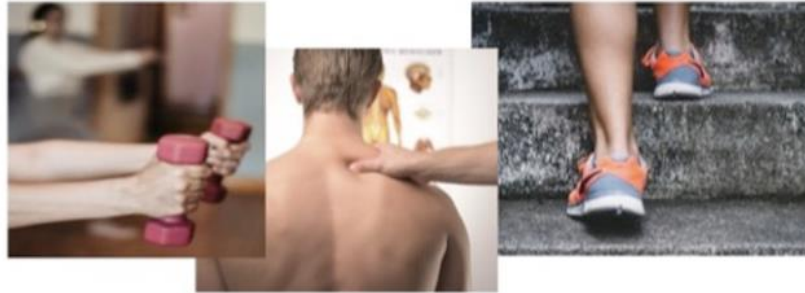
Principal investigator:

Shirin Shallwani, PT, PhD candidate

University of Ottawa School of Rehabilitation Sciences
[REDACTED]



uOttawa



Research Survey: Seeking Physiotherapists Working with Advanced Cancer Patients

We are a team of researchers at the University of Ottawa conducting a brief online survey with **physiotherapists** meeting the following criteria:

- Physiotherapists practicing in Canada
- Current or recent (last 5 years) clinical experience with adults diagnosed with advanced cancer

The objectives of this survey are to establish a better understanding of current Canadian physiotherapy practice with patients with advanced cancer and to learn about physiotherapists' experiences and thoughts related to working with this population. The survey is confidential and should take approximately 15 minutes to complete.

If you are interested in participating in the survey, please click on the following link:



A French translation of the survey is available upon request. If you have any questions or concerns, please contact us at [redacted]. The ethical aspects of the study have been approved by the uOttawa Research Ethics Board.

Principal investigator:

Shirin Shallwani, PT, PhD candidate
University of Ottawa School of Rehabilitation Sciences



Appendix D: Data Collection Tools

Interview Guide: Patient Interpretive-Description Study (Study 2)

LACAC Study: Patient Interview Guide

Patient Participant Code: _____ **Start:** _____

Date of Interview: _____ **End:** _____

Opening Script:

Hi my name is Shirin and I'm a PhD candidate at the University of Ottawa. Thank you so much for agreeing to speak with me. Is this still a good time for you to chat? The interview should last about 30-45 minutes. Does that work for you?

Before we begin, I want to let you know I am recording this interview and will be taking notes so I don't miss anything. All of the information that we talk about will remain confidential and I will not use your name or anything else to identify you. Also, all of the files from the interview will be stored and password protected.

Just to remind you, I am speaking with people diagnosed with stage 4 cancer to learn about their thoughts and experiences with leisure physical activity. For my study, I have defined leisure physical activity as activities you do in your free time, based on your personal interests. These might include exercise, walking, yoga, Tai Chi, biking, gardening, hiking, sports, dance and so much more – anything that gets you moving for fun.

Also, there are no right or wrong answers in this interview. This conversation is just to get your thoughts. If at any point, you don't want to answer a question or you need to stop the interview, that is completely fine. Do you still agree for me to interview you? Great, then let's begin!

Closing Script:

As we reach the end of our interview, is there anything else you want to share about this topic that you feel we haven't discussed already?

In terms of next steps, I will send you a summary of your interview within the next few weeks and you can provide any feedback / modifications, if you wish. At the end of the study, I can also share a report of the main findings if you are interested. If you know of anyone else who may be interested in participating in my study, please feel free to share the information with them. Once again, I want to thank you again for sharing your thoughts and experiences with me. I really appreciate your time. And we will be in touch soon!

LACAC Study: Patient Interview Guide (continued)

Physiotherapist Participant Code: _____

Date / Time of Interview: _____

Interview Questions	Follow-up Questions / Prompts
<p>Experiences</p> <ul style="list-style-type: none"> • Can you tell me about your experience with any LPA before cancer diagnosis? • Can you tell me about your experience with any LPA right now? 	<ul style="list-style-type: none"> • What type of LPA did you / do you participate in? • How did your experience with LPA change following diagnosis?
<p>Perceptions and beliefs</p> <ul style="list-style-type: none"> • How do you feel about participating in LPA after your cancer diagnosis? • What do you believe are some benefits of LPA for you? • What do you believe are some risks of LPA for you? 	<ul style="list-style-type: none"> • Do you believe LPA is important for you (or someone with a similar diagnosis)? • Do you believe it's safe for you to participate in LPA? • Do you believe you are able to participate in LPA?
<p>Facilitators and barriers</p> <ul style="list-style-type: none"> • What do you feel are important factors within you* that influence your LPA? • What do you feel are important factors within your relationships* and your environment* that influence your LPA? 	<ul style="list-style-type: none"> • Can you describe factors that help you participate in LPA? • Can you describe factors limit you from participating in LPA?
<p>Professional support</p> <ul style="list-style-type: none"> • Can you describe any information or professional support you received during your cancer experience about LPA? • If you could design the ideal LPA program for yourself, what would it look like? 	<ul style="list-style-type: none"> • Can you describe the source of LPA support or program (e.g. professional, independent)? • Can you describe the details of LPA support or program (e.g. types of activities, location / setting, timing, use of technology)?
<p>Impact of COVID-19</p> <ul style="list-style-type: none"> • Has COVID-19 impacted your participation in LPA? 	<ul style="list-style-type: none"> • Can you describe how COVID-19 has impacted your participation in LPA?

Interview Guide: Physiotherapist Mixed-Methods Study (Study 3)

LACAC Study: Physiotherapist Interview Guide

Physiotherapist Participant Code: _____

Start: _____

Date / Time of Interview: _____

End: _____

Opening Script

Thank you so much for participating in my study. Before we begin, I want to let you know I am recording this interview and will be taking notes so I don't miss anything. All of the information that we talk about will remain anonymous and I will not use your name or anything else to identify you. Also, all of the files from this interview will be stored and password protected.

I also want to remind you, this is not a clinical exam. There are no right or wrong answers in this interview and this conversation is just to get your thoughts and experiences. If at any point, you don't want to answer a question or you need to stop the interview, that is completely fine. The interview should last about 20-30 minutes.

As you know, I am interviewing Canadian physiotherapists who have clinical experience with patients diagnosed with advanced cancer to try to better understand physiotherapists' thoughts and experiences on working with this population. Advanced cancer has been defined as "cancer that is unlikely to be cured or controlled with treatment". I understand you may have experience with different types of cancer populations, so for the purpose of this interview, please try to focus on your experiences specifically with people with advanced cancer.

Are you ready to begin the interview?

Closing Script

As we reach the end of our interview, is there anything else you want to share that you feel we haven't discussed already? I want to thank you again for sharing your time, thoughts and experiences with me.

LACAC Study: Physiotherapist Interview Guide (continued)

Physiotherapist Participant Code: _____

Date / Time of Interview: _____

Clinical Practice

1. How many **years of clinical experience** do you have as a physiotherapist?
2. And how many **years of experience** do you have specifically working with **people with cancer**?
3. Can you describe the **clinical setting** where you provide physiotherapy services to patients diagnosed with advanced cancer? (*Prompts: Hospital, home care*)
4. Do people with cancer make up the **majority** of your clientele? What **cancer types** do you generally see?
5. Do you mostly work **independently** with patients or **within an interprofessional team** environment?

Knowledge / Skills

1. How did you **gain the knowledge and skills to work** with people diagnosed with advanced cancer? Where do you seek out **further knowledge** of working with this patient population? (*Prompts: School, web, courses, on-the-job training, physio colleagues, interprofessional colleagues?*)
2. Do you feel you have a **good foundation of knowledge and skills / expertise** to work with this population? (*Prompts: If yes, why? If not, why not?*)
3. Do you feel you have the knowledge to advise patients about their **leisure physical activities**? (*Prompts: Starting leisure activities or adapting pre-diagnosis activities?*)

Attitudes / Beliefs / Perspectives

1. What do you feel is the **role of physiotherapists** working with this population?
2. How do you think patients feel about **leisure physical activity**? How do they feel about **physiotherapists**, in general, and the **role of physiotherapy** in their care?
3. Can you share your **general thoughts and feelings** about working with patients with advanced cancer? (*Prompts: Reasons for working with this patient population?*)
4. What are some of the **challenges** as a physiotherapist working with people diagnosed with advanced cancer? (*Prompts: Physical challenges, emotional challenges*)
5. What are some of the **positive aspects** of working with this patient population? (*Prompts: Impact on own well-being / mental health, benefits*)

Final Question: Do you have anything else to tell me about your **overall experience** of working with people with advanced cancer as a physiotherapist?

Appendix E: Ethical Approval and Consent Forms

Certificate of Ethics Approval: Initial Application

17/08/2020

Université d'Ottawa

Bureau d'éthique et d'intégrité de la recherche

University of Ottawa

Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number

H-07-20-5937

Titre du projet / Project Title

Leisure-Time Physical Activity in
People With Advanced Cancer:
A Mixed-Methods Project
Exploring the Perspectives of
Adults Diagnosed With
Advanced Cancer and Oncology
Physiotherapists in Canada

Type de projet / Project Type

Thèse de doctorat / Doctoral
thesis

Statut du projet / Project Status

Approuvé / Approved

Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)

17/08/2020

Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)

16/08/2021

Équipe de recherche / Research Team

**Chercheur /
Researcher**

Affiliation

Role

Shirin Mehdi
SHALLWANI

École des sciences de la réadaptation / School of
Rehabilitation Sciences

Chercheur Principal / Principal
Investigator

Roanne THOMAS

École des sciences de la réadaptation / School of
Rehabilitation Sciences

Superviseur / Supervisor

Judy KING

École des sciences de la réadaptation / School of
Rehabilitation Sciences

Co-superviseur / Co-supervisor

Conditions spéciales ou commentaires / Special conditions or comments

550, rue Cumberland, pièce 154 550 Cumberland Street, Room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie | www.recherche.uottawa.ca/ethics

Certificate of Ethics Approval: Request for Modification

Université d'Ottawa

Bureau d'éthique et d'intégrité de la recherche

University of Ottawa

Office of Research Ethics and Integrity

H-07-20-5937 - MOD1-5937 - Modification approuvée / Modification Approved

(English message follows)

Cher/Chère Shirin Mehdi Shallwani,

Merci d'avoir soumis une demande de modification pour votre projet de recherche intitulé «Leisure-Time Physical Activity in People With Advanced Cancer: A Mixed-Methods Project Exploring the Perspectives of Adults Diagnosed With Advanced Cancer and Oncology Physiotherapists in Canada».

Ces modifications ont été approuvées et sont assujetties au certificat d'approbation éthique, valide jusqu'au 16-08-2021.

Sample: The sample size has increased to 15 participants (from 10), to allow for interviews with 13 physiotherapists who expressed interest in participating in the interviews.

Si vous avez des questions, n'hésitez pas à communiquer avec le Bureau d'éthique au ethique@uottawa.ca ou au 613-562-5387.

Vous pouvez voir votre demande en vous connectant à votre compte [eReviews](#).

Cordialement,

Marc Alain Bonenfant
Coordonnateur de l'éthique
Président(e) : Daniel Lagarec
CÉR : Comité d'éthique de la recherche en sciences de la santé et sciences / Health Sciences and Sciences Research Ethics Board

Ceci est une réponse automatisée, merci de ne pas répondre à ce courriel.

Dear Shirin Mehdi Shallwani,

Thank you for submitting a modification request for your research project titled "Leisure-Time Physical Activity in People With Advanced Cancer: A Mixed-Methods Project Exploring the Perspectives of Adults Diagnosed With Advanced Cancer and Oncology Physiotherapists in Canada".

These modifications are now covered under the certificate of ethics approval, valid until 16-08-2021.

Sample: The sample size has increased to 15 participants (from 10), to allow for interviews with 13 physiotherapists who expressed interest in participating in the interviews.

If you have any questions, please contact the Ethics Office at ethics@uottawa.ca or 613-562-5387.

You can view your project at any time by logging into [eReviews](#).

Best regards,

Marc Alain Bonenfant
Ethics Coordinator
Chair: Daniel Lagarec
REB: Comité d'éthique de la recherche en sciences de la santé et sciences / Health Sciences and Sciences Research Ethics Board

This is an automated message. Please do not reply directly to this email.

550, rue Cumberland, pièce 154 550 Cumberland Street, Room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie | www.recherche.uottawa.ca/ethics

Certificate of Ethics Approval: Renewal Application

19/07/2021

Université d'Ottawa

Bureau d'éthique et d'intégrité de la recherche

University of Ottawa

Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number

H-07-20-5937

Titre du projet / Project Title

Leisure-Time Physical Activity in
People With Advanced Cancer:
A Mixed-Methods Project
Exploring the Perspectives of
Adults Diagnosed With
Advanced Cancer and Oncology
Physiotherapists in Canada

Type de projet / Project Type

Thèse de doctorat / Doctoral
thesis

Statut du projet / Project Status

Renouvelé / Renewed

Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)

17/08/2020

Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)

16/08/2022

Équipe de recherche / Research Team

**Chercheur /
Researcher**

Affiliation

Role

Shirin Mehdi
SHALLWANI

École des sciences de la réadaptation / School of
Rehabilitation Sciences

Chercheur Principal / Principal
Investigator

Roanne THOMAS

École des sciences de la réadaptation / School of
Rehabilitation Sciences

Superviseur / Supervisor

Judy KING

École des sciences de la réadaptation / School of
Rehabilitation Sciences

Co-superviseur / Co-supervisor

Conditions spéciales ou commentaires / Special conditions or comments

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613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie | www.recherche.uottawa.ca/ethics

Consent Form: Patient Interpretive-Description Study (Study 2)

Title of the study: Perceptions and Experiences of People with Advanced Cancer Related to Leisure-Time Physical Activity: a Qualitative Interpretive-Descriptive Study

Principal Investigator(s): Ms. Shirin M. Shallwani
Ph.D. Candidate
School of Rehabilitation Sciences
University of Ottawa
Ottawa, ON

Co-investigator(s) (Supervisors): Dr. Judy King & Dr. Roanne Thomas
School of Rehabilitation Sciences
University of Ottawa

Invitation to Participate: You are invited to participate in the abovementioned research study conducted by Shirin M. Shallwani, a Ph.D. candidate supervised by Dr. Judy King & Dr. Roanne Thomas.

Participation: If you wish to participate in this interview, please complete the following online consent form and the demographic and medical questionnaire. Once completed, you will be contacted by the principal investigator over e-mail or phone to set up an interview over video-conferencing. The interview should take approximately 30-45 minutes to complete. You do not have to answer any questions that you do not want to answer.

Purpose of the Study: From this research, we wish to establish a better understanding of your thoughts, experiences, and preferences related to leisure physical activity. We hope that this research will guide the development of clinical programs, inform professional education initiatives and support future research.

Benefits: While there are no direct benefits to participating in this research, the information you provide will contribute to enhancing research knowledge on leisure-time physical activity in people with advanced cancer.

Risks: There are no major risks anticipated with participating in this research. Your participation in this study will take up your energy and your time and this may cause you to feel fatigued and inconvenience. However, we will try our best to accommodate your preferences for scheduling the interview and will share the questions with you in advance to avoid any difficulties during the interview process.

Review of Interview Transcript: Following completion of the interview, a summary of the interview transcript will be emailed to you for your review. The purposes of this step are to verify that we have accurately documented your thoughts and experiences and to give you the opportunity to edit your responses. You will be asked to provide any feedback within one week of receiving the email.

Confidentiality and Anonymity: The information that you will share will remain strictly confidential and will be used solely for the purposes of this research. The only people who will have access to the

research data are the principal investigator (Shirin Shallwani) and the co-investigators (Dr. Judy King & Dr. Roanne Thomas). Your interview responses may be used verbatim in presentations and publications but neither you (nor your organization) will be identified. In order to minimize the risk of security breaches and to help ensure your confidentiality we recommend that you use standard safety measures such as signing out of your account, closing your browser and locking your screen or device when you are no longer using them / when you have completed the interview.

Anonymity will be protected as no identifying information will be linked to your interview responses. Pseudonyms or numbers will be used to identify participants within any published or publically shared document related to the study. Additional identifying details (e.g. hospital names) will not be shared.

Conservation of data: The questionnaire responses, along with the interview recordings and notes will be kept in two password-protected USB / external hard drives. These will be stored in a locked filing cabinet at the principal investigator's office and then in the office of Dr. Roanne Thomas at the University of Ottawa for a period of 5 years at which time they will be securely destroyed.

Voluntary Participation: You are under no obligation to participate and if you choose to participate, you can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If you choose to withdraw, all data gathered until the time of withdrawal will be securely deleted and will not be used for research purposes.

If you have any questions or require more information about the study itself, you may contact the researcher or his/her supervisor at the numbers mentioned herein.

If you have any questions with regards to the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, tel.: (613) 562-5387 or ethics@uottawa.ca.

Please keep this form for your records.

Thank you for your time and consideration.

Shirin Shallwani, PhD candidate
Dr. Judy King
Dr. Roanne Thomas

Consent Form: Physiotherapist Mixed-Methods Study (Study 3: Survey Portion)

Title of the study: A Mixed-Methods Study Examining the Practices, Knowledge, Skills and Attitudes of Oncology Physiotherapists Working with People with Advanced Cancer (Survey Portion)

Principal Investigator(s): Ms. Shirin M. Shallwani
Ph.D. Candidate
School of Rehabilitation Sciences
University of Ottawa
Ottawa, ON

Co-investigator(s) (Supervisors): Dr. Judy King & Dr. Roanne Thomas
School of Rehabilitation Sciences
University of Ottawa

Invitation to Participate: You are invited to participate in the abovementioned research study conducted by Shirin M. Shallwani, a Ph.D. candidate supervised by Dr. Judy King & Dr. Roanne Thomas.

Participation: If you wish to participate in this study, please complete the online survey. Your decision to complete this survey will be interpreted as an indication of your consent to participate. The survey should take you approximately 15-20 minutes to complete. You do not have to answer any questions that you do not want to answer.

Purpose of the Study: From this research, we wish to establish a better understanding of current Canadian physiotherapy practice with patients diagnosed with advanced cancer and to learn about physiotherapists' experiences and thoughts related to working with this population.

Benefits: While there are no direct benefits to participating in this research, the information you provide will contribute to advancing research in Canadian physiotherapy practice for people with cancer.

Risks: There are no anticipated risks to participating in this research.

Confidentiality and Anonymity: The information that you will share will remain strictly confidential and will be used solely for the purposes of this research. The only people who will have access to the research data are the principal investigator (Shirin Shallwani) and the co-investigators (Dr. Judy King & Dr. Roanne Thomas). Your answers to open-ended questions may be used verbatim in presentations and publications but neither you (nor your organization) will be identified. In order to minimize the risk of security breaches and to help ensure your confidentiality we recommend that you use standard safety measures such as signing out of your account, closing your browser and locking your screen or device when you are no longer using them / when you have completed the study. Anonymity is expected since you are not being asked to provide your name or any personal information.

Conservation of data: The survey data will be kept in a password-protected electronic database and in a locked filing cabinet in the office of Dr. Roanne Thomas at the University of Ottawa for a period of 5 years at which time they will be destroyed.

Voluntary Participation: You are under no obligation to participate and if you choose to participate, you may refuse to answer questions that you do not want to answer. Completion of the questionnaire by you implies consent.

If you have any questions or require more information about the study itself, you may contact the researcher or his/her supervisor at the numbers mentioned herein.

If you have any questions with regards to the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, tel.: (613) 562-5387 or ethics@uottawa.ca.

Please keep this form for your records.

Thank you for your time and consideration.

Shirin Shallwani, PhD candidate
Dr. Judy King
Dr. Roanne Thomas

Consent Form: Physiotherapist Mixed-Methods Study (Study 3: Interview Portion)

Title of the study: A Mixed-Methods Study Examining the Practices, Knowledge, Skills and Attitudes of Oncology Physiotherapists Working with People with Advanced Cancer (Interview Portion)

Principal Investigator(s): Ms. Shirin M. Shallwani
Ph.D. Candidate
School of Rehabilitation Sciences
University of Ottawa
Ottawa, ON

Co-investigator(s) (Supervisors): Dr. Judy King & Dr. Roanne Thomas
School of Rehabilitation Sciences
University of Ottawa

Invitation to Participate: You are invited to participate in the abovementioned research study conducted by Shirin M. Shallwani, a Ph.D. candidate supervised by Dr. Judy King & Dr. Roanne Thomas.

Participation: If you wish to participate in this interview, please complete this online consent form. Once completed, you will be contacted by the principal investigator over e-mail or phone to set up an interview over video-conferencing. The interview should take approximately 30-45 minutes to complete. You do not have to answer any questions that you do not want to answer.

Purpose of the Study: From this research, we wish to establish a better understanding of current Canadian physiotherapy practice with patients diagnosed with advanced cancer and to learn about physiotherapists' experiences and thoughts related to working with this population.

Benefits: While there are no direct benefits to participating in this research, the information you provide will contribute to advancing research in Canadian physiotherapy practice for people with cancer.

Risks: There are no major risks anticipated with participating in this research. Your participation in this study will take up some of your time and this may cause you to feel inconvenience. However, we will try our best to accommodate your preferences for scheduling the interview and will share the questions with you in advance to avoid any difficulties during the interview process.

Review of Interview Transcript: Following completion of the interview, a summary of the interview transcript will be emailed to you for your review. The purposes of this step are to verify that we have accurately documented your thoughts and experiences and to give you the opportunity to edit your responses. You will be asked to provide any feedback within one week of receiving the email.

Confidentiality and Anonymity: The information that you will share will remain strictly confidential and will be used solely for the purposes of this research. The only people who will have access to the research data are the principal investigator (Shirin Shallwani) and the co-investigators (Dr. Judy King &

Dr. Roanne Thomas). Your interview responses may be used verbatim in presentations and publications but neither you (nor your organization) will be identified. In order to minimize the risk of security breaches and to help ensure your confidentiality we recommend that you use standard safety measures such as signing out of your account, closing your browser and locking your screen or device when you are no longer using them / when you have completed the interview.

Anonymity will be protected as no identifying information will be linked to your interview responses. Pseudonyms or numbers will be used to identify participants within any published or publically shared document related to the study. Additional identifying details (e.g. hospital names) will not be shared.

Conservation of data: The interview recordings and notes will be kept in two password-protected USB / external hard drives. These will be stored in a locked filing cabinet at the principal investigator's office and then in the office of Dr. Roanne Thomas at the University of Ottawa for a period of 5 years at which time they will be securely destroyed.

Voluntary Participation: You are under no obligation to participate and if you choose to participate, you can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If you choose to withdraw, all data gathered until the time of withdrawal will be securely deleted and will not be used for research purposes.

If you have any questions or require more information about the study itself, you may contact the researcher or his/her supervisor at the numbers mentioned herein.

If you have any questions with regards to the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, tel.: (613) 562-5387 or ethics@uottawa.ca.

Please keep this form for your records.

Thank you for your time and consideration.

Shirin Shallwani, PhD candidate

Dr. Judy King

Dr. Roanne Thomas

Appendix F: Contribution of Collaborators

Role of Primary Researcher and Funding

As the primary researcher, I take full responsibility for this dissertation (**Table F.1**), which is submitted in partial fulfillment of the requirements for the Doctorate in Philosophy degree in Rehabilitation Sciences. Over the course of my doctoral studies, I was financially supported by the University of Ottawa Excellence and Admission Scholarships, the Ontario Graduate Scholarship, the Queen Elizabeth II Graduate Scholarship in Science and Technology and the 2015 Ottawa Physio Race Scholarship in Rehabilitation Sciences. I was also awarded three conference grants from the University of Ottawa to present preliminary findings of my research at academic conferences, as well as one publication grant to support the open-access publication fee of a manuscript that is not included within my dissertation. The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscripts or the dissertation. There was no additional funding received directly for the conduct of this dissertation research.

Research Collaborators

My research was also supported by several collaborators, namely my supervisors and thesis advisory committee members (**Table F.1**). My supervisors, Dr. Roanne Thomas (RT) and Dr. Judy King (JK), provided instrumental support in conceptualizing and designing the research, offered guidance during data collection, participated in data analysis, and contributed to reviewing and editing the manuscripts and dissertation sections. Prior to her retirement, my past supervisor, Dr. Lucie Brosseau (LB), also helped guide the preparation of my research proposal, and supported the design, data collection and analysis, as well as the manuscript preparation for the scoping review (Study 1). My committee members, Dr. Stéphane Poitras (SP) and Dr. Karine Toupin-April (KTA), provided valuable feedback and guidance on the different elements of my dissertation work, particularly my research proposal and manuscript drafts.

RT is a Full Professor in the School of Rehabilitation Sciences at the University of Ottawa and holds a Canada Research Chair in Creative Practices and Well-being. She has served as my Ph.D. supervisor since my enrollment into the program in 2015. JK is a physiotherapist and an Associate Professor in the School of Rehabilitation Sciences at the University of Ottawa. She acted as a member of my thesis advisory committee until 2017, after which she took on the role of my co-supervisor with RT. LB is retired from her position as a Full Professor in the School of Rehabilitation Sciences at the University of Ottawa. Prior to her retirement in 2017, she served as my supervisor along with RT. SP has a professional background in physiotherapy and is a Full Professor in the School of Rehabilitation Sciences at the University of Ottawa and Director of the Physiotherapy Program. KTA has a professional background in occupational therapy and is an Adjunct Professor in the School of Rehabilitation Sciences at the University of Ottawa, Assistant Professor in the Department of Pediatrics at the University of Ottawa and an Associate Scientist Children's Hospital of Eastern Ontario Research Institute. SP and KTA have been members of my committee since 2016 and 2017, respectively.

Along with these collaborators, other individuals made important contributions to my work. The librarians at the University of Ottawa Health Sciences Library, Lindsey Sikora (LS) and Marie-Cécile Domecq (MCD), assisted me in developing the literature search strategy for the scoping review and updating the review, respectively. Dr. Marie-Christine Ranger (MCR), a former Ph.D. student at the University of Ottawa School of Rehabilitation Sciences, helped with the abstract screening and full-text review, as well as extracting data from the included studies for the scoping review (Study 1). She also assisted with pre-testing the interview guide for the patient interpretive-description study (Study 2). Dr. Grainne Sheill (GS) provided support by sharing the survey previously developed in her research work for use in the physiotherapist mixed-methods study (Study 3).

Table F.1 Summary of Collaborator Contributions

Chapter	Chapters 1 and 5	Chapter 2	Chapter 3	Chapter 4
<i>Details</i>	<i>Chapter 1: Introduction Chapter 5: Integrated Discussion</i>	<i>Manuscript 1: Scoping Review</i>	<i>Manuscript 2: Patient Interpretive-Description Study</i>	<i>Manuscript 3: Physiotherapist Mixed-Methods Study</i>
Design and conceptualization	SMS	SMS, LB, RT, SP, JK, MCR, LS, MCD	SMS, RT, JK, SP, KTA	SMS, RT, JK, SP, KTA, GS
Data collection	SMS	SMS, MCR	SMS	SMS
Data analysis and interpretation	SMS	SMS, LB, RT, JK	SMS, RT, JK	SMS, RT, JK
Initial draft preparation	SMS	SMS	SMS	SMS
Review and revision	SMS, RT, JK, SP, KTA	SMS, RT, LB, SP, JK, MCR, LS	SMS, RT, JK, KTA, SP	SMS, RT, JK, SP, KTA, GS
Approval of final version	SMS, RT, JK, SP, KTA	SMS, RT, LB, SP, JK, MCR, LS	SMS, RT, JK, KTA, SP	SMS, RT, JK, SP, KTA, GS,
Manuscript authorship (in order of authorship)	N/A	SMS, MCR, RT, LB, SP, LS, JK	SMS, RT, JK, KTA, SP	SMS, RT, SP, KTA, GS, JK
Responsible for content	SMS	SMS	SMS	SMS

GS: Grainne Sheill; JK: Judy King; KTA: Karine Toupin-April; LS: Lindsey Sikora; LB: Lucie Brosseau; MCD: Marie-Cécile Domecq; MCR: Marie-

Christine Ranger; RT: Roanne Thomas; SMS: Shirin Mehdi Shallwani; SP: Stéphane Poitras

In addition to these contributions, other individuals were involved in supporting my research as well. Alysson Rheault translated the survey for the physiotherapist study into French. Angela Yung, Chantal Ball, Hussein Baharoon, Nishanth Kumar and Sukhi Johal were involved with pre-testing the survey and interview guide for the physiotherapist study. Chantal Ball and Sandra Houle assisted with the transcription of interviews for both studies. Several individuals were involved in recruitment for both studies involving participants and the contributions of their organizations have been acknowledged within the respective manuscripts.

Manuscript Authorship

Criteria for authorship on manuscripts were based on the International Committee of Medical Journal Editors Uniform Requirements for Manuscripts. These guidelines require manuscript authors to make significant contributions to the research conception and design, data acquisition, or data analysis and interpretation; draft or critically revise the manuscript for important intellectual content; and approve the final version. Thus, the collaborators meeting the criteria for authorship of the respective manuscripts have been identified in **Table F.1**.