Improving the physical function and quality of life of adults living with advanced cancer: The role of physical activity

By

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A dissertation submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

(Population Health Sciences)

at the

UNIVERSITY OF WISCONSIN-MADISON

2023

Date of final oral examination: 12/01/2023

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Acknowledgments

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Funding Sources

This work was supported by the Virginia Horne Henry Foundation and my time was supported by the grant T32 AG00129 awarded to the Center for Demography of Health and Aging at the University of Wisconsin-Madison by the National Institute on Aging.

Date of IRB Approval

The IRB for the work conducted in Aim 1 was approved on 7/29/2019 as minimal risk by the University of Wisconsin-Madison's Minimal Risk Institutional Review Board (Protocol #2019-0767) and by the Carbone Cancer Center's Protocol Review and Monitoring Committee (Protocol UW18135). The IRB for the work conducted in Aims 2 and 3 was approved on 8/19/2022 as minimal risk by the University of Wisconsin-Madison's Minimal Risk Institutional Review Board (Protocol #2022-0966) and by the University of Wisconsin's Carbone Cancer Center's (UWCCC) Protocol Review and Monitoring Committee (Protocol UW22103).

Personal Acknowledgments

First and foremost, thank you to my husband, Michael, and dear friends and family in Madison and afar for their immense encouragement and continued patience with me as I embarked on this journey of pursuing my PhD. This work would not have been possible without the support and love of my family, especially my mom and dad, and friends near and far.

Also, a huge thank you to Dr. Shaneda Warren Andersen who tackled the role of becoming my advisor and dissertation chair with ease as I worked towards my goal of completing my dissertation. Thank you for your support and patience throughout this process. I must also thank Dr. Lisa Cadmus-Bertram for her immense support during her time at the university over the past three years. She has given me research opportunities that I did not think I would get during my time at the University of Wisconsin-Madison, and I am extremely grateful for her support (on and off the cyclocross course). And lastly, a thank you to all the members of my dissertation committee, Drs. Bea, Gangnon, Kwekkeboom, and Trentham-Dietz who pushed me to make every draft better than the last and supported my development as a researcher. Finally, I'd like to thank the research community at the university, including the Center for Demography of Health and Aging, for making me a better researcher. A special thank you to Dr. Amy Schultz for being a great friend and research mentor. My fellow PhD students including KJ Hansmann, Fiona Weeks, Hannah Olson-Williams, and Christian Schmidt were huge sources of support for me and my progress over the last four years. I'm immensely grateful to all of you for listening to my endless anxieties, and I look forward to many years of seeing what we are all able to accomplish beyond our PhDs!

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DISSERTATION ABSTRACT

Introduction: Physical activity is known to improve health-related quality of life (HRQoL) of cancer survivors; however, less is known about this relationship among adults with advanced cancer. **The goal of my dissertation is to better understand physical activity levels, changes, and associations with HRQoL among adults with advanced cancer and investigate their preferences for a supportive care intervention.**

Methods: For Aim 1, a qualitative analysis was conducted to assess factors influencing physical activity among adults with advanced cancer. For Aims 2 and 3, a mail-based, cross-sectional survey was fielded to understand physical activity levels, barriers, HRQoL, and preferences for a supportive care intervention among those with advanced cancer.

Results: Despite many reported barriers to physical activity, adults with advanced cancer were interested in gaining strength and maintaining independence. Most adults were engaging in light intensity activities (62%); and the majority of respondents had decreased their physical activity since their diagnosis (74%), which was associated with lower, and clinically meaningful differences in, HRQoL. Respondents were interested in a supportive care intervention designed to increase energy (88%) and improve physical health (86%) with physical therapy (73%), walking (72%), and resistance exercises.

Conclusions: Adults with advanced cancer were engaging in some physical activity with interest in activities designed to help them improve their energy and physical health. Lower physical activity levels and declines in physical activity since diagnosis were associated with lower HRQoL. Multi-modal supportive care interventions are a possible way forward to support adults with advanced cancer.

CHAPTER 1: INTRODUCTION

CANCER

1.1 WHAT IS CANCER?

Cancer is a disease resulting in the proliferation of cells due to genetic mutations that can be inherited or caused by random error or damage from environmental exposures e.g., tobacco smoke [1]. Uncontrolled cell growth can be caused by differences in cancer cells compared to normal cells, for example, cancer cells ignore programmed cell death i.e., apoptosis [1], [2]. While the human body has a variety of mechanisms to destroy cells with damaged deoxyribonucleic acid (DNA), these mechanisms become weaker as people age, leading to a higher incidence of cancer in older adults [1]. Although cancer tends to be diagnosed at later ages, there are millions of adults living with cancer in the United States of varying ages and it is important for researchers and clinicians to understand their unique health needs to better support them during their lifetime.

1.2 GROWING NUMBER OF CANCER SURVIVORS

Cancer is a leading cause of mortality and morbidity [3]. People who have received a cancer diagnosis are considered cancer survivors from the time of their diagnosis until the end of their life [4]. Due to an aging population, improved screening rates, and advances in cancer treatments, the US population of cancer survivors will grow to 26 million by 2040 [5]. People who are diagnosed at an early stage of disease tend to have a better prognosis; however, modern advances in treatments have led to improvements in survival for those diagnosed with advanced cancer as well [6], [7].

Many cancer survivors face physical and/or psychological sequelae following their diagnosis and treatment including fatigue, anxiety, depression, and the potential for developing other comorbidities [4], [8]–[11]. Further, cancer-related limitations in daily living are commonly reported among adults living with cancer. Up to 55% of people with a cancer diagnosis report restrictions in performing instrumental tasks of daily living, such as shopping or preparing meals, and 37% report restrictions in their ability to perform basic tasks of daily living, such as dressing or bathing [12]–[14]. Upwards of 60-90% of adults living with a current or past cancer diagnosis report unmet needs related to their physical health including dealing with chronic pain and neuropathy, and difficulties with self-care tasks [15]. While people with a cancer diagnosis can face symptoms from cancer and side effects from treatment, they also report issues related to the need for more information about their health and social concerns impacting their ability to take care of their home and foster important relationships in their lives [16].

Traditional cancer care focuses on treating the medical needs of the cancer patient and may not be adequately equipped to deal with the additional supportive care needs that affect those living with cancer. Supportive care programs can be multimodal and include physical, social, and/or psychological components, such as exercise for cancer recovery, nutritional support, counseling, and pain support [17]. Adults living with advanced cancer may have a variety of supportive care needs that differ from individuals with curative cancer. Advanced cancer refers to cancers that are unlikely to be cured and are treated without curative intent, which is different from curative cancer that is diagnosed at an earlier stage when it has a high chance to be cured with treatment [18], [19]. Individuals living with advanced cancer often suffer from unmet needs related to physical symptoms of their cancer, increased anxiety, and reduced quality of life [20]. More research is needed on ways to reduce physical and psychological impairments for people living with advanced cancer and improve their quality of life. My dissertation will focus on assessing the supportive care preferences of those living with advanced cancer. It is critical for researchers to determine which supportive care services are of interest for adults living with advanced cancer to better address their unique needs.

1.3 WHAT IS ADVANCED CANCER?

Advanced cancer is used to describe cancers that are unlikely to be cured due to the progression of the disease and poorer prognosis; however, some types of advanced cancer can be controlled for a long time [6], [18]. The goal of treatment(s) for advanced cancer is usually to extend life by shrinking the tumor, slowing the progression, or relieving symptoms [19]. Individuals living with advanced disease vary greatly in terms of prognosis, treatment(s) received, and functional status; some adults diagnosed with advanced can live for many years, due to advances in therapeutics, responses to treatment, or cancer type, while others can experience a rapid decline [18]. Advanced cancers may have spread to nearby lymph nodes and tissue, and/or distant sites, such as the bones, lungs, and brain [19]. Sometimes advanced cancer is synonymous with metastatic cancer, which refers to cancers that have spread to other parts of the body. For solid tumors, a stage IV diagnosis is given when the disease has spread outside the region of the body where the tumor originated, also referred to as a “distant metastasis” [21], and that is the definition I use for the purpose of defining solid tumors in my dissertation. However, I also include advanced hematologic malignancies that are not considered metastatic, but rather are considered advanced based on their curability or staging. There are some shared symptoms of advanced and metastatic cancer, such as fatigue, weight loss without trying, pain, and difficulty breathing [6].

In the U.S., in 2023, it’s estimated that there will be 1,958,310 total new cases of cancer [3]. Breast and prostate cancer diagnoses account for the greatest number of new cancer cases in the U.S. with 31% and 29% of new cancer cases in 2023, respectively [3]. Colon and rectum cancer cases account for about 8% of new cancer cases, and non-Hodgkin lymphoma cases account for about 4% of new cancer cases in 2023 [3]. Almost two-thirds (64%) of cancer survivors are 65 years of age or older [4]. For the purposes of my dissertation, I include stage IV breast, prostate, and colorectal solid tumor diagnosis, myeloma, and stages III and IV lymphomas.

Due to modern advances in treatments for cancer, many adults can live for years after a cancer diagnosis, and increasingly, in the case of an advanced cancer diagnosis. Data on the exact numbers and demographics of the population of advanced cancer survivors in the United States is lacking. A recent article by Gallicchio et al. (2022) used cancer registry data to estimate the number of cancer survivors living with metastatic disease for the six most common cancers. In 2018, in the United States, it is estimated that 623,405 individuals were living with either metastatic breast, prostate, lung, colorectal, or bladder cancer, or metastatic melanoma [22]. Approximately 61.4% of metastatic breast cancer cases, 43.9% of metastatic colorectal cancer cases, and 55.0% of metastatic prostate cancer cases were estimated to be due to recurrence, meaning the cancer coming back after an earlier diagnosis [22]. For individuals living with metastatic breast and colorectal cancer, estimates suggest that approximately 20%

of cases have survived for 10 or more years after diagnosis and these numbers are continuing to grow [22]. Among metastatic breast cancer patients in the Surveillance, Epidemiology, and End Results (SEER) database, Chen et al. (2017) found the median age at diagnosis was 62 years and younger patients (<50 years) had the best overall and breast-cancer specific survival compared to the eldest patients (>69 years; $p<0.001$) [23]. Black women tended to be diagnosed at a younger age compared to White women ($p<0.001$) and those presenting with bone metastases only had better survival compared to groups with other metastatic sites of disease including brain, liver, lung, or multiple sites ($p<0.001$) [23].

In the case of hematologic cancers, people with advanced non-Hodgkin's lymphoma (67%) and myeloma (59%) have relatively high 5-year survival rates compared to other advanced solid tumor diagnoses [24]. However, the disease and intensive treatments can negatively impact quality of life, fatigue, and physical functioning just like that of other advanced solid tumor cancers [25]. In the case of advanced solid tumors, the survival rates are lower overall with 32.3%, 30%, and 15.1% of people with distant disease (prostate, breast, and colorectal, respectively) surviving five or more years after diagnosis [24].

There are several common sites of metastatic spread including the bone, brain, liver, and lungs [26]. The most common site of metastatic disease is the bone for breast and prostate cancers [27]. The presence of bone involvement is of critical importance when thinking about physical activity guidance for this population. The International Bone Metastases Exercise Working Group (IBMEWG) recently released exercise recommendations for people with bone metastases and explicitly stated a lack of evidence base on the safety and efficacy of exercise for elderly people with myeloma, a population with up to 80% of patients developing bone lesions [28], [29]. Due to the limited evidence for physical activity recommendations for people with bone involvement, it is important to consider this population in future research. I have included both advanced prostate and breast cancer patients in my work as well as patients with myeloma as this cancer type has bone involvement, putting patients at a higher risk of developing fractures, which is a major factor to consider when developing physical activity recommendations for patients.

PHYSICAL ACTIVITY

1.4 PHYSICAL ACTIVITY FOR CANCER SURVIVORS

Physical activity is any bodily muscle movement that leads to an increase in energy expenditure [30]. Physical activity can be done for transportation, occupation, personal enjoyment, or to improve mental and physical health. In general, increasing physical activity is important for all cancer survivors, as it is known to reduce treatment side effects and recurrence, and improve quality of life; however, evidence on the acceptability and benefits of physical activity for survivors with advanced disease is limited [31], [32]. The timing of a cancer diagnosis is considered a critical opportunity or "teachable moment" whereby patients may be more interested in adopting healthier lifestyles as a result of their cancer diagnosis [33], [34]. These health behaviors can include quitting smoking, eating a healthier diet, and increasing physical activity. Research suggests a 21-45% lower mortality risk for those with breast, colorectal, and prostate cancer among those engaged in the highest post-diagnosis physical activity compared to the lowest. Again, this suggests that post-diagnosis physical activity is of critical importance and can lead to better outcomes [35]. It is unclear whether similar benefits exist for those diagnosed with advanced cancer.

There are many factors that may impact a person with cancer's ability to be active, such as the type and stage of their cancer, their treatment(s) received, and their fitness and strength before and during treatment [31]. The American College of Sports Medicine (ACSM) and the American Cancer Society (ACS) recommend that even engaging in a little bit of activity is better than none. Both organizations recently released updated guidance on physical activity recommendations for cancer survivors. The ACS recommends that cancer survivors achieve 150-300 minutes per week of moderate-intensity activity or 75-150 minutes per week of vigorous-intensity activity and muscle-strengthening activities on two or more days per week. The ACSM provides additional guidance on specific doses of physical activity that could improve cancer-related symptoms and quality of life [35], [35], [36]. For example, for improvements in health-related quality of life (HRQoL), the ACSM recommends combined moderate intensity aerobic activity with resistance training two to three times per week for at least 12 weeks both during and after treatment [32]. Additional strong evidence-based guidance is available for anxiety and depression, fatigue, lymphedema, and physical function [32]. Moderate evidence is given for bone health and sleep, and insufficient evidence is given for cardiotoxicity, chemotherapy-induced peripheral neuropathy, cognitive function, falls, nausea, pain, sexual function, and treatment tolerance mainly due to limitations of current trials [32]. Based on the existing research, the ACSM recommends that cancer survivors complete aerobic training at moderate intensity three or more times per week for at least 30 minutes for at least 8-12 weeks, and report that the addition of resistance training exercises a minimum of two times per week (at least two sets of 8-15 repetitions of the exercise) to aerobic training is similarly beneficial [32]. However, the ACSM acknowledges that the existing evidence from exercise randomized controlled trials used to develop these recommendations is based primarily on trials among breast cancer survivors and are likely to be healthier and higher functioning than the broader population of cancer survivors [32]. And thus, it is important to consider the individual's needs and abilities when recommending physical activity after a cancer diagnosis.

Many cancer survivors do not meet the national recommendations for physical activity, and most of the evidence used to develop these recommendations has excluded adults with advanced disease [6], [32], [35], [37], [38]. Furthermore, these recommendations may not be appropriate throughout the cancer journey from diagnosis through end-of-life, and more work needs to be done to determine the necessary components and timing of appropriate supportive care interventions that will best suit the unmet needs of adults living with advanced cancer. My work will focus on three components of supportive care interventions -- physical activity, nutrition, and coping support -- and determine preferences for the best timing to introduce this intervention to people with advanced cancer.

1.5 Types of Physical Activity

There are three important types of physical activity for people with cancer:

Stretching: Stretching helps to improve range of motion and flexibility, which is especially important during a patient's recovery from cancer surgery. [39]

Aerobic activity: Aerobic activity is any activity that makes a person breathe harder than normal and increases their heart rate. There are many different types of aerobic activity including walking, light cycling, swimming, and hiking. [40]

Strength training: Strength training helps a person build muscle, which is essential for people with cancer. It is important for cancer survivors to perform strength exercises to retain their ability to balance and/or remedy balance deficiencies and perform essential activities of daily living. [40]

Although these types of physical activity may be appropriate and acceptable to some cancer survivors, they are unlikely to be accessible to people of all types and stages of cancer. An important part of my dissertation research will explore types and intensity levels of activities people are currently doing and what types of activities they would like to incorporate into their daily lives. For example, occupational therapy exercises may be the most helpful for some patients to improve their ability to perform activities of daily living, while strength exercises may be preferred for those with increased ability.

1.6 PHYSICAL ACTIVITY INTERVENTIONS FOR CANCER SURVIVORS

Designing interventions based on the needs and preferences of the population of interest should increase the likelihood that patients will want to participate and be able to maintain increases in physical activity after completion of the intervention. Results from a meta-analysis of thirty-four randomized control trials of exercise among patients with cancer found exercise significantly improved quality of life and physical function in patients with cancer [41]. Only 2% of patients included in the randomized control trials had evidence of distant metastatic disease at baseline [41]. A more recent meta-analysis of physical activity behavior changes among cancer survivors found physical activity interventions to be effective at increasing MVPA by approximately 65 (95% CI = 45-85) minutes per week in the intervention group compared to 27 (95% CI = 11-43) minutes per week among the control group [42]. Studies were biased towards younger, female, and higher SES populations, which makes them unlikely to represent the broader population of people living with cancer that tend to be older with functional limitations [42]. The study population of my dissertation research will focus on the less studied population of adults living with advanced cancer that tend to be older and may have functional limitations.

1.7 PHYSICAL ACTIVITY FOR ADULTS LIVING WITH ADVANCED CANCER

Due to the lack of physical activity research on people living with advanced cancer, there is a need to understand their unique preferences for and barriers to physical activity. A recent paper by Knowlton et al. (2020) investigated the barriers to exercise among cancer survivors, including those with advanced disease, and found that only 34% of patients with advanced disease in their sample met the national physical activity guidelines compared to 44% of cancer survivors in their sample. Furthermore, they found that the desire to increase exercise was high with 78.6% of patients living with advanced disease in their sample reporting interest in obtaining more information about physical activity and exercise despite reported barriers to exercise. Understanding the unique preferences and barriers to physical activity among people with advanced cancer is extremely important for the purpose of designing tailored interventions for this population.

People living with a variety of advanced cancer types have reported several barriers to physical activity due to their cancer and its treatments. Houldin and Lewis

(2006) found that among 14 patients with a recent diagnosis of advanced colorectal cancer, individuals wanted to be able to control their physical and psychological distress to live life as normal as possible despite the negative impacts of symptoms and treatment side effects [43]. Primary barriers to physical activity among 24 people diagnosed with myeloma included fatigue and pain [44]. Among 20 men with advanced prostate cancer, pain, fatigue, and hormonal therapy that can lead to weight gain were the main reported barriers to physical activity [45]. Most qualitative studies focused on one cancer type, and my dissertation research is unique in that I include five distinct cancer types to look at differences across cancer types.

A recent systematic review of exercise interventions for people living with advanced cancer found that interventions resulted in improvements in aerobic capacity, strength, and components of physical function [46]. A metanalysis by Toohey et al. (2022) reviewed the evidence to date of exercise randomized controlled trials, which included advanced cancer patients in the palliative care phase and found exercise to be safe and feasible with no difference in risk of adverse events between exercise and usual care, good retention rates, and noted improvements in quality of life, physical fitness, and fatigue [47], [48]. However, there is still a lack of understanding about the consideration of the environment of the physical activity intervention [48], [49]. Another important piece of my dissertation research seeks to assess whether features of the built environment (e.g. walkability, safety) are considered important facilitators or barriers of physical activity among people living with advanced cancer in a geographically diverse sample.

1.8 SOCIAL COGNITIVE THEORY

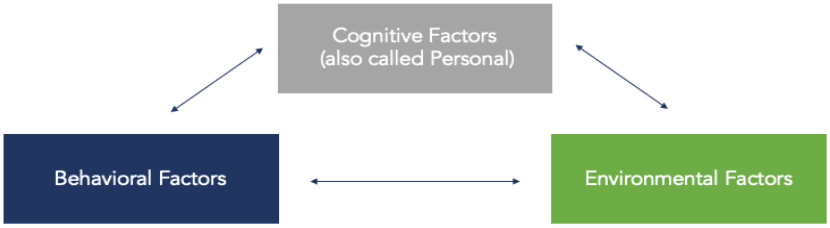

Figure 1. The Social Cognitive Theory adapted from Bandura (1998) [50].

The Social Cognitive Theory (SCT) was developed to address the social and personal determinants of health behaviors [50], and it has been used to investigate physical activity behaviors and decision-making among cancer survivors [51]–[53]. The SCT incorporates three core and interacting constructs: 1. environmental factors (e.g., access to physical activity-promoting assets), 2. behavioral factors (e.g., self-efficacy), and 3. cognitive/personal factors (e.g., attitudes and demographic factors) to understand physical activity behavior. These three constructs are particularly important for investigating physical activity behaviors because contextual factors, such as safety and traffic, can impact one's physical activity in addition to an individual's personal factors [51], [52]. Phillips & McAuley (2013) found self-efficacy, outcome expectations, and social support to be the most significant factors influencing physical activity behavior among long-term breast cancer survivors [51]. For my dissertation, we will build on the existing literature to investigate both the impact that personal and environmental factors may have on physical activity for people living with advanced cancer.

Evidence of whether greater access to neighborhood amenities leads to higher physical activity level is mixed among the general population and cancer survivors. A study by Lynch et al. (2010) found the physical environment (i.e., lack of suitable facilities, and perceiving neighborhood as unsafe and/or unattractive) to be significantly predictive of achieving recommended physical activity levels for colorectal cancer survivors at 5 months post-diagnosis, while McGowan et al. (2017) showed built environment variables to not be associated with physical activity for prostate cancer survivors [54], [55]. A recent review article by Namin et al. (2021) assessed the current literature on neighborhood landscapes and cancer survivorship; they found only four articles that investigated the relationship between neighborhood measures, such as access to exercise opportunities, and cancer-specific outcomes [56]–[58], [58]–[60]. Very few studies have looked at factors of perceived neighborhood safety as barriers to physical activity; however, these factors are important for assessing and addressing barriers to physical activity, and perhaps may be of greater importance for cancer survivors as they tend to be older [61]. In a cross-sectional analysis conducted among rural women in Wisconsin, women reported wanting to engage in walking but reported greater barriers to physical activity including access to places to exercise [62]. An important contribution of my dissertation research will be developing a better understanding of how people living with advanced cancer in Wisconsin describe their neighborhood environment and whether certain neighborhood factors, including perceived walkability and safety, may impact their decision to be physically active and their physical activity engagement.

SUPPORTIVE CARE

1.9 WHAT IS SUPPORTIVE CARE?

Supportive care is defined by the National Cancer Institute as “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” [63], [64]. Supportive care programs can be multimodal and include physical, social, and/or psychological components, such as exercise for cancer recovery, nutritional support, counseling, and pain support. Supportive care services are designed to complement the traditional cancer therapies meant to control and treat the cancer, such as surgery, stem cell transplants, radiation, chemotherapy, or immunotherapy [17]. Supportive care services designed to enhance rehabilitation, prevent secondary cancers, and improve survivorship and end-of-life care are key [63]. The development of these services is meant to improve the holistic health of the person and cater to their unique psychosocial, nutritional, and physical needs to better their quality of life [17].

Supportive care is sometimes used as a euphemism for palliative care; however, this is not the intent with this line of research. The definition of palliative care from the Center to Advanced Palliative Care is “specialized medical care for people living with serious illnesses. It is focused on providing patients with relief from the symptoms and stress of a serious illness” [63]. Research has shown that patients and providers have a more favorable view of “supportive care” compared to “palliative care” and are more likely to view supportive care as providing services including medical communication and information exchange, as well as mental and social support to patients [63], [65]. For the purposes of this research, palliative care is viewed as an important component of supportive care, but not synonymous with supportive care [66].

Supportive care programming may be particularly beneficial to improve long-term health and reduce future impairments for adults with an advanced cancer diagnosis because they endure particularly intensive treatments and have long recovery times. In addition, adults who have undergone stem cell transplants, most commonly as treatment for hematologic cancers, also have immense impacts on their physical function and quality of life, so it is important to understand their unique needs. To better support those living with advanced cancer, one important consideration is to determine when to introduce a supportive care intervention to a patient since supportive care interventions may begin as early as diagnosis and continue until the end of life [64].

There are two distinct windows designated as the "optimal" timing for introducing a supportive care intervention: before treatment, referred to as prehabilitation, and during or after treatment, called rehabilitation. Prehabilitation is a process that starts between a cancer diagnosis and the beginning of treatment. It can include both physical and psychological assessments to better understand baseline function and provides an opportunity for interventions to improve health and reduce the potential treatment-related impairments before treatment [67], [68]. Prehabilitation usually begins around the time of treatment and lasts 4-6 weeks depending on when treatment begins [69]. A recent exercise prehabilitation intervention for women with breast cancer awaiting surgery revealed clinically significant increases in aerobic functional capacity and preferences for multimodal interventions incorporating nutrition and psychological components [70].

In contrast to the goals of prehabilitation, rehabilitation aims to reduce complications and deteriorations in health and functioning after the initiation or completion of treatment. The post-treatment initiation of rehabilitation programming may be better suited to patients with advanced cancer since they may require intensive treatments that could begin shortly after diagnosis. Determining the optimal components of a multimodal supportive care intervention as well as the preferred timing of delivery are important considerations. More work is needed to determine preferences for programming and optimal timing for supportive care interventions among this population. My dissertation will include questions on preferred timing, activities for inclusion, and mode of delivery for this type of intervention.

1.10 CURRENT PROGRAMS AND CONSIDERATIONS FOR FUTURE INTERVENTIONS

Currently, supportive care programs are offered by some of the major cancer centers in the United States and around the world. Although some cancer centers offer supportive care programs and services, not all patients have equal access to services and there is a lack of consensus on what services to provide to patients. One successful model for providing supportive care services to patients and their families is the Cancer Supportive Care Program at the Stanford University Hospital and Clinics which began in 1999 [71]. The program currently includes a variety of services such as lectures by healthcare professionals, consultations and classes on nutrition, side effect management, free complementary and alternative medicine classes, support groups, exercises for recovery, and free chair massages for their patients [71]. The program evaluation of their free supportive care program provided early evidence of patients' interest in the program content and improved quality of life [17], [72].

More recent literature on supportive care interventions has focused on the use of technological advancements in mobile health (mHealth) to determine best practices for implementation. A recent article by Chan et al. (2020) shared results from the Annual Meeting of the Multinational Association of Supportive Care in Cancer and evaluated emerging mHealth technology as a method to enable the delivery of supportive care services [73]. Interventions incorporating mHealth to provide supportive care services could benefit patients who lack access to cancer centers due to geographical location or transportation constraints [73], like patients living in rural areas with limited access to cancer centers or urban-based services [74].

While people living with advanced cancers may be interested in a supportive care intervention, buy-in from clinicians is needed. Clinicians may need to complete baseline assessments or make referrals for the interventions, which means that they are an important piece of any supportive care program. A recent study of clinical hematologists' attitudes towards promoting exercise for patients with myeloma revealed that they felt uncertain about the timing of exercise recommendations during the disease course, stating that more guidance is needed on how to have these conversations with patients and appropriate referral pathways [75]. In another study focused on barriers to and facilitators of exercise promotion for individuals with breast cancer, health care professionals reported several barriers to discussing physical activity with their patients, including a lack of knowledge on exercise, lack of time with the patient, and inconsistencies in promoting exercise [76]. Addressing these implementation barriers is another important piece of ensuring success of supportive care programs for patients and their oncology care team. My research will include an assessment of how patients perceive discussions with their providers about physical activity in addition to any other supportive care needs.

CHAPTER 2: SPECIFIC AIMS

Increasing physical activity is important for cancer survivors, as it is known to reduce treatment side effects and recurrence, and improve quality of life, but evidence on this relationship among **adults living with advanced cancer is limited** [31], [32]**.** There is a growing number of cancer survivors in the United States and a consequent need to understand how to prevent declines in physical functioning and improve health-related quality of life (HRQoL) for cancer survivors [32]. Many cancer survivors do not meet the national recommendations for physical activity, and most of the evidence used to develop these recommendations has **excluded adults with advanced cancer**, i.e., cancers that are unlikely to be cured [6], [32], [35], [36], [38]. Furthermore, these recommendations may not be appropriate **throughout the cancer journey** from diagnosis through end-of-life, and more work needs to be done to determine the type and timing of appropriate interventions that will **best suit the needs of adults living with advanced cancer**. Adults living with advanced cancer **vary greatly in terms of treatment status, physical functioning, and prognosis** [18]. **Supportive care interventions** designed to meet the needs of adults living with advanced cancer can be multimodal and include exercise, nutrition, and/or psychological components and may be particularly beneficial to **improve long-term health and reduce future impairments** for adults with an advanced cancer diagnosis due to their particularly intensive treatments and long recovery times [67]–[69].

The goal of my dissertation is to better understand the physical activity levels, changes, and associations between physical activity and quality of life among adults living with advanced cancer as well as investigate preferences for a

supportive care intervention. My long-term goals are to develop interventions to support adults living with cancer, inclusive of all stages, to improve their physical functioning and health-related quality of life. My central hypothesis is that there will be significant differences in physical activity levels and intervention preferences among adults living with advanced cancer and that lower physical activity will be associated with worse health-related quality of life. I also hypothesize that supportive care programming will be viewed favorably by adults living with advanced cancer.

My specific aims are to:

Aim 1. Identify factors influencing physical activity among adults living with advanced cancer. I will conduct semi-structured interviews with adults living with advanced cancer in Wisconsin using an interview guide designed based on the Social Cognitive Theory and a reflexive thematic approach for analysis. I hypothesize that the sample will have unique physical activity goals and will want to engage in activities of lower intensity, like walking, making neighborhood walkability a salient factor in their physical activity decision-making.

Aim 2. Assess the relationship between physical activity levels, changes, and quality of life among adults with advanced cancer. I will develop and field a survey among adults living with advanced cancer in Wisconsin and use multiple linear regression to model the association between physical activity changes, levels, and quality of life. I hypothesize that the sample will have reduced their activity and that having greatly reduced physical activity will be associated with higher health-related quality of life.

Aim 3. Investigate barriers to physical activity and supportive care intervention preferences among adults with advanced cancer. I will use the survey from Aim 2 to assess barriers to physical activity by physical activity lelve. I will also assess if demographic and clinical characteristics impact preferences for a supportive care intervention (age, gender, urbanicity, cancer type, and treatment status). I hypothesize that most adults with advanced cancer will be interested in components of a supportive care intervention and that preferences will be impacted by demographic and clinical characteristics.

CHAPTER 3: AIM 1

"There is no expiration date": A qualitative analysis using the Social Cognitive Theory to identify factors influencing physical activity among adults living with advanced cancer

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The paper was submitted to the journal, *Supportive Care in Cancer,* in October 2023.

ABSTRACT

Purpose: To identify cognitive, behavioral, environmental, and other factors that influence physical activity in adults with advanced cancer using qualitative, semi-structured interviews. **Methods:** Eighteen semi-structured interviews were conducted with adults living with stage IV breast, prostate, or colorectal cancer; or multiple myeloma recruited from the University of Wisconsin Carbone Cancer Center. We used the Social Cognitive Theory to design the interview guide and a reflexive thematic approach for analysis.

Results: Participants were 62 years old on average and currently receiving treatment. Despite reporting numerous barriers to physical activity, most participants discussed engaging in some physical activity. Participants reported difficulties coping with changes in physical functioning especially due to fatigue, weakness, neuropathy, and pain. While cold weather was seen as a deterrent for activity, access to sidewalks was a commonly reported feature of neighborhood conduciveness for physical activity. Regardless of current activity levels, adults with advanced cancer were interested in engaging in activities to meet their goals of gaining strength and maintaining independence. Having a conversation with a provider from their cancer care team about physical activity was seen as encouraging for pursuing some activity.

Conclusions: Adults living with advanced cancer are interested in pursuing activity to gain strength and maintain independence despite reported barriers to physical activity. To ensure patients are encouraged to be active, accessible resources, targeted referrals, and interventions designed to address their goals are critical next steps.

Relevance: Integrating conversations about physical activity into oncology care for adults living with advanced cancer is an important next step to encourage patients to remain active and help them improve strength and maintain quality of life and independence.

Keywords: physical activity, well-being, advanced cancer, quality of life, intervention

INTRODUCTION

The US is home to a large and growing population of cancer survivors. Due to an aging population, improved screening rates, and advances in cancer treatments, the US population of cancer survivors is expected to grow to 26 million by 2040 [1]. Many cancer survivors face physical and/or psychological sequelae including functional limitations, fatigue, anxiety, and depression due to their cancer and subsequent cancer treatments [2]–[5]. Increasing physical activity is particularly important for cancer survivors, as it is known to reduce treatment side effects and improve health-related quality of life (HRQoL) but evidence on the feasibility and benefits of physical activity for those living with advanced cancer diagnoses is limited [6], [7]. The term “advanced cancer” is typically used to describe cancers that are unlikely to be cured [8]. Adults living with advanced cancer can vary greatly in terms of treatment, functional status, and prognosis [9]. It is evident that some adults living with advanced cancer can live for many years, while some have a short prognosis [10].

Most of the physical activity interventions designed to date have targeted breast or colon cancer survivors, and many have excluded those individuals with stage IV disease [6], [9]. Individuals with stage IV historically have been excluded from physical activity research for two reasons. First, there is recognition that the impact of behavioral interventions on cancer survival is likely attenuated after distant metastasis. Second, recruiting and retaining participants living with advanced disease to a physical activity trial poses methodological challenges (e.g., the need to plan for high attrition due to disease progression and mortality). The consequent exclusion of this group from physical activity research has resulted in a gap in knowledge and thus more work is needed to understand the physical activity abilities, goals, and preferences of this growing population.

While adults living with advanced cancer have been underrepresented in physical activity trials to date, this group may additionally benefit from physical activity interventions designed to reduce physical decline, improve functioning, and promote their overall quality of life [6], [11]. Due to the intensive and ongoing of treatments given to those living with advanced cancer, mounting treatment side effects can have a worsening impact on quality of life [12]. A few previous studies have shown that exercise interventions among adults with advanced cancer are effective at improving aerobic capacity, strength, fatigue, and quality of life, so finding ways to deploy physical activity interventions to improve both physical function and quality of life are essential [13]–[15].

Designing interventions based on the abilities, goals, and preferences of the target population may increase the likelihood of success in both intervention recruitment and potential sustained physical activity after completion of the intervention. A recent study by Knowlton et al. (2020) investigated the barriers to exercise among cancer survivors, including those with advanced disease, and found the most commonly reported barriers were: limitations by other conditions/illnesses (36%), not enough free time (16%), and not sure how much to exercise (8%) [9]. Furthermore, researchers found high levels of willingness to increase exercise among patients living with advanced disease with 79% of survivors interested in obtaining more information about physical activity and exercise despite reported barriers to exercise [9]. An overall assessment of abilities, goals, and preferences of this unique population is needed to develop a promising future intervention.

Assessing barriers to physical activity experienced by adults living with advanced cancer is necessary to develop effective interventions. Both cancer-specific barriers and general barriers to physical activity, such as lack of access to physical activity promoting amenities, including sidewalks and trails; and weather concerns, are addressed in this study. Due to the geographically diverse nature of Wisconsin, which has a high proportion of rural areas in addition to suburban and urban areas, residents in Wisconsin have a variety of experiences in terms of places to be physically active. In Wisconsin, lack of access to safe spaces for physical activity and traffic and safety concerns may be important considerations among our target population [16]. Consequently, these topics are explored to determine if these are impactful barriers among adults with advanced cancer living in non-urban settings.

The purpose of this investigation is to identify cognitive (knowledge, attitudes, expectations), behavioral (skills, practice, self-efficacy), environmental (social norms, access), and other factors that influence physical activity in adults with advanced cancer using qualitative, semi-structured interviews. We hypothesized that there would be commonly identified barriers and facilitators to activity as well as goals for future physical activity in this population of adults living with advanced cancer that will be critical for future intervention development.

METHODS

Study Overview

The investigation used qualitative research methods, including semi-structured interviews with N=18 adults living with advanced cancer (stage IV breast, prostate, colorectal cancer; or multiple myeloma). This study was approved as minimal risk by the University of Wisconsin-Madison's Minimal Risk Institutional Review Board (Protocol #2019-0767) and by the Carbone Cancer Center's Protocol Review and Monitoring Committee (Protocol UW18135).

The Social Cognitive Theory (SCT) was the theoretical framework used to develop the interview guide with questions designed around the cognitive, behavioral, and environmental constructs (Supplemental Material A: Interview Guide and Social Cognitive Theory Constructs) [17], [18]. The SCT contains the three core constructs of: (1) cognitive/personal factors, including attitudes, knowledge, and expectations; (2) behavioral factors, like self-efficacy, practice, and skills; and (3) environmental factors, such as traffic, safety, and access to amenities like gyms and trails (Figure 1) [18]. The SCT provided a suitable theoretical framework to explore a variety of factors that may impact physical activity engagement among adults with advanced cancer and has been used previously to investigate physical activity engagement among long-term breast cancer survivors [19]. Follow-up questions and probes based on responses were used to facilitate a deeper understanding of participants' experiences.

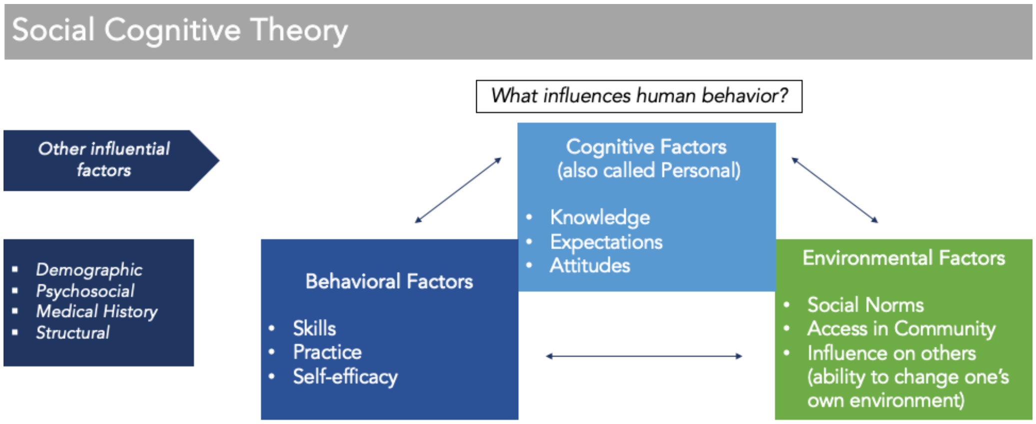

Fig. 1 The theoretical framework, Social Cognitive Theory, with constructs adapted from Bandura (1998) [20]

Recruitment and Participants

Using the NCI SEER*Explorer, incidence rates and 5-year distant survival rate percentages were assessed for a variety of cancers using the most recently available data (Figure 2). Three common cancer types were selected breast, prostate, and colorectal. The less common diagnosis, multiple myeloma, was also selected due to its high 5-year survival rate percentage with approximately 54% of patients expected to live 5 or more years after diagnosis.

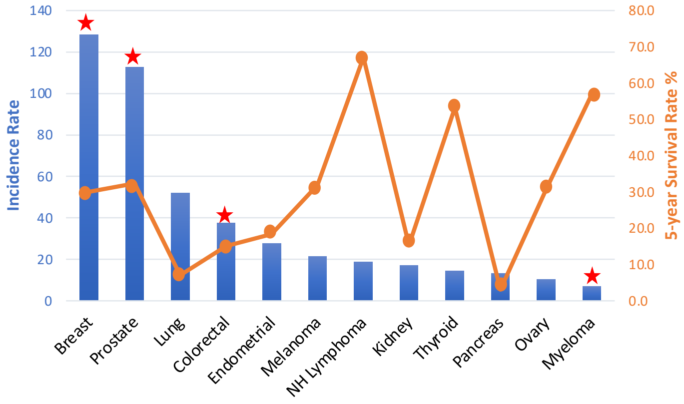

Fig. 2 Age-adjusted incidence rates (# of new cases/year per 100,000 population) and 5-year distant survival rate % (% of people with distant disease who lived at least 5 years). Distant refers to a stage IV diagnosis. Cancers in this study are marked with a red star. Data source: NCI SEER*Explorer, 2023

Patients were recruited through the University of Wisconsin's Carbone Cancer Center (UWCCC) by informing oncologists about the study and asking oncologists to refer eligible patients to the research staff at the Wisconsin Physical Activity Epidemiology Lab.

Each oncologist was given the eligibility criteria and asked to refer four patients seen in their clinic who met the following criteria: 18-75 years of age; stage IV breast, colorectal, or prostate cancer, or multiple myeloma diagnosis; an Eastern Cooperative Oncology Group's (ECOG) Performance Status rating of 0, 1, or 2; and fluent in spoken and written English. We excluded patients who were incapable of selfcare or confined to a bed or a chair for more than 50% of their waking hours, i.e. ECOG status of 3-4, as these patients were not expected to have capacity to engage in recommended levels of physical activity [21]. Exclusion criteria included having a significant cardio-metabolic abnormality including heart failure.

Oncologists asked eligible patients to complete a written permission to contact form which included information about the study and preferences for contact time and mode (by phone or email). Research staff at the Wisconsin Physical Activity Epidemiology Lab made up to three attempts to contact eligible patients. Once contact was made with a participant, they were screened to ensure eligibility criteria and willingness to complete an interview about physical activity, and to inquire about current participation in any other physical activity studies (none reported). Individuals provided verbal consent by agreeing to participate following a study explanation during the screening call. Interviews were scheduled based on the participant's preferred date and time. Research staff obtained participants' permission to record their interviews during the screening phone call and again at the time of the interview; participants were also told when the recording was started and stopped.

Oncologists reported failed screening for patients due to them being above the age limit (*n* = 6-8) and not fluent in spoken and written English (*n* = 1). Oncologists referred a total of *n* = 30 eligible patients who were willing to be contacted about the study. Research staff attempted to contact *n* = 25, and of those patients, *n* = 5 were not reachable after three contact attempts and *n* = 2 were no longer interested after learning more about the study. A total of *n* = 18 (72% of those contacted) agreed and completed the interview.

Data Collection

Research staff conducted interviews in-person at the UWCCC prior to the onset of the COVID-19 pandemic (*n* = 5; August-November 2019), and over the phone afterward (*n* = 1; March 2020; *n* = 12; October-December 2022). Researchers were students and faculty with educational training in physical activity epidemiology and personal experience with participation in sports and physical activity.

Interviews were recorded with permission from each participant and transcribed verbatim by a research assistant. Research staff wrote field notes during the interviews. The interviews were expected to last 30 minutes, and the mean duration of the interviews was 31 minutes (range = 21 – 43 min). Participants were given a token of $40 as appreciation for their time.

Data on the participants’ demographics (age group, education level, sex, and race/ethnicity) were collected at the end of the interview.

Data Analysis

A reflexive thematic approach was used as it allowed for flexibility for use of a theoretical framework, the Social Cognitive Theory, to both develop the line of inquiry and situate as researchers, while allowing the ability to inductively develop our analysis to share the perspectives of people living with advanced cancer [22], [23]. The analysis began with the first author (MA) familiarizing herself with the data through listening to each interview and ensuring the accuracy of the transcripts [22], [24].

MA and a research assistant open coded three transcripts with variation in cancer type to generate initial codes and met to discuss their initial findings. While both researchers independently coded the transcripts, we had regular research meetings to ensure codes were accurately capturing the data and discuss the evolving data structure and codes. MA developed a codebook to allow for ease of mapping the developing codes for both coders [25]. During the coding process, codes were condensed, deleted, or added to better reflect the data. MA reviewed the transcripts and codes for preliminary themes after both coders coded the transcripts and developed the preliminary themes based on the codes and data relevant to the research question. We reviewed the data associated with the preliminary themes and further refined them into themes and subthemes. We finally defined the themes and MA created a thematic map to illustrate the relationships between themes and subthemes (Figure 3) [23]. Participant quotes representative of each theme were identified to provide illustrative examples of our themes. Coding was done using Dedoose 9.0 software.

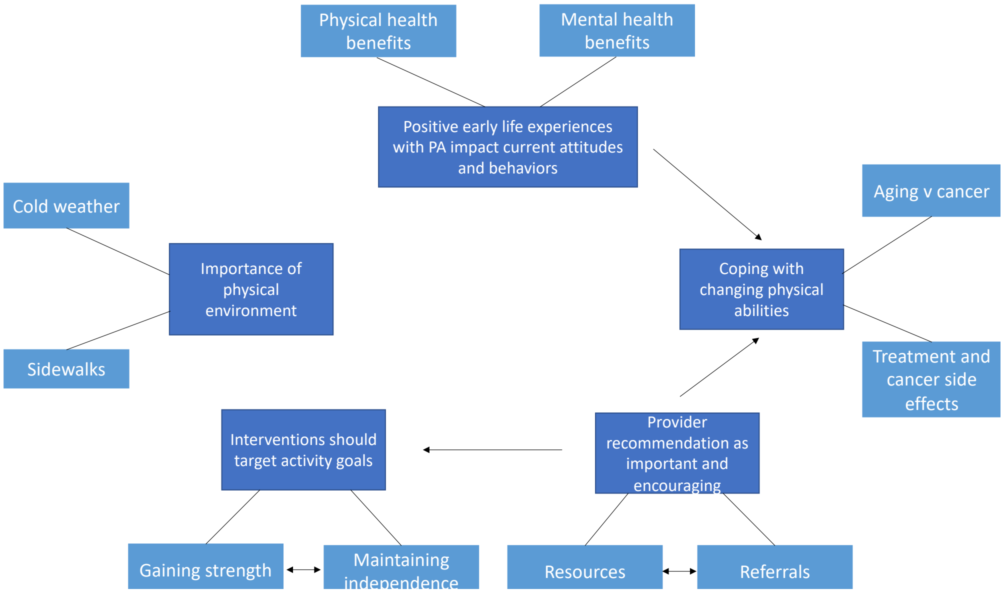

Fig. 3 Thematic map illustrating relationships between the major themes and associated subthemes

RESULTS

Participant Characteristics

The demographic and clinical characteristics of the participants (*n* = 18) can be found in Table 1. The average age of participants was 62 years with a range from 42-74 years of age. Most of the participants were male (56%) and high school graduates (44%) compared to completing some college (28%) or a Bachelor's degree (28%). All the participants were currently receiving one or multiple forms of treatment for their cancer including chemotherapy (*n* = 11), hormone therapy (*n* = 6), immunotherapy (*n* = 2), bone modifying treatment (*n* = 3), steroid injections (*n* = 2), and/or had a stem cell transplant less than 3 months ago (*n* = 1). More than half of the participants self-reported participating in physical activity on a regular basis (*n* = 10).

Major Themes

Five major themes were identified. The first theme, *positive early life experiences with physical activity impact current attitudes and behaviors*, investigates the types of activities that participants engaged in across their life and before their cancer diagnosis as well as the physical and mental health benefits of those activities. The second theme, *coping with changing physical abilities*, reflects the discussions of how cancer and its treatment have impacted participants' activity and specifically grappling with changes in physical functioning that may be due to cancer and/or aging. The third theme, *provider recommendation as important and encouraging*, describes the conversations participants recall having with their providers around physical activity and how these conversations were important for pursuing activity, but additional recommendations on resources and referrals might be warranted. The fourth theme, *interventions should target activity goals,* focuses on participants' specific goals of maintaining independence and gaining strength. The fifth theme, *importance of physical environment on physical activity decision making*, relates to the extent to which participants described features of their environment, such as sidewalks and weather, as important for engaging in physical activity. Representative quotes from the main text and additional quotes that that were not placed in the main text can be found in Table 2.

Theme One: Positive early life experiences with physical activity impact current attitudes and behaviors

Many of the participants discussed positive early life experiences with physical activity whether for team sports or leisure. Team sports were a common source of positive early life activity, as discussed by both male and female participants, including this male participant, *"I have always had good physical activity. I worked a lot and played ball and whatnot all my life. [...] Well, softball, baseball."* (Colorectal A). Another common form of early life physical activity was for leisure, like biking and hiking, as described by several participants. Manual labor jobs were also a source of physical activity for a few male participants, like this man living with colorectal cancer, *"…I've always had physical jobs [...] lifting heavy parts [on] a daily basis, always active."* (Colorectal B).

Positive early life experiences with physical activity impacted participants' current attitudes towards physical activity being beneficial for them despite reported barriers due to their illness and/or side effects of treatment. One female participant spoke of how her chemotherapy treatment affected her physical activity, but her early life experiences with physical activity made it easier for her to get back into being more active after her diagnosis:

> *"…I didn't have a lot of terrible side effects, but I was tired from it, and I lost some weight from it. So, I really just stopped doing any kind of regular working out during that time. I would say that probably lasted for five months where I kind of didn't feel like I wanted to work out. And then getting back into it, it was probably somewhat easier for me since I have been doing it my whole life, but I will say, that it kind of made me-- it went two ways, one was I knew I had to do it because it was good for me to do-- it would help my cancer diagnosis. And another was that I didn't know if my body was ready for it or not, so I started really slow and really easy."* (Breast A)

Specifically, participants with positive early life experiences freely spoke about the positive mental and physical health benefits they experienced when they engaged in activity on a regular basis. Some participants discussed the positive mental health and physical health benefits of physical activity including relaxation and increased energy. An active male participant with prostate cancer discussed the physical and mental benefits of physical activity describing physical activity as *"…believe it or not, it's relaxation to me. It clears my mind, makes my body feel better. It's a goal that I want to continue reaching."* (Prostate B). An active female participant living with breast cancer described how she experiences mental health benefits when she is swimming, *"…for me it's almost like just a sign of meditation or kind of like a meditation."* (Breast D).

Although some participants reported not engaging in much current activity, they still spoke of the many positive benefits of physical activity for mental health and thought that if they were more active, it would be beneficial for their mental and physical health. One female participant living with myeloma discussed how she thought getting more exercise could help with her mental health, *"Well, I certainly feel like it could improve my health. There's no doubt about it, I would be stronger and safer, you know? I'd be happier mentally and I c[ould] do more things."* (Myeloma A). Another woman with myeloma discussed how being more active would improve her mental health and self-esteem, *"Oh, I feel like it would improve my health for sure, because I['d] just feel better about myself. I've gained a lot of weight which I also somewhat attribute to the steroids, but also, it's probably just having to deal with everything."* (Myeloma B).

Theme Two: Coping with changing physical abilities

Coping with, in some cases, dramatic changes in physical functioning from their cancer and side effects of treatments was discussed by most of the participants. Participants discussed some common functional changes due to their cancer or its treatment including increased fatigue, weakness, pain, and neuropathy. One male participant discussed how he'd noticed a reduction in his stamina and strength which made him change how he did things:

> *"...I used to have a lot more stamina. But with the cancer and stuff and the strength-- so, I lost a lot of muscle mass and that's hard to get used to, but I can still do it if I want to. It may take a little bit longer, you know, to find different ways to do things. More with equipment or machinery, you know?"* (Prostate C)

A female participant with myeloma expressed a similar sentiment that she couldn’t do things in the same way as she did prior to her cancer diagnosis, *“…it’s much more of a chore to go do something that I want to do than it was before. I can’t say that I don’t do the things that I like to do, it just takes me longer and I might not be everything exactly the way I used to.”* (Myeloma D)

In terms of increasing pain and neuropathy, this was more commonly discussed by participants with colorectal cancer and myeloma. A participant living with colorectal cancer discussed how he was struggling with these substantial changes to his physical function, *“shooting pains would come up my legs all the way to my hips and my arms, you know, from my hands all the way up my arms, you know? They would wake me up and I just couldn’t sleep.”* (Colorectal B). These challenges with pain were particularly apparent for myeloma participants due to their commonly reported bone fractures. One woman discussed the impact of her disease on her bone integrity which led to fractures, and in turn, severe pain, *“with the fractured vertebrae and these broken ribs, and so I was not doing a lot of anything because it hurt to move. I had to be dragged out of the chair. […] I was walking with a walker, barely. So, that was certainly a big slow down.”* (Myeloma A).

During several of the interviews, participants discussed the challenge of attributing their declines in physical functioning to aging, cancer, treatment, or some combination of factors. The following example illustrates a participant describing his uncertainties, *“I’m not steady on my feet like I used to be. And, like I said, I don’t know if it’s from the medicine or the age.”* (Prostate D). Others discussed how it had been a few years since their diagnosis and they expected some decline in their activities as they got older. In contrast, a few participants discussed how they thought their decline in ability was due to aging, but not their cancer. One participant with breast cancer discussed how she thought most of her decline in mobility was due to aging and her lack of exercise, but not her cancer:

> "*I don't feel like I have the strength that I used to have. Once in a while, I am just like, wow, this isn't-- I just don't have the juice in my joints, but I guess I don't feel as though my cancer has affected my activity, it's more my age."* (Breast C)

Theme Three: Provider recommendation as important and encouraging

For those participants who discussed having a conversation with a member of their oncology care team about physical activity, a provider recommendation to be active was seen as important and encouraging. Almost all participants mentioned having conversations with their provider about physical activity. One male with prostate cancer described the following recommendation, *"You don't know what to expect and you know you're thinking they told me that you've got to keep active, you just gotta keep doing what you're doing, so that's what I kept doing."* (Prostate E). Another male participant recounted how his providers discussed activity with him and how these conversations encouraged him to try to remain active:

> "*Well, they tell me to do what I can, you know, to try to stay active, which I do. I try not to be a total coach potato here; I get up and do things. I try to do a lot of housework, you know, vacuuming and whatnot when I can*." (Colorectal A)

When asked about whether they received information from their providers about physical activity, several participants described the general recommendation from their providers to "stay active" which encouraged them to remain active. Those participants who were already active felt as if they had what they needed and encouragement from their provider was sufficient to continue to be active.

A few participants made it clear that they were the ones to bring up the topic of physical activity to their providers to ask for advice and felt as though their providers did not provide them with resources or enough information. In the context of the question about conversations with providers about physical activity, a woman with breast cancer recalled a time when she asked her provider about ways to keep herself healthy and felt like she didn't receive adequate information:

> "*When I was first diagnosed, I said, 'what should I do to help myself?', and she said, 'keep yourself healthy', and I said, 'what would that mean for me? What would you suggest for me?' and she said, 'keep yourself healthy'. And I'll never forget that because I thought that's not enough*." (Breast C)

Participants with myeloma mentioned that their providers encouraged them to be active but careful in their activities. In addition, all participants with myeloma discussed their oncologist's referral to physical therapy as an important resource for them to either maintain strength before treatment or increase their strength after treatment. One woman with myeloma discussed her experience with physical therapy and how it helpful was for her, "*And [physical therapy] was tremendously helpful, strengthening the core and helping with my back issues with the fractures and everything."* (Myeloma A).

Theme Four: Interventions designed to help adults living with advanced cancer meet their goals are needed.

In terms of activity goals for the future, most participants spoke of wanting to maintain a certain level of independence for as long as possible. One male participant with myeloma discussed his goal of wanting to do things on his own, like shopping, *"I want to move and get around and go shopping when I need to go shopping and I can do it on my own. That's good for me. I know there's going to come a time when I can't do* *that."* (Myeloma C). Another male participant with prostate cancer described his goal of wanting to maintain what he's doing:

> *"And so, my goal would probably be to continue doing what I'm doing so that I'm able to keep doing it. You know, if you don't use it, you lose it. Even though I've lost so much, but I'm maintaining what I have, and that's the goal to me..."* (Prostate C)

In terms of other commonly discussed goals, many participants discussed the goal of gaining strength. A woman living with myeloma described how she'd like to make herself stronger and more in balance through yoga:

> *"…that was the kinda the impetus to do the yoga thing because at least that's what it's all about is balance and I can make myself stronger without killing myself saying like 'oh I have to run even though it makes me feel miserable,' so that was the biggest thing, but yeah, I definitely think it would help my mental and physical well-being to just be more in balance and have a better physical activity."* (Myeloma B)

In addition, a few participants discussed wanting to get back to old activities they enjoyed, such as playing with their grandchildren and light intensity activities like bowling. Although some participants discussed goals in the context of the goal question, others described goals in response to the question on how physical activity might improve or worsen health, one woman with myeloma responded that she was afraid of becoming totally dependent on other people due to health declines, something she did not want, *"…I'm afraid that if I don't keep moving and doing things, that it'll just-- it'll get worse, so I don't want that to happen. You know, totally dependent on other people or something."* (Myeloma D).

Theme Five: Importance of physical environment on physical activity decision making

As part of the interview guide developed using the Social Cognitive Theory, participants were asked several questions about their neighborhood environment to better understand their access to opportunities for physical activity close to home and whether their neighborhood's conduciveness for physical activity was important to them. Responses to these questions were mixed with some participants feeling that the traffic and lack of sidewalks in their neighborhood were problematic for engaging in physical activity while others reported feeling that their neighborhood did not impact their physical activity because they did their activity indoors. One male participant discussed that he chooses to bike on roads with less traffic, *"I bike on roads because I live in [CITY] and there [are] no bike paths, so I go on a country road that is less traveled. I don't like going on highways of course, you know, with the busy travel."* (Prostate E). Another male said he doesn't feel safe due to the lack of a shoulder on the road and too much traffic, *"I live on a country road that is not safe to walk on. […] There is no edge and a lot of traffic."* (Colorectal C).

Sidewalks were the most reported feature of access to opportunities to be active among participants. One participant with myeloma describes how sidewalks make it accessible and safe for walking, *"…a couple years ago, they put sidewalks in. So, it's a very residential area, so there's lots of places to walk. There's a lot of parks. You know, I feel like it's a safe place to live."* (Myeloma D). One participant discussed how he chooses to walk in one direction due to the condition of sidewalks in his neighborhood, *"…the one direction I don't go because the sidewalks are not very good. The other way, the sidewalk's a lot flatter and less cracks."* (Colorectal B).

Interestingly, a few participants who lived in rural settings felt that where they lived was "walkable" because they enjoyed walking on their own property and didn't have concerns about traffic or lack of sidewalks when considering their activities.

Cold weather was another environmental factor that impacted participants' physical activity. This type of environmental barrier to activity is an important consideration in Wisconsin and other temperate climates. One participant discussed wanting to join a fitness club in the winter to manage the cold, *"I was thinking about joining a fitness club during the wintertime because it is getting colder and stuff like that just to work on my muscles."* (Prostate E); in another interview, a participant mentioned that they avoid walking outside in winter, only doing so "in the summer, when it was warm" (Myeloma C).

DISCUSSION

Major Themes

Our study sought to assess cognitive (knowledge, attitudes, expectations), behavioral (skills, practice, self-efficacy), environmental (social norms, access), and other factors that influence physical activity in adults living with advanced cancer. We found that participants recounted positive early life experiences with physical activity, current challenges coping with their illness and treatment side effects, and common goals for future activity. To our knowledge, this is the first study to investigate both individual and contextual factors that may impact physical activity decision making among adults living with several types of advanced cancer in the US.

We found that most participants discussed participating in some form of activity during early life (e.g., team sports, general activities for fun like biking and walking, or manual labor jobs), not just for formal exercise. Already having experience participating in physical activity can lead to a higher self-efficacy for exercise which is an important factor for people to determine whether to engage in physical activity [18], [20]. In addition, these past experiences can influence one’s knowledge, attitudes, and expectations towards the behavior of physical activity [18], [20]. Positive early life experiences with physical activity impacted participants’ current attitudes towards physical activity being beneficial for them despite reported barriers to being active due to their illness and side effects of treatment. Further, participants who spoke about the positive physical and mental health benefits of activity who were not currently engaging in activity were interested in engaging in activity to reap those benefits. A study by Bland et al. (2022) found that exercise offered people with advanced cancer and cachexia psychological benefits such as improved mood and acted as an emotional outlet to help take one’s mind off their diagnosis; similarly, patients in our study spoke of the various mental health benefits of being active whether from exercise or participation in activities of daily living [26].

Considering whether declines in a patient’s physical functioning are due to cancer or aging could be useful for the purpose of determining components of an appropriate physical activity intervention. If patients think that these declines are a normal part of aging, they may be less likely to bring them up to their oncology care team as concerns related to side effects of treatment or symptoms of their cancer. In certain cases, some of these declines can be treated by therapies such as physical therapy (PT) or occupational therapy (OT). If patients discuss these concerns, specifically declines in balance and strength, an oncology care provider could make a necessary referral and it’s possible that these deficits could be reduced, at a minimum. In addition, cases where cancer may be causing pain could be dealt with using palliative modalities and referral to a palliative care provider might be warranted. Accelerated aging is also a necessary consideration among this population as they may experience greater physical declines compared to similarly aged individuals as a result of undergoing intensive, and in the case of advanced cancer, ongoing cancer treatments [29], [30].

For patients who may not be as familiar with physical activity, a provider recommendation from the oncology care team along with resources and/or referrals to get them started may be needed. Several participants discussed having conversations with their doctor about physical activity and found these conversations encouraging for engaging in some activity. Social support for physical activity, especially from a healthcare provider, was seen as motivating for some participants, and could reinforce already established positive beliefs about the importance of physical activity [26]. A qualitative study by Chang et al. (2020) focused on people living with metastatic lung cancer and similarly found that physician social support was critical to encourage patients with advanced cancer to exercise [27]. Other research has shown that recall of physical activity advice from a provider after diagnosis with colorectal cancer was associated with higher levels of physical activity [28]. Incorporating social support for physical activity from a member of an oncology care team could be a critical piece of any physical activity intervention designed for patients with advanced cancer. Since many of the participants reported how highly they valued their care team in other parts of the interview, a recommendation from a member of their care team could be vital to the success of a patient’s attempt(s) to engage in more physical activity. It is important to note that this type of recommendation may be more impactful and important for patients not engaging in any activity and who have less prior experience engaging in activity than some of the participants in our sample. Among the sample with myeloma, a referral to physical therapy was viewed as an important factor in maintaining strength before or increasing strength after treatment. A few participants described not receiving enough information on physical activity from their providers, so acknowledging the importance of targeted resources and referrals from providers is a critical next step.

It is imperative to tailor a physical activity intervention to meet the target population's physical activity goals. The goals provide motivation and can give the participant a sense of control, and in the case of adults living with advanced cancer, there is a lack of control in other aspects of their lives making this a key component of a future intervention [20]. Many of the participants discussed wanting to maintain independence for as long as possible, and this was true especially among older participants. An overall desire to improve strength to maintain independence and feel stronger was also discussed by several participants across the age spectrum of our sample.

An important contribution of our study was that we considered not only the individual-level barriers to physical activity among people living with advanced cancer, but also the contextual barriers, i.e., aspects of the neighborhood environment, that can impact anyone's ability to be physically active. We hypothesized that the neighborhood's conduciveness for activity would be important for this population since light intensity activities, like walking, may be preferred based on existing literature supporting walking as a preferred activity among people with advanced cancer [26], [31]. Overall, some participants felt that their neighborhood was important, particularly the presence of sidewalks for walking, but some participants who lived in rural environments considered their own property to be equally or safer with natural spaces and no traffic. The importance of access to exercise facilities was not mentioned by many of the participants because they either already had space in their home or on their property to be active or were able to drive to bike paths and other locations that suited their needs [32]. In terms of safety for exercising outdoors, the importance of the availability of bike paths and sidewalks for walking that are separated from traffic was discussed by a few participants [32], [33]. In a small study of female cancer survivors, DeGuzman et al (2019) found that regular activity was supported by access to walking paths and visual variety in the built environment [33]. Although not a major theme identified in our study, some participants discussed the varied terrain and parks as pleasurable environments for walking in their neighborhoods. In addition to neighborhood, the cold weather was a commonly reported barrier by several participants, as found in other studies investigating physical activity among people with advanced cancer and the general population [34], [35].

Strengths and Limitations

One strength of our study is that participants were diverse in terms of sex, age, cancer type, and treatments received, which allowed for capturing a wider range of experiences among participants. Another strength was using a theory-informed design for the interview guide so we could better capture the scope of individual- and neighborhood-level factors that may influence one’s engagement in physical activity.

Our sample may be subject to selection bias on the part of the clinician identifying patients to recruit into study. We asked clinicians to recruit a diverse set of patients in terms of physical abilities while still having an ECOG performance status of

0-2, however, it is possible that clinicians chose patients who were more likely to engage in physical activity to participate. We did have diversity in our responses to questions about current abilities and future goals, so we do not think this is a major source of bias in our sample. Another possible source of selection bias is that patients more interested in physical activity may have agreed to participate in the study as opposed to those who decided not to participate, however only five patients declined to participate after agreeing to be screened.

CONCLUSIONS

Despite participants reporting numerous cancer- and treatment-specific barriers to physical activity, some adults living with advanced cancer were still participating in physical activity. Most of the adults living with advanced cancer, regardless of current activity level, were interested in engaging in activities to meet their goals of gaining strength and maintaining independence. Some participants also described a desire to get back to pre-diagnosis activities, such as playing with their grandchildren and light intensity activities like bowling.

Having a conversation with a provider from their cancer care team about physical activity was seen as important and encouraging for pursuing some activity. Most of the participants who spoke about physical activity with a provider were already pursuing some activity and discussed the physical and mental health benefits of physical activity. To ensure that all patients are encouraged to be active, including patients who are not as active or lack self-efficacy, more direct resources and referrals are needed to motivate patients.

Designing physical activity interventions to meet the unique needs of adults living with advanced cancer are needed, specifically to help them meet their goals of maintaining independence and gaining strength.

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TABLES AND FIGURES

Table 1. Demographic and Clinical Characteristics of Interview Respondents

Characteristics	***n* (%)**
Demographics	
Age Group	
40-49 years	2 (11%)
50-59 years	1 (5%)
60-69 years	12 (67%)
70-75 years	3 (17%)
Education	
High school graduate	8 (44%)
Some college	5 (28%)
Bachelor's or higher	5 (28%)
Sex	
Male	10 (56%)
Female	8 (44%)
Clinical Characteristics	
Cancer Type	
Breast	5 (28%)
Colorectal	4 (22%)
Multiple Myeloma	4 (22%)
Prostate	5 (28%)
Disease Stage	
Metastatic	17 (94%)
Locally Advanced	1 (6%)
Current Treatment Type[a]	
Chemotherapy	11 (61%)
Hormone therapy	6 (33%)
Immunotherapy	2 (11%)
Bone treatment	3 (17%)
Stem cell transplant (<3 months ago)	1 (6%)
Steroid injections	2 (11%)
Treatment Status	
On Treatment	18 (100%)

[a] Patients could report being on more than one treatment, so these numbers do not add up to 100%.

Table 2. Representative Quotes of Major Themes

Major Themes	Representative Quotes
Positive early life experiences with physical activity (PA) impact current attitudes and behaviors	*"I have always had good physical activity. I worked a lot and played ball and whatnot all my life. [...] Well, softball, baseball."* (Colorectal A, 60-69 years old) *"I've always had physical jobs [...] lifting heavy parts [on] a daily basis, always active..."* (Colorectal B, 60-69 years old) *"...I didn't have a lot of terrible side effects, but I was tired from it, and I lost some weight from it. So, I really just stopped doing any kind of regular working out during that time. I would say that probably lasted for five months where I kind of didn't feel like I wanted to work out. And then getting back into it, it was probably somewhat easier for me since I have been doing it my whole life, but I will say, that it kind of made me-- it went two ways, one was I knew I had to do it because it was good for me to do-- it would help my cancer diagnosis. And another was that I didn't know if my body was ready for it or not, so I started really slow and really easy."* (Breast A, 40-49 years old) **Physical and mental health benefits of physical activity** *"…believe it or not, it's relaxation to me. It clears my mind, makes my body feel better. It's a goal that I want to continue reaching."* (Prostate B, 60-69 years old) "…[swimming] *for me it's almost like just a sign of meditation or kind of like a meditation*." (Breast D, 70-75 years old) *"Well, I certainly feel like it could improve my health. There's no doubt about it, I would be stronger and safer, you know? I'd be happier mentally and I c[ould] do more things."* (Myeloma A, 60-69 years old) *"Oh, I feel like it would improve my health for sure, because I just feel better about myself. I've gained a lot of weight which I also somewhat attribute to the steroids, but also, it's probably just having to deal with everything."* (Myeloma B, 40-49 years old)
Coping with changing physical abilities	*"...I used to have a lot more stamina. But with the cancer and stuff and the strength-- so, I lost a lot of muscle mass and that's hard to get used to, but I can still do it if I want to. It may take a little bit longer, you know, to find different ways to do things."* (Prostate C, 60-69 years old)

	“*…it’s much more of a chore to go do something that I want to do than it was before. I can’t say that I don’t do the things that I like to do, it just takes me longer and I might not be everything exactly the way I used to.*” (Myeloma D, 60-69 years old) *“…shooting pains would come up my legs all the way to my hips and my arms, you know, from my hands all the way up my arms, you know? They would wake me up and I just couldn’t sleep.”* (Colorectal B, 60-69 years old) *“…with the fractured vertebrae and these broken ribs, and so I was not doing a lot of anything because it hurt to move. I had to be dragged out of the chair. […] I was walking with a walker, barely. So, that was certainly a big slow down.”* (Myeloma A, 60-69 years old) *“I still get tired, but I have, you know, a few hours in there, where I can be quite busy and going and doing, but then by four or five o’clock, I have to stop. And that is not like me.”* (Colorectal C, 50-59 years old) **Grappling with functional declines due to aging, cancer, treatment, or some combination of factors** *“I’m not steady on my feet like I used to be. And, like I said, I don’t know if it’s from the medicine or the age.”* (Prostate D, 60-69 years old) “*I don’t feel like I have the strength that I used to have. Once in a while, I am just like, wow, this isn’t-- I just don’t have the juice in my joints, but I guess I don’t feel as though my cancer has affected my activity, it’s more my age.”* (Breast C, 60-69 years old)
Provider recommendation to engage in physical activity is important and encouraging	*“You don’t know what to expect and, you know, you’re thinking they told me you’ve got to keep active, you just gotta keep doing what you’re doing, so that’s what I kept doing.”* (Prostate E, 60-69 years old) “*Well, they tell me to do what I can, you know, to try to stay active, which I do. I try not to be a total coach potato here; I get up and do things. I try to do a lot of housework, you know, vacuuming and whatnot when I can*.” (Colorectal A, 60-69 years old)

	“They encourage me to-- both my nurse practitioner and my oncologist are like just if you even just walk every day, it will do wonders.” (Myeloma B, 40-49 years old) *“Well, they want me to get up and walk and be active and I’m trying to do that. You know, sometimes you’ve just gotta drive yourself to do it, like I said, and it’s hard, you know? But, like I said, I’m an outdoorsman. I have a yard, a big garden, I mean I’m always outside and putzing and doing something probably maybe not as physically demanding as it should be, but I go until I get tired and then I sit down.”* (Prostate D, 60-69 years old) **Recommended resources and referrals are needed** *“When I was first diagnosed, I said, ‘what should I do to help myself’, and she said, ‘keep yourself healthy’, and I said, ‘what would that mean for me? What would you suggest for me?’ and she said, ‘keep yourself healthy’. And I’ll never forget that because I thought that’s not enough.”* (Breast C, 60-69 years old) “*And [physical therapy] was tremendously helpful, strengthening the core and helping with my back issues with the fractures and everything*.” (Myeloma A, 60-69 years old) *“[Physical therapy] was something that we talked about while I was in the hospital. It was a consensus between me and the doctors to help me out. […] it was something that I had to do to get better. It was no second thought with me […] I was going to try to do it.”* (Myeloma C, 70-75 years old)
Interventions should target activity goals	**Gaining strength and maintaining independence** *“I want to move and get around and go shopping when I need to go shopping and I can do it on my own. That’s good for me. I know there’s going to come a time when I can’t do that.”* (Myeloma C, 70-75 years old) “*And so, my goal would probably be to continue doing what I’m doing so that I’m able to keep doing it. You know, if you don’t use it, you lose it. Even though I’ve lost so much, but I’m maintaining what I have, and that’s the goal to me...”* (Prostate C, 60-69 years old) *“…that was the kinda the impetus to do the yoga thing because at least that’s what it’s all about is balance and I can make*

	myself stronger without killing myself saying like 'oh I have to run even though it makes me feel miserable,' so that was the biggest thing, but yeah, I definitely think it would help my mental and physical well-being to just be more in balance and have a better physical activity." (Myeloma B, 40-49 years old) *"…'cause I'm afraid that if I don't keep moving and doing things, that it'll just-- it'll get worse, so I don't want that to happen. You know, totally dependent on other people or something."* (Myeloma D, 60-69 years old) *"…that has always been my goal is to go out jogging-- going out and doing things. Stage four does not-- there is no expiration date. You could live for a long, long time."* (Breast B, 60-69 years old)
Importance of physical environment	*"I bike on roads because I live in [CITY] and there [are] no bike paths, so I go on a country road that is less traveled. I don't like going on highways of course, you know, with the busy travel."* (Prostate E, 60-69 years old) **Sidewalks** *"I live on a country road that is not safe to walk on. […] There is no edge and a lot of traffic."* (Colorectal C, 50-59 years old) *"Well, we just had, a couple years ago, they put sidewalks in. So, it's a very residential area, so there's lots of places to walk. There's a lot of parks. You know, I feel like it's a safe place to live."* (Myeloma D, 60-69 years old) *"Uh, the one direction I don't go because the sidewalks are not very good. The other way, the sidewalk's a lot flatter and less cracks."* (Colorectal B, 60-69 years old) **Cold weather** *"I was thinking about joining a fitness club during the wintertime because it is getting colder and stuff like that just to work on my muscles. I got cardio down, but you know, the muscle part kind of worries me sometimes."* (Prostate E, 60-69 years old) *"Other than me going to the store or to school to pick up the kids or to the park, I don't go walking around through the park in the winter. I did in the summer when it was warm."* (Myeloma C, 70-75 years old)

CHAPTER 4: AIM 2

Physical Activity Levels, and Changes in Activity and Associations with Quality of Life: A Cross-sectional Study of Adults Living with Advanced Cancer

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The paper has been formatted for submission to the *Cancer Epidemiology, Biomarkers & Prevention*.

ABSTRACT

Background: Physical activity (PA) is associated with better quality of life for cancer survivors; however, less is known about this relationship among those with advanced cancer, a growing subpopulation due to improvements in treatment and survival. This study assesses whether changes in physical activity after an advanced cancer diagnosis are associated with differences in health-related quality of life (HRQoL) outcomes.

Methods: Data arise from 247 participants in a cross-sectional study of adults aged 30-81 ($\bar{x}$=67 years) with advanced cancer who visited the University of Wisconsin Carbone Cancer Center (January 2021-2023). PA was assessed using the Godin-Shepard Leisure Score Index (insufficiently active, moderately active, and active). HRQoL was assessed using the Functional Assessment of Cancer Therapy – General (FACT-G) and Patient-Reported Outcomes Measurement Information System (PROMIS) short-form measures of physical function, fatigue, and pain interference. We used generalized linear models to assess relationships between PA and HRQoL.

Results: Respondents included 247 adults with advanced cancer (53% insufficiently active, 21% moderately active, 26% active). Among our sample, 41% were a lot less active, 33% a little less active, and 26% the same/more active compared to prior to their diagnosis using self-report. Differences were observed by activity change whereby adults who were a lot less active compared to those who were a little less or the same/more active had lower physical function scores, ($\bar{x}$=40.3 vs. $\bar{x}$=47.3 and $\bar{x}$=52.5), and higher fatigue ($\bar{x}$=59.3 vs. $\bar{x}$=51.4 and $\bar{x}$=42.3) and pain interference scores ($\bar{x}$=55.5 vs. $\bar{x}$=48.8 and $\bar{x}$=45.6). In fully adjusted models, those a lot less active had lower

HRQoL scores compared to those the same or more active (-17.2, 95% CI: -22.0, -12.5, p<.0001).

Conclusions: Adults living with advanced cancer who experience reductions in PA have worse HRQoL, especially related to higher pain and fatigue and lower physical function.

INTRODUCTION

Cancer Survivors and Physical Activity

According to the American Cancer Society, advanced cancer is used to describe cancers that are unlikely to be cured; however, some types of advanced cancer can be controlled for long periods and are considered a chronic illness [1]–[3]. Due to modern advances in treatments for cancer, including targeted therapeutics, many adults are living considerably longer, i.e., five or more years, after an advanced cancer diagnosis [3]–[5]. Despite increases in survival rates, living longer with advanced cancer is associated with complex needs including physical and psychosocial challenges that are not well understood [3], [6]. Physical activity is an important behavior that has a variety of health benefits and may be able to address some of these health needs [6-8].

The American Cancer Society (ACS) recommends that cancer survivors achieve 150-300 minutes per week of moderate-intensity activity or 75-150 minutes per week of vigorous-intensity activity, in addition to muscle-strengthening activities on two or more days per week [8]. The American College of Sports Medicine (ACSM) recommends that cancer survivors complete aerobic training at moderate intensity three or more times per week for at least 30 minutes, and report that the addition of resistance training exercises a minimum of two times per week (at least two sets of 8-15 repetitions of the exercise) to aerobic training has comparable benefits [9]. Both the ACS and ACSM encourage those living with cancer to move more and sit less since even a little activity is better than none [9].

Adults living with early-stage cancers do not meet national physical activity recommendations for cancer survivors, and levels of activity are likely even lower among adults living with advanced cancer. It is likely that this population engages in lower levels of physical activity than earlier-stage cancer survivors, due to their more intense initial treatments that contribute to greater long-term toxicities than treatments provided to early-stage cancers (e.g., surgery alone) and their ongoing need for treatment(s) [3]. A recent single cancer center study by Knowlton et al. (2020) found that only 34% of patients with advanced cancer in their sample met the national physical activity guidelines compared to 44% of patients with early-stage disease [10]. Although there is some existing data on aerobic physical activity levels among adults living with advanced cancer, little information is known about the amount and types of strength-based activities performed by adults living with advanced cancer. The National Cancer Institute also recognizes the growing need to better understand the physical activity levels of adults living with advanced and metastatic cancers due to the lack of research on this growing population [3].

Changes in Physical Activity and Health-related Quality of Life

Health behaviors, such as physical activity, may change following an advanced cancer diagnosis due to an increase in negative side effects from cancer itself and/or its treatments [12]–[14]. Physical activity is promoted as an important component of survivorship for cancer survivors, due to its multitude of physical and mental health benefits, and growing evidence that higher physical activity increases quality of life for adults living with advanced cancer [9-14], [15], [16]. A systematic review with meta-analysis conducted by Toohey et al. (2022) to evaluate the safety, feasibility, and effectiveness of exercise for people with advanced cancer found no difference in risk of adverse events between exercise and usual care groups. Further, they found an improvement in health outcomes of quality of life, fatigue, aerobic fitness, and lower-body strength associated with exercise [11]. A recent randomized control trial pilot study of a walking intervention among people with recurrent or metastatic cancer, CanWalk, was found to be acceptable and well-tolerated, suggesting the potential benefits of activities like walking for the advanced cancer population [17]. Assessing how changes in physical activity may be associated with differences in quality-of-life measures is a critical next step among this understudied and growing population of adults living with advanced cancer.

Little is known about the association between changes in physical activity since diagnosis with advanced cancer and quality of life among this population. Research suggests that health declines can vary greatly among those living with advanced cancer from physical concerns, such as increasing fatigue and pain, to emotional challenges, like trouble coping with their illness which may lead to declines in physical activity [3], [6]. Due to cancer and/or its treatment, many survivors also face diverse functional limitations leading to potential increased pain, fatigue, neuropathy, and sleep disruptions which could impact their activity [18]. These functional limitations and health declines are likely to be of greater concern to adults living with advanced cancer who may have more intense treatments or cycle on and off treatment for many years leading to a potential reduced overall quality of life.

The purpose of this cross-sectional analysis among the understudied population of adults living with advanced cancer is to assess: (1) changes in physical activity; (2) physical activity levels and intensity, including both aerobic and strength-based activities; (3) the relationship between physical activity and health-related quality of life outcomes.

METHODS

Study Design and Population

Using the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER)*Explorer Application, this study assessed the incidence rates and 5-year distant survival rate percentages for a variety of cancers using the most recently available data [19]. We selected three of the most common cancer types with noted increases in their 5-year survival rates: breast, prostate, and colorectal. We selected stages 3 and 4 lymphoma (non-Hodgkin's and Hodgkin's) and myeloma because these hematologic malignancies have high 5-year survival rates with approximately 67%, 84%, and 59% of patients, respectively, expected to live 5 or more years after diagnosis with distant disease [19].

Eligibility criteria included the following: cancer type and stage [stage 4 breast, prostate, or colorectal cancer; stage 3 or 4 lymphoma (non-Hodgkin's and Hodgkin's); or myeloma], 18-80 years of age as of January 2023, date of eligible diagnosis (January 2021-January 2023), valid mailing address, alive at the time of contact, and English speaking. The study aimed to capture those who recently received care at UWCCC within the previous two years as they were more likely to be alive, able to recount recent treatment(s) received, and have a valid current address. A list of patients was populated in RedCap where the research team had secure access to contact information for mailing postcards and surveys. The survey included questions related to physical activity, quality of life, and demographic and clinical characteristics.

This study was approved as minimal risk by the University of Wisconsin-Madison's Minimal Risk Institutional Review Board (Protocol #2022-0966) and by the University of Wisconsin's Carbone Cancer Center's (UWCCC) Protocol Review and Monitoring Committee (Protocol UW22103).

Data Collection

We used a modified Dillman et al. approach to minimize participant burden and the number of contacts of this population [20]. We recruited through the UWCCC by mailing surveys to eligible patients based on a patient list provided by the Clinical and Health Informatics Institute (CHI2) team at the University of Wisconsin Institute for Clinical and Translational Research. A pre-notice postcard was mailed to patients in March 2023, notifying them that a survey about their health (but not mentioning cancer specifically) would arrive in two weeks. The postcard also included contact information for the study team so that patients could opt out of receiving the survey for any reason. Two weeks after the postcards were mailed, researchers mailed the survey to patients who did not opt out. A small incentive ($2) was included with the first mailing of the survey. Five weeks after the first survey mailing, the study team sent a second copy of the survey to eligible patients who had not opted out or returned a survey.

Surveys were collected from April 3, 2023-July 31, 2023. Among the eligible study participants (n=683), n=9 (1%) refused (opted out), n=3 (0.4%) returned a blank survey, and n=393 (58%) did not respond. The final sample consisted of 278 patients who returned a completed survey for a final response rate of 41%. The final sample for analysis in this paper included those who had complete data on the FACT-G and covariates (n=247, 89%).

Survey Measures

Data on changes in physical activity since diagnosis came from the question, “Compared to your physical activity level before your cancer diagnosis, how much physical activity are you doing currently?“ which was asked as a 5-point Likert scale question with the following response options: a lot less activity, a little less activity, about the same amount of activity, a little more activity, and a lot more activity.

Aerobic physical activity data were collected using a modified Godin-Shepard Leisure-Time Physical Activity Questionnaire (GSLTPQ) to ask about activity completed during the past seven days with three designated intensities: light, moderate, and strenuous. We also included questions about average time spent in one session (in minutes) for each intensity category. The GSLTPQ has been used previously to collect physical activity data in oncology research [21], [22]. Muscle strengthening physical activity data were collected using a modified Muscle-Strength Exercise Questionnaire (MSEQ), which asked about types and durations of strength-based activities during the past seven days [23].

The Functional Assessment of Cancer Therapy-General (FACT-G) was used to assess health-related quality of life (HRQoL), which is a standardized measure used to assess health-related quality of life among cancer patients. The FACT-G assesses health-related quality of life across four domains: physical well-being (7 questions), social/family well-being (7 questions), emotional well-being (6 questions), and functional well-being (7 questions) [24], [25]. The FACT-G uses a five-point Likert scale ranging from 0 (not at all) to 4 (very much) for each question. The FACT-G has a total score range from 0-108 and is computed based on the score of each of the four subscales if the overall response rate is 80% (at least 22 of the 27 items must be answered). In a study evaluating FACT-G scores of cancer patients and the general population, the average overall FACT-G for adults with cancer was 81 and for adults without cancer was 80 [26]. For reference, a clinically meaningful difference is considered a 5-point difference in FACT-G total score and a 2-point difference in subscale scores [26].

To measure several important dimensions of health-related quality of life, we used the Patient-Reported Outcomes Measurement Information System (PROMIS) 4a short-form instruments of physical function v2.0, fatigue v1.0, and pain interference v1.1. Available PROMIS short-form instruments were used to minimize response burden on respondents [27]–[32]. All four questions for each PROMIS measure must have been answered to receive a score. A *T* score of 50 and standard deviation of 10 represents the general US population for most PROMIS instruments, and a score difference of 3 points was considered a clinically meaningful difference [33], [34]. Higher scores reflect more of the domain being measured (i.e., higher score = higher physical function, fatigue, or pain interference). For clinical reference, physical function scores range from: severe impairment (<30), moderate impairment (30-40), mild impairment (40-45), to normal (≥45); fatigue scores range from severe impairment (≥75), moderate impairment (55-74), mild impairment (50-54), to normal (<50); and pain interference scores range from severe impairment (≥70), moderate impairment (60-69), mild impairment (50-59), to normal (<50) [35], [36].

Comorbidity data were collected using the Functional Comorbidity Index (FCI) [37].

Statistical Analysis

Data were double entered into REDCap (Research Electronic Data Capture), which is a secure platform for data storage and reviewed for quality and completeness using REDCap's data comparison tool [38]. All analyses were conducted in SAS 9.4 (Cary, NC).

Due to a low sample size of respondents reporting a little or a lot more activity since their diagnosis, we combined the categories of "same amount of activity" (n=44, 17.8%), "a little more activity" (n=16, 6.4%), and "a lot more activity" (n=5, 2.0%) for all analyses. Sensitivity analyses were conducted to assess if our results differed using a 4-category measure for activity change, i.e., a lot less activity, a little less activity, the same activity, a little or a lot more activity (Appendix B6). Results were similar with no significant differences in outcomes between the same or more activity groups.

Physical activity data were categorized by light, moderate, and strenuous, and all three activity intensities were included in the Leisure Score Index calculation. Number of times of strenuous activity was multiplied by 9, number of times of moderate activity was multiplied by 5, and number of times of light activity was multiplied by 3 to get an overall Leisure Score Index (LSI) value. Physical activity categories using the Leisure Score Index (LSI) cut points for active (LSI of 24 or higher), moderately active (LSI of 14 to less than 24), and insufficiently active (LSI less than 14). For respondents who did not report any aerobic activity, they were categorized with a value of zero, corresponding to insufficiently active.

Cancer type was derived from the eligible patient list. An overall functional comorbidity index score was calculated based on the number of self-reported “yes” responses to the list of 18 comorbidities and a categorical measure was created ranging from zero comorbidities to four or more comorbidities. We used data from self-reported weight and height to calculate a value for body mass index and replaced the value for “obesity” based on the well-established obesity cutpoint of a body mass index greater than or equal to 30 kg/m^2.

PROMIS raw scores were converted to *T* scores using the short form conversion tables for each domain.

Descriptive statistics including means and standard deviations of continuous variables and frequencies of categorical variables were calculated. Analysis of variance (ANOVA) tests were used to assess differences in mean scores of the FACT-G subscales and mean *T* scores of PROMIS measures (i.e., physical function, fatigue, and pain interference) by category of change in physical activity since diagnosis (i.e., a lot less activity, a little less activity, the same or more activity).

Multiple linear regression models were used to assess the association between category of change in physical activity since diagnosis (i.e., a lot less activity, a little less activity, the same or more activity) and health-related quality of life (i.e., FACT-G score) as a continuous measure. Covariates were decided *a priori* based on established and hypothesized relations between exposures and outcomes, and included the following:

current physical activity level (i.e., Leisure Score Index (LSI) category: insufficiently active, moderately active, active), current age (categorical: <60 years, 60-70 years, 70+ years), gender (man, woman), marital status (married or living with partner; separated, divorced, widowed, or single), education level (high school or less, some college or associate's degree, Bachelor's degree or higher), employment status (full or part time; not employed, retired; not employed, other), urbanicity (rural, suburban, urban); and clinical characteristics: cancer type (breast, colorectal, prostate, myeloma, lymphoma), current treatment status (on treatment, not on treatment), and Functional Comorbidity Index score (categorical: none, 1 comorbidity, 2 comorbidities, or 3 or more comorbidities).

RESULTS

Sample Characteristics

Adults living with advanced cancer in our sample (n=247) were on average 66 years of age (SD 10.3), and the majority of respondents identified as men (60%) (Table 1). Most of the respondents were married or living with a partner (75%) and retired (62%). The sample also contained variation by urbanicity with 35% residing in rural areas, 25% in urban areas, and 40% in suburban areas. In terms of clinical characteristics, respondents consisted of 32% adults with advanced prostate cancer, 23% adults with myeloma, 16% adults with advanced lymphoma, 18% adults with advanced breast cancer, and 11% adults with advanced colorectal cancer. Most respondents were currently undergoing treatment (80%) with almost half of respondents last receiving treatment up to two weeks ago (47%). Most adults had at least one comorbidity with only 18% of our sample reporting no comorbidities.

Changes in Physical Activity Since Diagnosis Among Analytic Sample

Among our analytic sample, 41% (n=100) were a lot less active, 33% (n=82) were a little less active, and 26% (n=65) were the same or more active compared to prior to their cancer diagnosis (Table 1). Compared to adults doing a little less or the same or more activity, those adults who reported a lot less activity since their diagnosis were less likely to be college graduates (40% vs. 60% and 51%) and working full or part time (20% vs. 24% and 39%). Adults on chemotherapy, immunotherapy, and/or hormone therapy were less likely to be engaging in the same or more activity compared to a lot less activity (58% vs. 77%). Those with no comorbidities were more likely to be engaging in the same or more activity compared to a lot or little less activity (31% vs. 13% and 14%). In terms of physical activity levels, adults who were a lot less active were most likely to be considered insufficiently active/sedentary (76%), while adults who were the same or more active were most likely to be considered active (49%) by the Godin Leisure Score Index.

Assessment of Physical Activity Levels (Aerobic and Strength Activities)

Most respondents reported engaging in light activity (n=153, 62%) compared to moderate (n=97, 39%) and/or strenuous activity (n=36, 15%) (Table 2). Among our sample engaging in light activity activities, on average, respondents were engaging in light activity 4.1 (SD 3.7) times in the past week with less times reported by insufficiently active respondents 2.4 (SD 1.1) times and more by active respondents 6.6 (SD 5.5) times. Among those engaging in any aerobic activity, light activity averaged 45 (SD 66) minutes in the past week, moderate activity 39 (SD 33) minutes in the past week, and strenuous activity 34 (SD 22) minutes in the past week. Among adults living with advanced cancer who were engaging in at any strength activity on one or more days in the previous week, the majority reported using resistance bands or free weights (n=45; 18%), followed by body weight exercises (n=32; 13%), weight machines (n=24; 10%), and holistic exercises (n=17; 7%). Adults considered active by Leisure Score Index were more likely to be performing muscle strength exercises than those who were moderately active or insufficiently active.

Association Between Changes in Physical Activity and Current Quality of Life

Adults who were a lot less active had lower overall FACT-G health-related quality of life scores compared to those who were a little less or the same or more active (Figure 1, Supplementary Table 1). Across the FACT-G subscales, adults engaging in a lot less activity had the lowest, and clinically meaningful differences in, mean scores for physical well-being (x̄=18.6; 95% CI: 17.8, 19.5) compared to those a little less active (x̄=23.2; 95% CI: 22.3, 24.2) and the same or more active (x̄=25.7; 95% CI: 24.7, 26.8). Functional well-being was also lowest and showed clinically meaningful differences between adults engaging in a lot less activity (x̄=15.3; 95% CI: 14.3, 16.4) compared to those engaging in a little less activity (x̄=19.2; 95% CI: 18.1, 20.3) or the same or more activity (x̄=22.8; 95% CI: 21.5, 24.1).

Adults who were a lot less active reported lower PROMIS physical function scores, and higher fatigue and pain interference scores compared to those who were a little less active or the same or more active (Figure 2, Supplementary Table 1). Adults who were a lot less active had a mean physical function score of 40.3 (95% CI: 38.8, 41.8) which corresponds to borderline moderate impairment, compared to a little less active (x̄=47.3; 95% CI: 45.6, 48.9) and the same or more active adults (x̄=52.5; 95%

CI: 50.6, 54.3) who were within normal limits (F-value=51.7; p<.0001). Adults who were the same or more active reported the lowest fatigue scores compared to a little less or a lot less active adults ($\bar{x}$=42.3; 95% CI: 40.0, 44.6) vs. 51.4 and 59.3; p<.0001), and fatigue scores ranged from moderate impairment among those a lot less active, 59.3 (95% CI: 57.5, 61.1) mild impairment for those a little less active, 51.4 (95% CI: 49.4, 53.5) and within normal limits for those the same or more active, 42.3 (95% CI: 40.0, 44.6). Adults who were the same or more active also reported the lowest pain interference scores, 45.6 (95% CI: 43.5, 47.6) compared to a little less active 48.8 (95% CI: 47.0, 50.7) or a lot less active adults 55.5 (95% CI: 53.8, 57.2); those a lot less active had mild impairment of pain interference, while those a little less active and the same or more active were within normal limits.

Overall, there was an association between greater decreases in physical activity since diagnosis and lower overall health-related quality of life scores as measured by the FACT-G (Table 3). Adults who reported being a lot less active had 17.2-point lower health-related quality of life scores (β=-17.2, 95% CI: -22.0, -12.5; p<0.0001) than those who were the same or more active after adjusting for physical activity level and important demographic and clinical covariates. Adults who reported being a little less active since their diagnosis had lower health-related quality of life scores compared to those who the same or more active, 6.0-point lower score (β=-6.0, 95% CI: -10.6, -1.5; p<.0001) after adjustment. Being moderately active compared to insufficiently active was associated with a 6.3-point higher (β=6.3, 95% CI: 1.8, 10.7; p=0.02) health-related quality of life score after adjustment. Being under the age of 60 years of age was associated with a 7.5-point lower (β=-7.5, 95% CI: -13.7, -1.3; p=0.02) health-related quality of life score compared to being over 70 years old after adjusting for all other covariates. Those who reported being unemployed - other had worse health-related quality of life scores (β=-8.2, 95% CI: -14.1, -2.4; p=0.02) compared to those who were retired after adjustment. Adults with three or more comorbidities also reported worse health-related quality of life scores compared to those with no comorbidities, (β=-8.1, 95% CI: -13.0, -3.2; p=0.01) adjusted for all other covariates. Finally, those living in suburban environments reported higher quality of life scores (β=5.1, 95% CI: 0.8, 9.4; p=0.04) than those in urban environments after adjustment.

DISCUSSION

To our knowledge, this is the first study to assess physical activity levels and changes with the inclusion of associations with health-related quality of life among a U.S.-based sample limited to adults living with advanced cancer. Little is known about the amount of physical activity completed by adults living with advanced cancer in the United States. Our study finds that adults living with advanced cancer in Wisconsin engage in some activity including aerobic and muscle strengthening activities; however, most of the respondents are considered insufficiently active using the Godin Leisure Score Index cutoffs [21]. Adults with advanced cancer also have greatly reduced their activity level since their diagnosis and these reductions are associated with worse health-related quality of life.

We find that less than half of our sample (47%) is moderately active or active using the Godin Leisure Score Index (LSI). Knowlton et al.'s single cancer center study found 34% of patients with advanced cancer meeting physical activity guidelines; however, they combined aerobic and strength-based activities in their calculations, and we separately assessed aerobic minutes by intensity and strength-based minutes by Leisure Score Index category [10]. They also had a much lower proportion of their sample over 70 years of age and operationalized advanced cancer in a different way. Separately assessing intensity of aerobic activity and types of strength-based activities using two validated instruments is a strength our analysis and shows potentially important trends in activity across our sample of adults with advanced cancer.

Although much of our sample is considered insufficiently active by the Godin Leisure Score Index (LSI), 53%, in terms of activity intensity, light intensity activities are the most reported activities among this sample compared to moderate or strenuous activities. Sixty-two percent of our sample is engaging in some light intensity activity with lower average times per week of activity among those considered insufficiently active compared to moderately active or active. These findings may be of importance for future interventions designed for those living with advanced cancer and older cancer survivors who are unlikely to engage in higher intensity activities and may serve as an initial target for improving physical activity [39].

In this cross-sectional analysis of adults living with advanced cancer, we observe a decline in physical activity since diagnosis. Although our overall sample had a mean FACT-G score similar to a reference study of adults with and without cancer, noticeable differences emerged by changes in physical activity since diagnosis [26]. In terms of specific indicators of quality of life, we find lower overall physical function scores and higher fatigue scores relative to cancer patients with limited or no evidence of disease and the general US population. We also find clinically meaningful and significantly higher fatigue and pain interference and lower physical function scores among those engaging in a lot less activity compared to a little less or the same or more activity. These findings are in line with a study by Jensen et al. (2017) which found similar deficits in physical function and higher levels of pain interference and fatigue in persons with cancer and worse levels of impairment among those with advanced cancer compared to those with limited or no evidence of disease [34]. In their study, among those with advanced disease, physical function was 41.1, fatigue was 55.8, and pain interference was 55.2, while in our study, these scores were most similar among our sample of those a lot less active [34]. Scores in our sample are higher among those who were a little less active or the same or more active and correspond more closely to Jensen et al.'s findings for patients with limited or no evidence of disease [34]. Due to factors like more intensive treatments associated with long-term toxicities, functional limitations, fatigue, and pain interference are likely of greater concern for the advanced cancer population than those early-stage cancer survivors. Given our results, regularly assessing the functional status and determining ways to improve quality of life in these domains should be a critical step for future research of adults living with advanced cancer.

When comparing overall health-related quality of life scores, it is useful to consider clinically meaningful differences. Using the FACT-G, a clinically meaningful difference is considered a five-point difference in the overall FACT-G score [26]. Comparing our results to a US-based cancer survivor sample including multiple cancer types and stages, which had an overall mean score of 81, our sample of adults living with advanced cancer had a mean crude health-related quality of life score of 80, which is similar to the general US-based cancer survivor sample [26]. However, in our sample, greater reductions in physical activity are associated with lower health-related quality of life scores, ranging from 17.2 points lower among those a lot less active compared to the same or more active and 6.0 points lower among those a little less active compared to the same or more active in fully adjusted models. These findings demonstrate a clinically meaningful difference between those engaging in a lot or little less physical activity compared to those who are engaging in the same or more activity since diagnosis. Further, being moderately active or active compared to insufficiently active is associated with higher health-related quality of life in fully adjusted models, which shows the value of engaging in some activity despite any reductions since diagnosis. Being under the age of 60 compared to over the age of 70 is also associated with a lower and clinically meaningful difference in health-related quality of life after adjustment, which is an important finding that may be relevant for developing targeted interventions among those who are younger and experiencing worse health-related quality of life than their older counterparts.

Adults with comorbidities in our sample, as measured by the Functional Comorbidity Index, also report worse health-related quality of life scores. In Pergolotti et al.’s (2017) study examining activity, function, and health-related quality of life among older adults with cancer, i.e., over the age of 65, they found a higher mean FACT-G score of 85, however their sample included patients of all stages. They also found that patient-reported decreased levels of function were independently associated with poor health-related quality of life. We find that having comorbidities is associated with lower and clinically meaningful differences in health-related quality of life in our fully adjusted models. This is not a surprising finding due to the large number of self-reported comorbidities associated with functional limitations in our sample, and the mounting evidence that the number of cancer survivors with functional limitations is increasing. A recent study by Patel et al (2023) found an increase in self-reported functional limitations among cancer survivors, from 57.0% in 1999 to 70.1% in 2018 [41]. Further acknowledging the need to address concerning trends in lower health-related quality of life among those who have comorbidities could be useful for future research designed to improve the health-related quality of life of adults living with advanced cancer.

Strengths and Limitations

Strengths of our study include a specific focus on the understudied population of adults living with advanced cancer. Cancer diagnosis is an electronic health record-validated diagnosis with advanced cancer in the past two years and diverse cancer types to get a range of perspectives within the advanced cancer population. Our study uses well-validated measures of health-related quality of life, the FACT-G and PROMIS measures, and physical activity, the GSLTPAQ and MSEQ. We also include five different cancer types to get a broader scope of the population of advanced cancer survivors living with both solid tumor and hematologic malignancies.

Limitations of our study include the self-reported physical activity data, as opposed to accelerometers or other wearables, which may have led to an overestimation of physical activity levels among respondents [22], [42]. However, a study of physical activity in breast cancer survivors by Welch et al. (2017) found the mean difference in moderate-vigorous activity estimates between accelerometry and self-report using the GSLTPAQ to be less than 5 minutes reflecting a strong correlation between the two measurement types among their sample [22]. They also found that those over the age of 60 tended to underestimate their moderate-vigorous activity on the GSLTPAQ compared to younger survivors. Another limitation is that our study is restricted to one cancer center in the Midwest which limits the generalizability of our results outside this context. Finally, there is potential for healthy responder bias meaning that those who responded were more likely to be healthier than the average member of the population of interest.

CONCLUSIONS

Adults living with advanced cancer face immense health challenges and potential declines in physical activity following their diagnosis. Our study finds that many adults living with advanced cancer participate in some light intensity physical activity and strength-based activity. Our study provides insights regarding incorporating and promoting light intensity activities among this growing population. Those engaging in less activity since their advanced cancer diagnosis experience lower levels of physical function and higher levels of pain and fatigue compared to those engaging in the same or more activity since diagnosis. We also demonstrate an association between a reduction in physical activity and lower health-related quality of life among adults living with advanced cancer, and provide insight into subgroups experiencing worse health-related quality of life who may benefit from additional support and resources.

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Tables and Figures

Table 1. Characteristics of the Study Sample by Changes in Physical Activity Since Diagnosis

Characteristics	**Analytic Sample**	**A lot less activity**	**A little less activity**	**The same or more activity**
	n (%) or Mean (SD)			
	n=247	*n*=100 (41)	*n*=82 (33)	*n*=65 (26)
Demographics				
Current Age - Mean (SD)	66.3 (10.3)	66.6 (9.9)	66.5 (10.3)	65.4 (10.9)
Age Group				
< 60 years old	52 (21)	20 (20)	16 (20)	16 (25)
60 to 70 years old	86 (35)	34 (34)	28 (34)	24 (37)
> 70 years old	109 (44)	46 (46)	38 (46)	25 (38)
Gender				
Woman	99 (40)	41 (41)	33 (40)	25 (38)
Man	148 (60)	59 (59)	49 (60)	40 (62)
Marital Status				
Married or living with partner	185 (75)	69 (69)	63 (77)	53 (82)
Not married or living with partner	62 (25)	31 (31)	19 (23)	12 (18)
Education Level				
High school or less	52 (21)	22 (22)	19 (23)	11 (17)
Some college/associate's degree	73 (30)	38 (38)	14 (17)	21 (32)
Bachelor's degree or higher	122 (49)	40 (40)	49 (60)	33 (51)
Employment Status				
Full or part time	65 (26)	20 (20)	20 (24)	25 (39)
Not employed, retired	153 (62)	65 (65)	52 (64)	36 (55)
Not employed, other	29 (12)	15 (15)	10 (12)	4 (6)
Urbanicity				
Urban	61 (25)	24 (24)	20 (24)	17 (26)
Suburban	99 (40)	41 (41)	30 (37)	28 (43)
Rural	87 (35)	35 (35)	32 (39)	20 (31)

Clinical Characteristics				
Cancer Type				
Breast	45 (18)	22 (22)	14 (17)	9 (14)
Colorectal	27 (11)	10 (10)	7 (9)	10 (15)
Myeloma	57 (23)	26 (26)	21 (26)	10 (15)
Prostate	79 (32)	30 (30)	29 (35)	20 (31)
Lymphoma	39 (16)	12 (12)	11 (13)	16 (25)
Current Treatment Type				
Chemo/Immune/Hormone therapy	181 (73)	77 (77)	66 (80)	38 (58)
Radiation therapy	21 (9)	12 (12)	5 (6)	4 (6)
Surgery (in the past 6 months)	14 (6)	7 (7)	4 (5)	3 (5)
Bone marrow or stem cell transplant (in the past 6 months)	6 (2)	3 (3)	3 (4)	0 (0)
Current Treatment Status				
On treatment	198 (80)	86 (86)	70 (85)	42 (65)
Not on treatment	49 (20)	14 (14)	12 (15)	23 (35)
Functional Comorbidity Index Category				
No comorbidities	45 (18)	13 (13)	12 (14)	20 (31)
1 comorbidity	48 (19)	21 (21)	17 (21)	10 (15)
2 comorbidities	52 (21)	20 (20)	18 (22)	14 (22)
3 or more comorbidities	102 (41)	46 (46)	35 (43)	21 (32)
FACT-G Score - Mean (SD)	79.7 (15.5)	70.3 (16.4)	82.6 (11.8)	90.7 (12.6)
Physical Activity Level				
Godin Leisure Score Index Category				
Insufficiently active/sedentary	130 (53)	76 (76)	38 (46)	16 (25)
Moderately active	52 (21)	18 (18)	17 (21)	17 (26)
Active	65 (26)	6 (6)	27 (33)	32 (49)

[a] Respondents could select more than one treatment type, so these data reflect the number who checked each box and do not add up to 100%.

Note: FACT-G = Functional Assessment of Cancer Therapy-General.

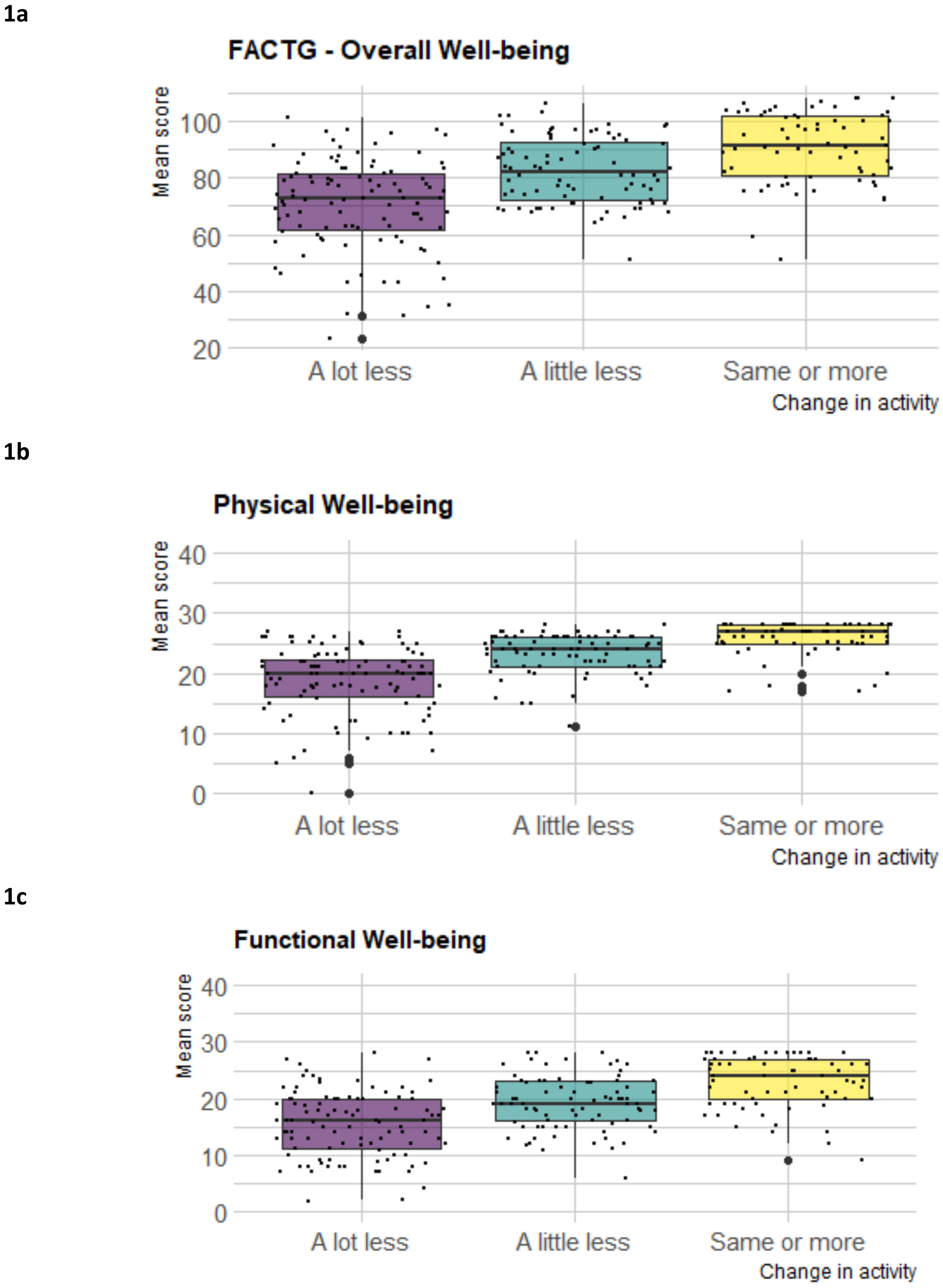
Table 2. Physical Activity Intensities in Times and Minutes per Week by Leisure Score Index (LSI) (total *n*=247)

Activity Levels	**Overall**		**Insufficiently Active (LSI <14)**		**Moderately Active (LSI 14-23)**		**Active (LSI 24+)**		**P-value**
	n (%)	Mean (SD)	*n* (%)	Mean (SD)	*n* (%)	Mean (SD)	*n* (%)	Mean (SD)	
Number of Times in Past 7 Days									
Light Activity	153 (62)	4.1 (3.7)	66 (27)	2.4 (1.1)	41 (17)	4.2 (2.1)	46 (19)	6.6 (5.5)	**<.0001**
Moderate Activity	97 (39)	3.7 (2.6)	15 (6)	1.3 (0.5)	27 (11)	2.5 (1.0)	55 (22)	5.0 (2.7)	**<.0001**
Strenuous Activity	36 (15)	3.3 (2.0)	0	0	8 (3)	1.4 (0.5)	28 (11)	3.8 (1.9)	**0.001**
Minutes per Session in Past 7 Days									
Light Activity[a]	152 (62)	45 (66)	66 (27)	45 (83)	41 (17)	46 (59)	45 (18)	42 (40)	0.97
Moderate Activity	97 (39)	39 (33)	15 (6)	36 (23)	27 (11)	32 (18)	55 (22)	44 (40)	0.25
Strenuous Activity	36 (15)	34 (22)	0	0	8 (3)	25 (19)	28 (11)	36 (23)	0.21
Number of Times in Past 7 Days									
Use weight machines	24 (10)	3.0 (1.1)	4 (2)	2.3 (1.0)	4 (2)	2.3 (1.3)	16 (6)	3.3 (1.0)	0.08
Body weight exercises	32 (13)	3.4 (2.1)	5 (2)	4.4 (2.4)	7 (3)	2.1 (2.4)	20 (8)	3.7 (2.0)	0.15
Use resistance bands or free weights	45 (18)	3.7 (1.9)	12 (5)	3.4 (1.6)	8 (3)	3.8 (2.8)	25 (10)	3.8 (1.7)	0.87
Holistic exercises	17 (7)	3.2 (2.3)	2 (1)	4.0 (4.2)	7 (3)	3.3 (1.9)	8 (3)	3.0 (2.6)	0.88
Minutes Per Session in Past 7 Days									
Use weight machines	24 (10)	42 (50)	4 (2)	10.0 (0)	4 (2)	40.6 (33.9)	16 (6)	50.5 (57.0)	0.36
Body weight exercises[b]	31 (13)	24 (16)	5 (2)	25.0 (20.6)	7 (3)	25.4 (17.0)	19 (8)	22.5 (15.7)	0.91
Use resistance bands or free weights[c]	41 (17)	20 (14)	12 (5)	15.6 (11.4)	8 (3)	21.3 (17.1)	21 (9)	22.7 (14.7)	0.39
Holistic exercises[d]	14 (6)	39 (31)	1 (0.4)	30.0 (.)	6 (2)	53.3 (39.8)	7 (3)	27.1 (19.1)	0.33

[a] Missing n=1; [b] Missing n=1; [c] Missing n=4; [d] Missing n=3

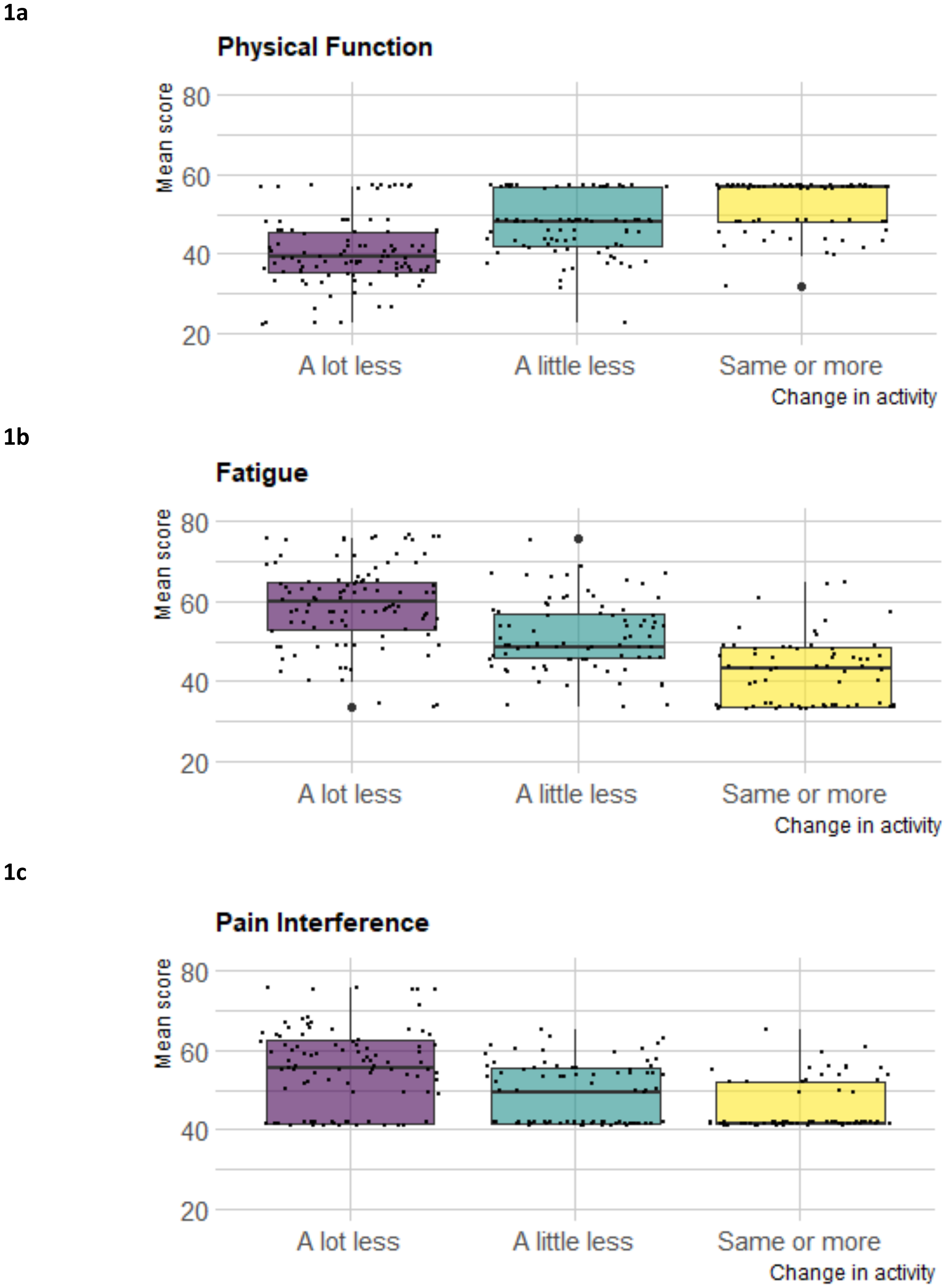
Note: Percentages are out of the total analytic sample (*n*=247). P-value is of analysis of variance (ANOVA) to assess whether differences exist between the means of the three activity groups.

Figure 1. Distribution of Mean FACT-G Overall and Subscale Scores by Changes in Physical Activity Since Diagnosis Among Adults with Advanced Cancer



Note: For all FACT-G scores, p-values were generated using analysis of variance (ANOVA) tests to assess whether differences exist between the mean scores of the three groups. Plots were made using ggplot in R. Sample means, 95% confidence intervals of means, F-test values, and p-values are displayed in Supplementary Table 1.

Figure 2. Distribution of Mean PROMIS Scores by Changes in Physical Activity Since Diagnosis Among Adults with Advanced Cancer



Note: For all three PROMIS domain scores, p-values were generated using analysis of variance (ANOVA) tests to assess whether differences exist between the mean scores of the three groups. Plots were made using ggplot in R. Sample means, 95% confidence intervals of means, F-values, and p-values are displayed in Supplementary Table 1.

Table 3. Association between Changes in Physical Activity Since Diagnosis and Health-related Quality of Life Among Adults with Advanced Cancer (*n*=247)

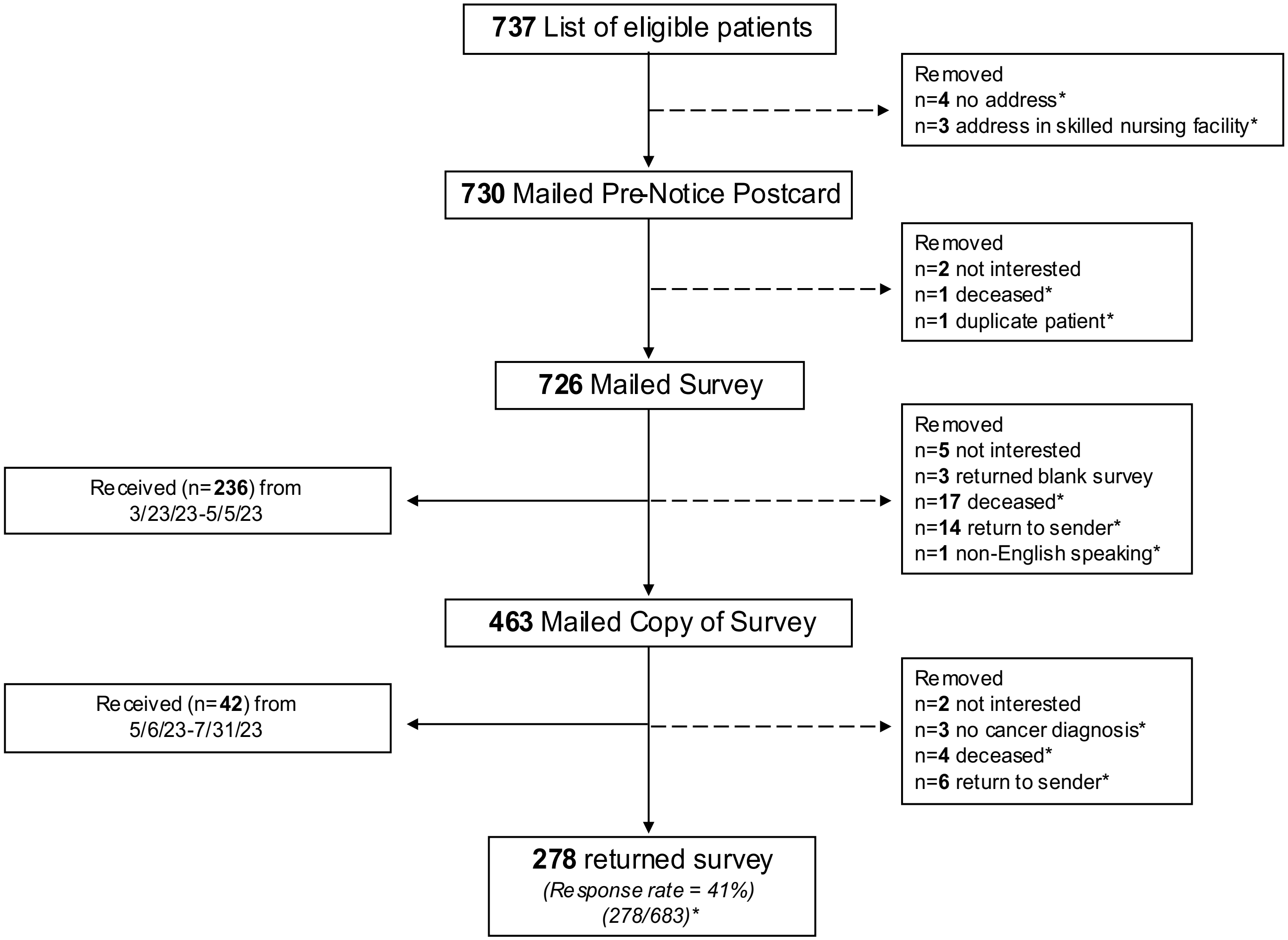
	Model		
Parameter	**Beta Estimate**	**CI**	**P-value**
Activity Change *(ref = Same or more active)*			**<.0001**
A little less active	-6.0	(-10.6, -1.5)	
A lot less active	-17.2	(-22.0, -12.5)	
Activity Level *(ref = Insufficiently active)*			**0.02**
Active	2.4	(-2.4, 7.1)	
Moderately active	6.3	(1.8, 10.7)	
Education Level *(ref = Bachelor's or higher)*			0.57
High school or less	2.5	(-2.5, 7.5)	
Some college or Associate's	1.5	(-2.6, 5.7)	
Employment *(ref = Retired)*			**0.02**
Full time or part time	-0.7	(-5.7, 4.2)	
Not employed other	-8.2	(-14.1, -2.4)	
Gender *(ref = Man)*			0.98
Woman	0.08	(-4.9, 5.1)	
Age (*ref = 70+ years old)*			**0.02**
<60 years old	-7.5	(-13.7, -1.3)	
60 to 70 years old	0.3	(-3.9, 4.4)	
Marital Status *(ref = Married or living with partner)*			0.08
Not married or living with partner	-3.5	(-7.5, 0.5)	
Comorbidities *(ref = No comorbidities)*			**0.01**
1 comorbidity	-5.2	(-10.8, 0.4)	
2 comorbidities	-3.5	(-9.0, 2.0)	
3 comorbidities	-8.1	(-13.0, -3.2)	
Cancer Type *(ref = Prostate)*			0.36
Breast	-0.3	(-7.6, 7.0)	

Colorectal	-0.1	(-7.0, 6.8)	
Lymphoma	1.9	(-4.2, 8.1)	
Myeloma	4.2	(-1.1, 9.5)	
Treatment Status *(ref = On treatment)*			0.98
Not on treatment	-0.1	(-5.2, 5.0)	
Urbanicity *(ref = Urban)*			**0.04**
Rural	1.2	(-3.5, 5.8)	
Suburban	5.1	(0.8, 9.4)	

Note: CI (95% confidence interval), ref = Reference group; P-value is for the Type III tests of fixed effects. Model was adjusted for physical activity level, education, gender, age (categorical), marital status, cancer type, functional comorbidity index score (categorical), on treatment status, and urbanicity.

Supplementary Tables and Figures

Supplementary Figure 1. Flowchart to show study sample recruitment



Note: We removed patients marked with * from overall list of eligible patient sample (*n*=737) to calculate eligible sample (*n*=683).

Supplementary Table 1. Univariate Analysis of the Health-related Quality of Life Measures by Changes in Activity Since Diagnosis (*n*=247)

Measure	***n***	**Overall (Mean)**	**CI**	**A lot less activity (Mean)**	**CI**	**A little less activity (Mean)**	**CI**	**Same or more activity (Mean)**	**CI**	**F-value**	**P-value**
FACT-G	247	79.7	(77.7, 81.8)	70.3	(67.5, 73.1)	82.6	(79.5, 85.6)	90.7	(87.3, 94.2)	44.3	**<.0001**
Physical	247	22.0	(21.4, 22.7)	18.6	(17.8, 19.5)	23.2	(22.3, 24.2)	25.7	(24.7, 26.8)	59.5	**<.0001**
Social	247	21.1	(20.5, 21.8)	19.5	(18.5, 20.5)	21.9	(20.8, 23.1)	22.6	(21.4, 23.9)	8.6	**0.0002**
Emotional	247	18.0	(17.5, 18.6)	16.9	(16.0, 17.7)	18.2	(17.3, 19.1)	19.6	(18.6, 20.6)	8.3	**0.0003**
Functional	247	18.6	(17.8, 19.3)	15.3	(14.3, 16.4)	19.2	(18.1, 20.3)	22.8	(21.5, 24.1)	42.1	**<.0001**
Physical Function[a]	245	45.8	(44.7, 46.9)	40.3	(38.8, 41.8)	47.3	(45.6, 48.9)	52.5	(50.6, 54.3)	51.7	**<.0001**
Fatigue[b]	244	52.3	(50.8, 53.7)	59.3	(57.5, 61.1)	51.4	(49.4, 53.5)	42.3	(40.0, 44.6)	65.6	**<.0001**
Pain Interference[c]	243	50.6	(49.5, 51.8)	55.5	(53.8, 57.2)	48.8	(47.0, 50.7)	45.6	(43.5, 47.6)	29.7	**<.0001**

[a]Missing *n*=2; [b]Missing *n*=3; [c]Missing *n*=4; *Note*: CI = 95% confidence interval of mean; P-values were generated using analysis of variance (ANOVA) tests to assess whether differences exist between the mean scores of the three groups.

CHAPTER 5: AIM 3

Barriers to Physical Activity and Variation in Supportive Care Intervention Preferences: A Survey of Adults Living with Advanced Cancer

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The paper has been formatted for submission to *BMC Cancer*'s call for papers on "Diet and physical activity during and after cancer treatment".

ABSTRACT

Background: Physical activity is an important health behavior and may greatly benefit adults living with advanced cancer, however barriers to physical activity and preferences for interventions are not well understood. The purpose of this analysis is to assess barriers to physical activity and differences in supportive care intervention preferences by demographic and clinical characteristics among adults with advanced cancer.

Methods: Data come from a cross-sectional study of 247 adults with advanced cancer aged 30-81 ($\bar{x}$=67 years). Surveys were mailed to adults with advanced cancer who recently visited the University of Wisconsin Carbone Cancer Center (January 2021-January 2023). The Godin-Shepard Leisure Score Index (insufficiently active, moderately active, and active) was used to assess physical activity. General and cancer-specific barriers were reported as mean scores (1-5: not at all to a great deal). Variation in supportive care intervention preferences including reasons for participating, types of activities, and delivery mode was assessed using chi-squared tests.

Results: In our sample, adults living with advanced cancer (n=247) were insufficiently active (53%), moderately active (21%), or active (26%). Respondents identified several barriers to physical activity spanning tiredness ($\bar{x}$=3.2), winter weather concerns ($\bar{x}$=3.2), and lack of motivation ($\bar{x}$=2.7). Respondents were most interested in a supportive care intervention designed to increase energy (88%) and improve physical health (86%) with physical therapy (73%), walking (72%), and resistance exercises (72%). Differences in preferences emerged by demographic characteristics and to a lesser extent by clinical characteristics.

Conclusions: Most adults with advanced cancer fell under the category of insufficiently active. Active adults with advanced cancer reported fewer barriers to physical activity than those who were insufficiently active. Future interventions designed to support adults with advanced cancer should focus on increasing energy and physical health and reduce barriers of tiredness and winter weather concerns. Developing multimodal interventions that aim to reduce barriers to physical activity among this population is a critical next step.

Keywords: advanced cancer, physical activity, barriers, supportive care, intervention

INTRODUCTION

Cancer Survivors and Physical Activity

Cancer survivors comprise make up a growing part of the US population. With a growing aging US population and advances in early detection of cancer and cancer treatments, there are approximately 18 million survivors as of 2023 (1,2). An increasing number of individuals are living longer with advanced or metastatic cancer. The term advanced cancer is used to describe those cancers that have progressed or spread past the primary cancer site (3). Despite the metastatic cancer population expected to grow to an estimated 700,000 in 2025, their needs are not well understood (3,4). A better understanding of how to meet the complex physical, functional, and emotional needs of this growing population is critically needed.

Physical activity may benefit those living with advanced cancer through mechanisms such as improving energy, sleep, levels of pain, and overall health-related quality of life (HRQoL); such as reducing symptoms of anxiety and depression (6,7). While the American College of Sports Medicine has acknowledged the lack of existing knowledge on the safety, benefits, and feasibility of physical activity among adults living with advanced cancer, evidence is growing that physical activity is safe and beneficial for adults living with advanced cancer (6,8). A recent systematic review and metanalysis by Toohey et al. (2022) found that among palliative care patients, physical activity was not only safe and feasible, but also led to a decrease in fatigue as well as an increase in quality of life (9).

Assessing barriers to physical activity among the advanced cancer population can enable researchers to develop interventions that aim to address and mitigate these barriers to physical activity. An assessment of both general barriers, such as lack of time or a safe environment for physical activity, and cancer-specific barriers, like neuropathy or side effects of treatment is needed (10,11). Barriers might impact adults living with advanced cancer more than early-stage cancer survivors due to their intensity, i.e., greater fatigue or pain, or greater challenges for those with advanced cancer, i.e., lack of safe environment or fear of falls or injury. A necessary first step is to describe the presence or absence of general and cancer-specific barriers to physical activity among adults living with advanced cancer to develop interventions to reduce these barriers for this growing population (6).

Supportive Care Interventions to Address Barriers

Supportive care is defined by the National Cancer Institute as “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” (12,13). Supportive care interventions can be multi-modal and include physical, social, and/or psychological components, such as exercise, nutritional support, counseling, and pain support to target declines in health and support ongoing health concerns of the whole person with advanced cancer. Existing supportive care interventions have shown promise for improving quality of life among people living with cancer and into survivorship (14–16).

Supportive care interventions may be particularly beneficial to improve long-term health and reduce future impairments for adults living with advanced cancer, due to the fact that they endure particularly intensive treatments, cycle on and off treatment, and have long recovery times (17–19). Supportive care interventions may begin as early as diagnosis and continue until the end of life (13). As people are living longer with advanced cancer, determining the best path forward for optimizing the health and well-being of adults living with advanced cancer is critical.

To better design supportive care interventions that fit the complex needs of this population, an assessment of barriers to physical activity and preferences for a future intervention is needed. This study aims to assess: (1) barriers to physical activity by physical activity level, and (2) variation in supportive care intervention preferences by age, gender, urbanicity, retirement status, cancer type, and treatment status.

METHODS

Patients were recruited from the University of Wisconsin Carbone Cancer Center (UWCCC) to complete an optional, mail-based survey with questions on physical activity, barriers to physical activity, quality of life, supportive care program preferences, and demographic and clinical characteristics; for more information, see Aim 2. Eligibility criteria included the following: cancer type and stage [stage 4 breast, prostate, or colorectal cancer; stage 3 or 4 lymphoma (non-Hodgkin’s and Hodgkin’s); or myeloma], 18-80 years of age as of January 2023, date of eligible diagnosis (January 2021-January 2023), valid mailing address, alive at the time of contact, and English speaking. We wanted to recruit those who recently received care at UWCCC as they were more likely to be alive, able to recount recent treatment(s) received, and have a valid current address.

Data Collection

In brief, we followed a modified Dillman approach and fielded a survey from April-July 2023 among patients at UWCCC (20). Participants were given a small incentive of $2 with the first mailing of the survey; however, participation was completely voluntary and opt out information was included with each of the three mailings (pre-notice postcard, mailing of survey two weeks later, mailing of copy of survey to non-responders five weeks later).

Surveys were collected from April 3, 2023-July 31, 2023. Among the eligible patients (n=683), n=9 (1%) refused (opted out), n=3 (0.4%) returned a blank survey, and n=393 (58%) did not respond. The final sample consisted of 278 patients who returned a survey for a final response rate of 41%. The final sample for analysis included those who had complete data on demographic and clinical characteristics (n=247, 89%).

This study was approved as minimal risk by the University of Wisconsin-Madison's Minimal Risk Institutional Review Board (Protocol #2022-0966) and by the University of Wisconsin's Carbone Cancer Center's (UWCCC) Protocol Review and Monitoring Committee (Protocol UW22103).

Survey Measures

Physical activity levels were assessed using a modified Godin-Shepard Leisure-Time Physical Activity Questionnaire (GSLTPQ) to ask about activity during the past seven days with three designated intensities: light, moderate, and strenuous. The GSLTPQ has been used to collect physical activity data among cancer survivors previously (21,22). Muscle strengthening physical activity data were collected using a modified Muscle-Strength Exercise Questionnaire (MSEQ), which asked about types and durations of strength-based activities during the past seven days (23).

Questions on barriers to physical activity were developed for use in this survey based on prior research (10,11). Response categories for the eighteen barriers used a five-point Likert scale ranging from 1 “not at all” to 5 “a great deal”. Since most respondents had not had a recent surgery (n=233; 94%) and thus the “surgical complications” barrier did not apply, it was removed as a barrier from analyses leaving seventeen barriers remaining for analyses.

Questions regarding intervention preferences were developed for the survey. The question of, “How interested are you in participating in a supportive care program designed for people with cancer consisting of physical activity, nutrition, and/or coping support?” was asked as a 5-point Likert scale question with responses ranging from “not at all interested” to “extremely interested”. We asked the intervention preference questions in a yes/no format for each option, while allowing respondents to write in other responses in addition to or instead of selecting predetermined responses.

Comorbidity data were collected using the Functional Comorbidity Index (24).

Statistical Analysis

Data were double entered into REDCap (Research Electronic Data Capture) and reviewed for quality and completeness using REDCap's Data Comparison tool (25). Data were analyzed using SAS 9.4 (Cary, NC).

To analyze physical activity data, light, moderate, and strenuous activities were included in the Leisure Score Index calculation. Weekly frequencies of each intensity category were multiplied by their corresponding metabolic equivalents of task (MET) value. Number of times of strenuous activity was multiplied by 9, number of times of moderate activity was multiplied by 5, and number of times of light activity was multiplied by 3 to get an overall Leisure Score Index (LSI) value. Physical activity level was categorized using the Leisure Score Index (LSI) cut points for active (LSI of 24 or higher), moderately active (LSI of 14 to less than 24), and insufficiently active (LSI less than 14). For respondents who did not report any aerobic activity, they were categorized with a value of zero, corresponding to insufficiently active. Meeting the strength guideline was categorized as answering “yes” to the question “Do you usually do muscle-strengthening exercise?” and reporting 2 or more days to the question “How many days, in the last 7 days, did you do muscle-strengthening exercise?”. For respondents who did not report any muscle strength activity, they were categorized with a value of zero, corresponding to not meeting the strength guideline.

An overall Functional Comorbidity Index score was calculated based on the number of self-reported “yes” responses to the list of 18 comorbidities and a categorical measure was created ranging from zero comorbidities to four or more comorbidities. We used data from self-reported weight and height to calculate a value for body mass index and replaced the value for “obesity” based on the well-established obesity cutpoint of a body mass index greater than or equal to 30 kg/m^2.

Descriptive statistics including means and standard deviations of continuous variables and frequencies of categorical variables were calculated. Analysis of variance (ANOVA) tests were used to assess differences in mean “barrier to physical activity” scores by Leisure Score Index (LSI) category. Two-sample *t* tests were used to assess differences in mean “barrier to physical activity” scores by meeting the strength guideline. Pearson’s Chi-squared tests were used to assess differences in intervention preferences by demographic (gender, age group, urbanicity, and retirement status) and clinical characteristics (cancer type and treatment status).

RESULTS

Sample Characteristics

Of the respondents (n=247), adults living with advanced cancer in our sample were on average 66 years of age (SD_10.3) and the majority identified as men (60%) (Table 1). In terms of demographic characteristics, most of the respondents were not employed - retired (62%) and married or living with a partner (75%). About a third (30%) of the sample was residing in a rural area (35%) with 25% living in an urban area and 40% in a suburban area. In terms of clinical characteristics, respondents included adults living with advanced prostate cancer, 32%, myeloma, 23%, advanced lymphoma, 16%, advanced breast cancer, 18%, and advanced colorectal cancer, 11%. Most of our sample reported currently receiving chemotherapy, immunotherapy, and/or hormone therapy (73%) and had one or more comorbidities (82%).

Assessment of Interest in Supportive Care Intervention Among Analytic Sample

Most adults with advanced cancer were at least a little interested in a supportive care intervention (72%) (Table 1). Adults who were more interested in an intervention were younger (65.2 years v 69.0 years) and identified as women. Those who had a bachelor's degree or higher education level (53%) compared to some college/associate's degree (32%), or a high school or less education level (15%) were more interested in an intervention. Those respondents who were working full- or part-time were more interested in an intervention than those who were retired or not working for other reasons. Respondents with advanced breast cancer were most likely to be interested compared to the other cancer types. The majority of respondents were insufficiently active (53%), and those who were insufficiently active were less likely to be interested in an intervention than other activity groups (Supplementary Table 1). Most adults did not meet the strength-based physical activity guideline of strength-based activity on two or more days per week (73%), and those meeting the muscle strength guideline were more interested in an intervention than those not meeting the muscle strength guideline.

Assessment of General and Cancer-Specific Physical Activity Barriers by Activity Level

Results of the barrier scores varied by respondent's level of activity, i.e., insufficiently active, moderately active, or active; and meeting the muscle strength guideline. In general, those who were insufficiently active had higher mean scores for all barriers except lack of time compared to those who were moderately active or active. The highest reported barriers to physical activity were attributed to winter weather concerns with higher scores reported by those who were insufficiently active compared to moderately active or active ($\bar{x}$=3.2 vs. $\bar{x}$=2.8 and $\bar{x}$=2.4), tiredness ($\bar{x}$=3.2, $\bar{x}$=2.7, x̄=2.2), and difficulty getting motivated (x̄=2.7 vs. x̄=2.4 and x̄=1.9); (Figure 1, Supplementary Table 2). Fear of falls or injury mean scores were also greater among those insufficiently active adults (x̄=2.2) compared to those who were moderately active or active (x̄=1.4 and x̄=1.5, respectively). In terms of cancer specific-barriers, neuropathy mean scores were greater among those who were insufficiently active (x̄=2.2) compared to those who were moderately active or active (x̄=1.9 and x̄=1.7, respectively). Similar trends were found when comparing those who met the strength guideline to those who did not meet the strength guideline (Figure 1, Supplementary Table 3).

Intervention Programming Preferences by Demographic and Clinical Characteristics

Overall, adults with advanced cancer were interested in a supportive care intervention (70%) with most interested in a program designed to increase energy (88%), improve physical health (86%), and develop muscle strength (81%), (Table 2). In terms of demographic differences, women were more interested than men in an intervention to improve mental health and older individuals were more interested than younger individuals in an intervention to improve balance. Physical therapy (73%), walking (72%), and resistance exercises using weights or bands (72%) were the most selected options for physical activity preferences. We found higher interest in holistic exercises, chair-based exercises, and group aerobics among women compared to men. Younger individuals were also more interested than older individuals in holistic exercises such as Yoga or Tai-Chi. Differences by cancer type emerged for interest in holistic exercises and chair-based exercises; individuals with advanced breast cancer showed the most interest in both activities compared to the other cancer types (Table 3).

Interest in nutrition programming was strongest for receiving nutrition information/recipes for people with cancer, 74% overall, with high endorsement across all demographic characteristics. A consult with a dietician and cooking classes were of higher interest among younger individuals compared to older individuals. Preferences were similar across clinical characteristics.

Among coping support activities, interest was highest for individual therapy with a provider (62%) with higher endorsement among women versus men and younger age groups compared to the oldest age group. Overall, mindfulness techniques for people with cancer received greater endorsement (59%) than group therapy sessions for people with cancer (46%). In terms of clinical characteristics, individual therapy with a provider was of greater interest among those not currently on treatment (79%) compared to those on treatment (58%) and group therapy sessions for people with cancer was also of greater interest among those not currently on treatment (64%) compared to those on treatment (42%).

Intervention Delivery Preferences by Demographic and Clinical Characteristics

Several intervention delivery preferences differed by demographic and clinical characteristics (Table 4). Generally, preferences for timing were similar with most respondents endorsing at diagnosis for the best time to introduce the program (28%) followed by after diagnosis but before treatment begins (24%) compared to other timepoints throughout the cancer journey. Women most strongly preferred for the intervention to start at diagnosis (41%) compared to men (19%). In terms of clinical characteristics, individuals with advanced breast cancer and myeloma most strongly preferred at diagnosis for the best time to start an intervention compared to other treatment types (Table 5).

Most respondents were interested in delivery via in-person activities at the cancer center before or after a clinic visit, 54% overall, followed by in person at a facility close to home, 49% overall. Women and younger individuals preferred delivery via in-person activities at a facility close to home. Delivery mode preferences were similar across clinical characteristics.

In terms of participation, respondents were most interested in one-on-one activities with a provider (51%), followed closely by in a group with other people with cancer (50%), and on your own (49%). The preference for one-on-one activities with a provider was highest for women and younger age groups. There were similar participation preferences across clinical characteristics.

Printed materials (69%) followed by on the internet (website, online videos) (58%) were the top two overall preferences for information delivery. In terms of differences by age group, younger individuals had higher preference for information delivery on the internet or an app compared to older individuals. Information delivery preferences were similar across clinical characteristics.

Almost all respondents had personal access to a smartphone or tablet (90%) and internet access at home (96%); however, younger individuals had greater personal access to a smartphone or table than older individuals. Most respondents did not use an activity tracker to track health or activity (61% overall), but many respondents were interested in using a device to track health or activity (60% overall). More women and individuals in younger age groups reported current use of an activity tracker for health or activity. Interest in a device to track health and activity was highest among individuals with advanced breast and colorectal cancer compared to other cancer types.

DISCUSSION

Our study investigates general and cancer-specific barriers to physical activity along with variation in supportive care intervention preferences among a sample of adults with advanced cancer, a growing population whose barriers to activity are not well understood. In terms of physical activity levels, less is known about the amount of physical activity completed by adults living with advanced cancer in the United States. Our study finds that while respondents engage in some activity including aerobic and muscle strengthening activities, most of the respondents were considered insufficiently active using both the Godin Leisure Score Index cutoffs and muscle strength guideline (21). We also demonstrate key barriers to physical activity and preferences for future interventions among this population.

Our findings show differences in both general and cancer-specific barriers to physical activity by current activity level among adults with advanced cancer. We also find that adults who were moderately active or active tend to rate most barriers less strongly than their insufficiently active counterparts. Overall, the highest average barrier score corresponds with “somewhat a barrier” to weather issues in the winter and tiredness or fatigue among those who are insufficiently active. Similar to our findings, Knowlton et al. found fatigue to be a commonly reported barrier among patients living with advanced disease (44.6%) (7). Research among Australian adults with myeloma and German adults living with advanced cancer found fatigue and tiredness/insomnia to be the most frequently reported barriers to physical activity (26,27). This finding is important for designing future interventions that aim to target the barrier of fatigue and tiredness in this population. We also find the greatest interest in an intervention designed to increase energy, which further supports the existing knowledge that individuals with advanced cancer face this barrier to physical activity. Physical activity is also known to counteract the potential effects of fatigue and tiredness that cancer survivors face, and this should be taken into consideration for future interventions among this population (28–30). In contrast to our findings, bad weather was not considered a highly reported barrier among the sample of adults living with advanced cancer in Germany with only 4.3% considering it a barrier (26). This difference could be due to the differences in weather experienced by both populations. Another study in a Wisconsin sample of rural women found that weather issues in the winter were also reported as a notable barrier to physical activity (10). Our assessment of intervention preferences includes a variety of delivery modalities that could all be completed indoors during winter months if preferred. Acknowledging the potential impacts of differing patterns of local weather during the timeframe of the intervention is another concern for researchers to consider, especially for interventions among populations living in harsh and varying climates.

Our findings support the existing evidence that adults living with advanced cancer have an interest in light- or moderate-intensity activities with our sample having the highest interest in physical therapy and walking activities (31). In a study conducted among older breast, prostate, and colorectal cancer survivors who participated in a 1-year, home-based diet and exercise intervention, Blair et al (2014) found that increasing levels of light-intensity activity were associated with higher scores of physical function measures (32). We also find a greater interest for light- to moderate-intensity activities like physical therapy and walking among our sample of adults living with advanced cancer.

Our results show a variety of differences in supportive care intervention programming preferences by demographic characteristics; however, we find less variation in differences by clinical characteristics. In a survey of metastatic cancer survivors in Alabama, Bail et al. (2021) found interest in supportive care interventions (57%) with the highest overall preference for nutrition classes (46%), metastatic cancer support groups (38%), and gardening (31%) (33). While our study finds more interest in supportive care interventions among our sample (70%), the greatest interest is demonstrated in light to moderate-intensity physical activity modalities and nutrition information/recipes for people with cancer, and we did not find a lot of interest in cooking classes (29%). This contrast in findings may be due to differences in the demographic and clinical characteristics of the two survey samples. In our assessment of delivery preferences for a supportive care intervention, we find that most participants have access to a smartphone or tablet and internet at home, which is a promising finding for assessing the delivery possibilities of a future supportive care intervention.

Strengths and Limitations

Strengths of our analysis include a focus on the growing population of adults living with advanced cancer. Our study includes an electronic health record-verified cancer diagnosis and well-validated measures of physical activity, GSLTPAQ and MSEQ. We also investigate multiple types of physical activity and general and cancer-specific barriers among our sample, which is necessary to design future interventions best suited to meet the needs of adults living with advanced cancer. In terms of questions addressing intervention preferences, we include questions on both types of programming and delivery preferences to better tailor future interventions to meet the unique needs of the population.

Limitations of our study include self-reported demographic and clinical treatment data which may not accurately reflect the respondents' characteristics. We also use self-reported physical activity data, as opposed to accelerometers or other wearables, which may have led to an overestimation of physical activity levels among respondents (22,34). However, a study by Welch et al. (2017) found little difference in moderate-vigorous activity estimates between accelerometry and self-report using the GSLTPAQ to assess physical activity among breast cancer survivors (22). Our study sample is limited to one university affiliated cancer center in the Midwest which may limit the generalizability of our results outside of this context.

CONCLUSIONS

Despite general and cancer-specific barriers to physical activity among this population, our study finds that many adults in our sample participate in some physical activity. Future interventions designed to improve physical activity among adults living with advanced cancer should pay particular attention to the current activity levels and barriers to activity among this growing population. In terms of designing supportive care interventions to meet the needs of adults living with advanced cancer, our study points to an interest in interventions designed to improve energy and physical health with physical therapy and walking activities among adults with advanced cancer. Future interventions should consider barriers to activity and intervention preferences to best meet the diverse needs of the growing population of adults living with advanced cancer.

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Tables and Figures

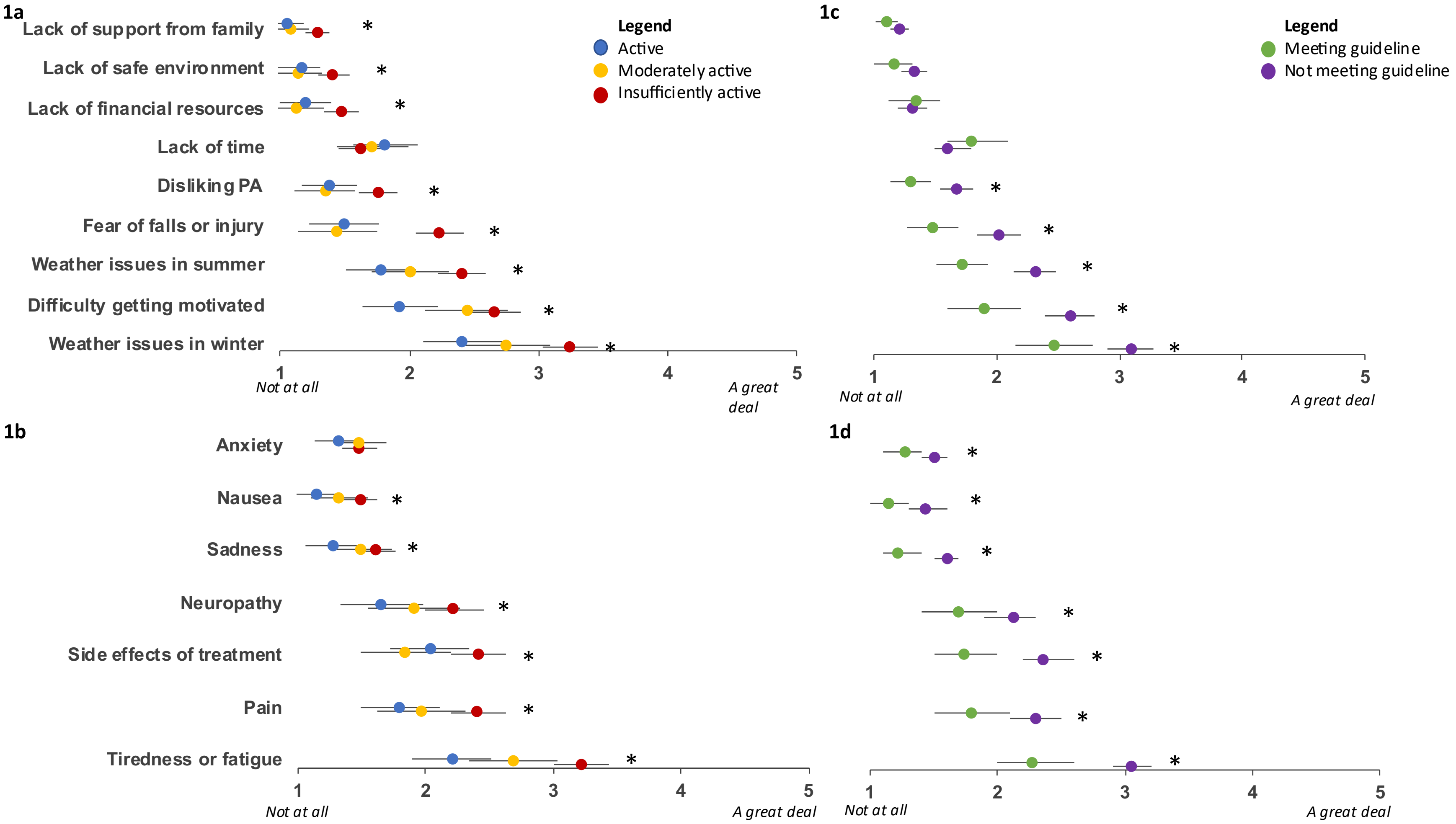
Table 1. Characteristics of the Study Sample by Interest in Supportive Care Intervention

Characteristics	**Analytic Sample**	**Not at all Interested**	**At least a little interested**
	n (%) or Mean (SD)		
	n=247	*n*=68 (28)	*n*=179 (72)
Demographics			
Current Age - Mean (SD)	66.3 (10.3)	69.0 (8.1)	65.2 (10.8)
Age Group			
< 60 years old	52 (21)	8 (12)	44 (25)
60 to 70 years old	86 (35)	25 (37)	61 (34)
> 70 years old	109 (44)	35 (51)	74 (41)
Gender			
Woman	99 (40)	20 (29)	79 (44)
Man	148 (60)	48 (71)	100 (56)
Marital Status			
Married/Living with Partner	185 (75)	54 (79)	131 (73)
Not married/living with partner	62 (25)	14 (21)	48 (27)
Education Level			
High school or less	52 (21)	26 (38)	26 (15)
Some college/associate's degree	73 (30)	15 (22)	58 (32)
Bachelor's degree or higher	122 (49)	27 (40)	95 (53)
Employment Status			
Full or part time	65 (26)	11 (16)	54 (30)
Not employed, retired	153 (62)	48 (71)	105 (59)
Not employed, other	29 (12)	9 (13)	20 (11)
Urbanicity			
Urban	61 (25)	11 (16)	50 (28)
Suburban	99 (40)	33 (49)	66 (37)
Rural	87 (35)	24 (35)	63 (35)

Clinical Characteristics			
Cancer Type			
Breast	45 (18)	4 (6)	41 (23)
Colorectal	27 (11)	8 (12)	19 (10)
Myeloma	57 (23)	20 (29)	37 (21)
Prostate	79 (32)	27 (40)	52 (29)
Lymphoma	39 (16)	9 (13)	30 (17)
Current Treatment Type[a]			
Chemo/Immune/Hormone therapy	181 (73)	45 (66)	136 (76)
Radiation therapy	21 (9)	6 (9)	15 (8)
Surgery (in the past 6 months)	14 (6)	3 (4)	11 (6)
Bone marrow or stem cell transplant (in the past 6 months)	6 (2)	3 (4)	3 (2)
Current Treatment Status			
On treatment	198 (80)	53 (78)	145 (81)
Not on treatment	49 (20)	15 (22)	34 (19)
Functional Comorbidity Index Category			
No comorbidities	45 (18)	14 (21)	31 (17)
1 comorbidity	48 (19)	13 (19)	35 (20)
2 comorbidities	52 (21)	18 (26)	34 (19)
3 or more comorbidities	102 (41)	23 (34)	79 (44)
Physical Activity Levels			
Godin Leisure Score Index Category			
Insufficiently active/sedentary	130 (53)	39 (57)	91 (51)
Moderately active	52 (21)	11 (16)	41 (23)
Active	65 (26)	18 (27)	47 (26)
Meeting Muscle Strength Guideline			
Yes	67 (27)	15 (22)	52 (29)
No	180 (73)	53 (78)	127 (71)

[a] Since respondents could select more than one treatment type, these data reflect the number who checked each box and do not add up to 100%.

Figure 1. General and Cancer-Specific Barriers to Physical Activity by Leisure Score Index (LSI) and Meeting Strength Guideline



Note: Total missingness for barriers from 1.6% (*n*=2) for lack of time to 2.8% (*n*=7) for side effects of treatment in Figure 1. Statistical significance (*) is defined as $p<0.05$, and precise values are presented in Supplementary Tables 2 and 3. Bars represent 95% confidence intervals for mean scores. For 1a and 1b leisure score index categories (active, moderately active, insufficiently active), p-value is of analysis of variance (ANOVA) to assess whether differences exist between the mean scores of the three activity groups. For 1c and 1d meeting strength guideline categories (meeting strength guideline, not meeting strength guideline), p-value is of pooled equal variances *t* test to assess whether there is a difference between the mean scores of the two groups.

Table 2. Supportive Care Intervention Programming Preferences by Demographic Characteristics (*n*=173)

			Gender		Age Group (years)			Urbanicity			Retired	
Programming Preferences	**Overall**		**Women**	**Men**	**<60**	**60-70**	**70+**	**Urban**	**Suburban**	**Rural**	**Yes**	**No**
	n	%	*n=77*	*n=96*	*n=43*	*n=60*	*n=70*	*n=49*	*n=62*	*n=62*	*n=100*	*n=73*
Total	173	0.70	*Percent*									
Reasons for Participating												
To increase your energy	153	0.88	0.86	0.91	0.88	0.88	0.89	0.92	0.94	0.81	0.88	0.89
To improve physical health	149	0.86	0.87	0.85	0.86	0.85	0.87	0.84	0.87	0.87	0.86	0.86
To develop muscle strength	140	0.81	0.79	0.82	0.74	0.82	0.84	0.82	0.85	0.76	0.85	0.75
To find support and motivation	135	0.78	0.84	0.73	0.79	0.80	0.76	0.76	0.82	0.76	0.76	0.81
To improve mental health	134	0.77	**0.86**	**0.71**	0.86	0.82	0.69	0.80	0.71	0.82	**0.72**	**0.85**
To improve your balance	114	0.66	0.61	0.70	**0.51**	**0.67**	**0.74**	0.63	0.69	0.65	**0.75**	**0.53**
Physical Activities												
Physical therapy	126	0.73	0.69	0.76	0.70	0.75	0.73	0.71	0.74	0.73	0.73	0.73
Walking	125	0.72	0.73	0.72	0.67	0.65	0.81	0.69	0.74	0.73	0.77	0.66
Resistance exercises	124	0.72	0.75	0.69	0.67	0.75	0.71	**0.65**	**0.85**	**0.63**	0.72	0.71
Using weight machines	90	0.52	0.44	0.58	0.53	0.57	0.47	0.55	0.56	0.45	0.47	0.59
Holistic exercises	88	0.51	**0.70**	**0.35**	**0.63**	**0.58**	**0.37**	0.59	0.55	0.40	**0.44**	**0.60**
Occupational therapy	71	0.41	0.40	0.42	0.23	0.50	0.44	0.47	0.39	0.39	0.43	0.38
Chair-based exercises	63	0.36	**0.45**	**0.29**	0.23	0.43	0.39	0.33	0.39	0.37	0.38	0.34
Group aerobics class	55	0.32	**0.48**	**0.37**	0.35	0.32	0.30	0.33	0.27	0.35	0.28	0.37
Nutrition Programming												
Nutrition information/recipes	128	0.74	0.77	0.72	0.77	0.80	0.67	0.69	0.81	0.71	0.69	0.81
Consult with dietician	94	0.54	0.62	0.48	**0.65**	**0.62**	**0.41**	0.49	0.58	0.55	0.49	0.62
Cooking classes	51	0.29	0.30	0.29	**0.44**	**0.30**	**0.20**	0.29	0.24	0.35	**0.21**	**0.41**
Coping Support												
Individual therapy with provider	107	0.62	**0.70**	**0.55**	**0.77**	**0.67**	**0.49**	0.59	0.60	0.66	**0.53**	**0.74**
Mindfulness techniques	102	0.59	**0.75**	**0.46**	0.65	0.60	0.54	0.53	0.63	0.60	0.56	0.63
Group therapy sessions	80	0.46	0.48	0.45	0.44	0.42	0.51	0.43	0.47	0.48	0.46	0.47

Note: Shading and **bold** reflect a statistically significant p-value <0.05 from a Chi-squared test separately for gender, age group, urbanicity, and retired within each variable. The proportions are out of each column total and reflect those who selected at least one reason for participating and at least one activity (n=173).

Table 3. Supportive Care Intervention Programming Preferences by Clinical Characteristics (*n*=173)

Programming Preferences	**Cancer Type**					**On Treatment Status**	
	Breast	**Colorectal**	**Prostate**	**Myeloma**	**Lymphoma**	**No**	**Yes**
	n=41	*n=19*	*n=49*	*n=36*	*n=28*	*n=33*	*n=140*
	Percent						
Reasons for Participating							
To increase your energy	0.93	0.79	0.96	0.78	0.89	0.85	0.89
To improve physical health	0.95	0.74	0.88	0.83	0.82	0.79	0.88
To develop muscle strength	0.80	0.74	0.90	0.81	0.71	0.70	0.84
To find support and motivation	0.88	0.79	0.69	0.78	0.79	0.82	0.77
To improve mental health	0.88	0.84	0.67	0.69	0.86	0.82	0.76
To improve your balance	0.68	0.42	0.78	0.64	0.61	0.61	0.67
Physical Activities							
Physical therapy	0.63	0.58	0.82	0.81	0.71	0.76	0.72
Walking	0.80	0.63	0.71	0.75	0.64	0.70	0.73
Resistance exercises using bands or weights	0.78	0.84	0.73	0.61	0.64	0.73	0.71
Using weight machines	0.41	0.68	0.59	0.53	0.43	0.52	0.52
Holistic exercises such as Yoga or Tai-Chi	**0.78**	**0.53**	**0.39**	**0.44**	**0.39**	0.42	0.53
Occupational therapy	0.37	0.21	0.45	0.42	0.54	0.52	0.39
Chair-based exercises	**0.54**	**0.11**	**0.39**	**0.42**	**0.18**	0.30	0.38
Group aerobics class	0.44	0.26	0.24	0.31	0.32	0.36	0.31
Nutrition Programming							
Nutrition information/recipes for people with cancer	0.71	0.74	0.78	0.78	0.68	0.76	0.74
Consult with dietician	0.61	0.42	0.55	0.47	0.61	0.61	0.53
Cooking classes	0.32	0.32	0.24	0.25	0.39	0.33	0.29
Coping Support							
Individual therapy with provider	0.63	0.58	0.49	0.67	0.79	**0.79**	**0.58**
Mindfulness techniques for people with cancer	0.73	0.53	0.49	0.61	0.57	0.61	0.59
Group therapy sessions for people with cancer	0.46	0.58	0.39	0.44	0.54	**0.64**	**0.42**

Note: Shading and **bold** reflect a statistically significant p-value <0.05 from a Chi-squared test separately for cancer type and treatment status within each variable. The proportions are out of each column total and reflect those who selected at least one reason for participating and at least one activity (n=173).

Table 4. Supportive Care Intervention Delivery Preferences by Demographic Characteristics (*n*=173)

			Gender		**Age Group (years)**			**Urbanicity**			**Retired**	
Delivery Preferences	**Overall**		**Women**	**Men**	**<60**	**60-70**	**70+**	**Urban**	**Suburban**	**Rural**	**Yes**	**No**
	n	%	*n=77*	*n=96*	*n=43*	*n=60*	*n=70*	*n=49*	*n=62*	*n=62*	*n=100*	*n=73*
Total	173	0.70	Percent									
Timing[a]												
At diagnosis	49	0.28	**0.41**	**0.19**	0.42	0.32	0.16	0.31	0.33	0.23	**0.17**	**0.44**
After diagnosis, but before treatment	41	0.24	**0.21**	**0.26**	0.22	0.30	0.18	0.33	0.20	0.21	**0.26**	**0.21**
During treatment	34	0.20	**0.22**	**0.18**	0.15	0.18	0.22	0.16	0.13	0.29	**0.26**	**0.11**
During a break from treatment	25	0.15	**0.04**	**0.23**	0.09	0.08	0.22	0.10	0.20	0.13	**0.17**	**0.11**
Other	23	0.13	**0.12**	**0.15**	0.09	0.12	0.16	0.10	0.15	0.15	**0.13**	**0.14**
Delivery Mode												
In person, at cancer center before/after visit	93	0.54	0.55	0.53	0.53	0.60	0.49	0.63	0.53	0.47	0.52	0.56
In person, at a facility close to home	85	0.49	**0.60**	**0.41**	**0.60**	**0.55**	**0.37**	0.57	0.45	0.47	**0.39**	**0.63**
Remotely, at own home	70	0.40	**0.49**	**0.33**	0.47	0.43	0.34	0.43	0.42	0.37	0.37	0.45
In person, during a clinic visit	65	0.38	0.42	0.34	0.33	0.40	0.39	0.49	0.27	0.39	0.38	0.37
Participation												
One-on-one with a provider	89	0.51	**0.61**	**0.44**	**0.65**	**0.57**	**0.39**	0.63	0.47	0.47	**0.43**	**0.63**
In a group with other people with cancer	87	0.50	0.57	0.45	0.51	0.50	0.50	0.45	0.56	0.48	0.47	0.55
On your own	84	0.49	0.52	0.46	0.49	0.55	0.43	0.49	0.47	0.50	0.46	0.52
With a family member or friend	57	0.33	0.35	0.31	0.35	0.33	0.31	0.33	0.40	0.26	0.31	0.36
Delivery of Information												
Printed materials	120	0.69	0.71	0.68	0.65	0.67	0.74	0.63	0.71	0.73	0.69	0.70
On the internet (website, online videos)	100	0.58	0.64	0.53	**0.70**	**0.68**	**0.41**	0.63	0.65	0.47	0.52	0.66
On an app (e.g., smartphone-based content)	43	0.25	**0.38**	**0.15**	**0.42**	**0.23**	**0.16**	0.18	0.32	0.23	**0.17**	**0.36**
Phone call	39	0.23	0.27	0.19	0.19	0.25	0.23	0.31	0.13	0.26	0.21	0.25
Video call	21	0.12	**0.21**	**0.05**	0.09	0.20	0.07	0.16	0.11	0.10	0.15	0.08
Access to Internet and Phone												
Yes - Personal access to smartphone or tablet	155	0.90	0.95	0.85	**0.98**	**0.92**	**0.83**	0.88	0.94	0.87	0.89	0.90
Yes - Internet access at home[b]	165	0.96	**1.00**	**0.93**	0.98	0.95	0.96	0.94	0.98	0.95	0.98	0.93
Device Use to Track Health or Activity												

Yes, I do currently	42	0.24	**0.30**	**0.20**	**0.44**	**0.18**	**0.17**	0.24	0.31	0.18	0.18	0.33
Yes, I have in the past but do not currently	26	0.15	**0.26**	**0.06**	**0.12**	**0.20**	**0.13**	0.08	0.15	0.21	0.16	0.14
No	105	0.61	**0.44**	**0.74**	**0.44**	**0.62**	**0.70**	0.67	0.55	0.61	0.66	0.53
Interest in Device to Track Health or Activity[c]												
Yes	97	0.60	0.68	0.54	0.80	0.56	0.52	0.57	0.60	0.64	0.54	0.69
No	64	0.40	0.32	0.46	0.20	0.44	0.48	0.43	0.40	0.36	0.46	0.31

Note: Shading and **bold** reflect a statistically significant p-value <0.05 from a Chi-squared test separately for gender, age group, urbanicity, and retired within each variable. The proportions are out of each column total and reflect those who selected at least one reason for participating and at least one activity (n=173). [a-c]Total missingness for these variables is 0.1% (n=1) for "time to start an intervention" and "access to internet", and 7% (n=12) for "interest in device to track health or activity".

Table 5. Supportive Care Intervention Delivery Preferences by Clinical Characteristics (*n*=173)

Delivery Preferences	**Cancer Type**					**On Treatment Status**	
	Breast	**Colorectal**	**Prostate**	**Myeloma**	**Lymphoma**	**No**	**Yes**
	n=41	*n=19*	*n=49*	*n=36*	*n=28*	*n=33*	*n=140*
	Percent						
Timing[a]							
At diagnosis	**0.39**	**0.11**	**0.20**	**0.40**	**0.25**	0.21	0.30
After diagnosis, but before treatment	**0.22**	**0.42**	**0.22**	**0.14**	**0.29**	0.36	0.21
During treatment	**0.22**	**0.16**	**0.12**	**0.29**	**0.21**	0.12	0.22
During a break from treatment	**0.02**	**0.26**	**0.27**	**0.06**	**0.14**	0.21	0.13
Other	**0.15**	**0.05**	**0.18**	**0.11**	**0.11**	0.09	0.14
Delivery Mode							
In person, at cancer center before/after visit	0.51	0.47	0.51	0.50	0.71	0.67	0.51
In person, at a facility close to home	0.56	0.42	0.45	0.50	0.50	0.55	0.48
Remotely, at own home	0.56	0.32	0.39	0.33	0.36	0.30	0.43
In person, during a clinic visit	0.37	0.53	0.33	0.31	0.46	0.52	0.34
Participation							
One-on-one with a provider	0.59	0.53	0.45	0.50	0.54	0.48	0.52
In a group with other people with cancer	0.56	0.58	0.41	0.53	0.50	0.61	0.48
On your own	0.56	0.47	0.43	0.47	0.50	0.58	0.46
With a family member or friend	0.32	0.32	0.31	0.36	0.36	0.33	0.33
Delivery of Information							
Printed materials	0.73	0.53	0.61	0.78	0.79	0.73	0.69
On the internet (website, online videos)	0.71	0.53	0.55	0.50	0.57	0.64	0.56
On an app (e.g., smartphone-based content)	0.37	0.37	0.14	0.17	0.29	0.30	0.24
Phone call	0.20	0.21	0.18	0.25	0.32	0.33	0.20
Video call	0.22	0.11	0.04	0.17	0.07	0.06	0.14
Access to Internet and Phone							
Yes - Personal access to smartphone or tablet	0.95	0.95	0.82	0.94	0.86	0.85	0.91
Yes - Internet access at home[b]	1.00	1.00	0.92	0.97	0.93	0.94	0.96
Device Use to Track Health or Activity							

Yes, I do currently	0.29	0.32	0.24	0.19	0.18	0.18	0.26
Yes, I have in the past but do not currently	0.29	0.11	0.06	0.19	0.07	0.06	0.17
No	0.41	0.58	0.69	0.61	0.75	0.76	0.57
Interest in Device to Track Health or Activity[c]							
Yes	**0.81**	**0.78**	**0.52**	**0.50**	**0.46**	0.58	0.61
No	**0.19**	**0.22**	**0.48**	**0.50**	**0.54**	0.42	0.39

Note: Shading and **bold** reflect a statistically significant p-value <0.05 from a Chi-squared test separately for cancer type and treatment status within each variable. The proportions are out of each column total and reflect those who selected at least one reason for participating and at least one activity (n=173). [a-c]Total missingness for these variables is 0.1% (n=1) for "time to start an intervention" and "access to internet", and 7% (n=12) for "interest in device to track health or activity".

Supplementary Tables

Supplementary Table 1. Characteristics of the Study Sample by Leisure Score Index (LSI)

Characteristics	Analytic Sample	Insufficiently Active (LSI <14)	Moderately Active (LSI 14-23)	Active (LSI 24+)
	n (%) or Mean (SD)			
	n=247	*n*=130 (53)	*n*=52 (21)	*n*=65 (26)
Demographics				
Current Age - Mean (SD)	66.3 (10.3)	67.2 (9.8)	65.5 (11.2)	65.1 (10.6)
Age Group				
< 60 years old	52 (21)	25 (19)	12 (23)	15 (23)
60 to 70 years old	86 (35)	40 (31)	20 (38)	26 (40)
> 70 years old	109 (44)	65 (50)	20 (38)	24 (37)
Gender				
Woman	99 (40)	57 (44)	18 (35)	24 (37)
Man	148 (60)	73 (56)	34 (65)	41 (63)
Marital Status				
Married/Living with Partner	185 (75)	93 (72)	37 (71)	55 (85)
Not married/living with partner	62 (25)	37 (28)	15 (29)	10 (15)
Education Level				
High school or less	52 (21)	39 (30)	9 (17)	4 (6)
Some college/associate's degree	73 (30)	43 (33)	14 (27)	16 (25)
Bachelor's degree or higher	122 (49)	48 (37)	29 (56)	45 (69)
Employment Status				
Full or part time	65 (26)	26 (20)	15 (29)	24 (37)
Not employed, retired	153 (62)	84 (65)	32 (61)	37 (57)
Not employed, other	29 (12)	20 (15)	5 (10)	4 (6)
Urbanicity				
Urban	61 (25)	29 (22)	17 (33)	15 (23)
Suburban	99 (40)	51 (39)	20 (38)	28 (43)
Rural	87 (35)	50 (38)	15 (29)	22 (34)

Clinical Characteristics				
Cancer Type				
Breast	45 (18)	25 (19)	9 (17)	11 (17)
Colorectal	27 (11)	14 (11)	5 (10)	8 (12)
Myeloma	57 (23)	35 (27)	13 (25)	9 (14)
Prostate	79 (32)	39 (30)	17 (33)	23 (35)
Lymphoma	39 (16)	17 (13)	8 (15)	14 (22)
Current Treatment Type[a]				
Chemo/Immune/Hormone therapy	181 (73)	100 (77)	37 (71)	44 (68)
Radiation therapy	21 (9)	12 (9)	2 (4)	7 (11)
Surgery (in the past 6 months)	14 (6)	9 (7)	3 (6)	2 (3)
Bone marrow or stem cell transplant (in the past 6 months)	6 (2)	3 (2)	3 (6)	0 (0)
Current Treatment Status				
On treatment	198 (80)	110 (85)	42 (81)	46 (71)
Not on treatment	49 (20)	20 (15)	10 (19)	19 (29)
Functional Comorbidity Index Category				
No comorbidities	45 (18)	18 (14)	6 (12)	21 (32)
1 comorbidity	48 (19)	23 (18)	10 (19)	15 (23)
2 comorbidities	52 (21)	29 (22)	12 (23)	11 (17)
3 or more comorbidities	102 (41)	60 (46)	24 (46)	18 (28)
Interest in Supportive Care Intervention				
Not at all interested	68 (28)	39 (30)	11 (21)	18 (28)
At least a little interested	179 (72)	91 (70)	41 (79)	47 (72)

[a] Since respondents could select more than one treatment type, these data reflect the number who checked each box and do not add up to 100%.

Supplementary Table 2. Mean Scores for General and Cancer-Specific Barriers by Leisure Score Index (LSI) (*n*=247)

Barrier	**Insufficiently Active**	**95% Confidence Interval**	**Moderately Active**	**95% Confidence Interval**	**Active**	**95% Confidence Interval**	**P-value**	**Missing *n***	**Total *n***
Lack of time	1.6	(1.4, 1.8)	1.7	(1.4, 2.0)	1.8	(1.6, 2.1)	0.46	2	245
Difficulty getting motivated	2.7	(2.4, 2.9)	2.4	(2.1, 2.8)	1.9	(1.6, 2.2)	**0.0004**	4	243
Weather issues in winter	3.2	(3.0, 3.5)	2.8	(2.4, 3.1)	2.4	(2.1, 2.7)	**<.0001**	2	245
Weather issues in summer	2.4	(2.2, 2.6)	2.0	(1.7, 2.3)	1.8	(1.5, 2.0)	**0.0006**	6	241
Disliking PA	1.8	(1.6, 1.9)	1.3	(1.1, 1.6)	1.4	(1.2, 1.6)	**0.002**	3	244
Lack of safe environment	1.4	(1.3, 1.5)	1.1	(0.9, 1.3)	1.1	(1.0, 1.3)	**0.008**	2	245
Lack of support from family	1.3	(1.2, 1.4)	1.1	(0.9, 1.2)	1.0	(0.9, 1.2)	**0.003**	4	243
Fear of falls or injury	2.2	(2.0, 2.4)	1.4	(1.1, 1.7)	1.5	(1.2, 1.8)	**<.0001**	2	245
Lack of financial resources	1.5	(1.3, 1.6)	1.1	(0.9, 1.3)	1.2	(1.0, 1.4)	**0.009**	3	244
Nausea	1.5	(1.4, 1.6)	1.3	(1.1, 1.5)	1.1	(1.0, 1.3)	**0.02**	4	243
Tiredness or fatigue	3.2	(3.0, 3.4)	2.7	(2.3, 3.0)	2.2	(1.9, 2.5)	**<.0001**	3	244
Pain	2.4	(2.2, 2.6)	2.0	(1.6, 2.3)	1.8	(1.5, 2.1)	**0.003**	3	244
Side effects of treatment	2.4	(2.2, 2.6)	1.8	(1.5, 2.2)	2.0	(1.7, 2.3)	**0.01**	7	240
Neuropathy	2.2	(2.0, 2.5)	1.9	(1.5, 2.3)	1.7	(1.3, 2.0)	**0.01**	6	241
Sadness	1.6	(1.5, 1.8)	1.5	(1.3, 1.7)	1.3	(1.1, 1.5)	**0.03**	3	244
Anxiety	1.5	(1.3, 1.6)	1.5	(1.3, 1.7)	1.3	(1.1, 1.5)	0.32	4	243
Doctor or nurse advice not to exercise	1.1	(1.0, 1.2)	1.0	(0.9, 1.1)	1.0	(0.9, 1.1)	0.18	5	242

Note: Statistical significance (**bold**) is defined as $p<0.05$. For leisure score index categories (active, moderately active, insufficiently active), p-value is of analysis of variance (ANOVA) to assess whether differences exist between the mean scores of the three activity groups.

Supplementary Table 3. Mean Scores for General and Cancer-Specific Barriers by Meeting Strength Guideline (*n*=247)

Barrier	Not Meeting Guideline	95% Confidence Interval	Meeting Guideline	95% Confidence Interval	P-value	Missing *n*	Total *n*
Lack of time	1.6	(1.5, 1.8)	1.8	(1.6, 2.1)	0.27	2	245
Difficulty getting motivated	2.6	(2.4, 2.8)	1.9	(1.6, 2.2)	**<.0001**	4	243
Weather issues in winter	3.1	(2.9, 3.3)	2.5	(2.1, 2.8)	**0.001**	2	245
Weather issues in summer	2.3	(2.1, 2.5)	1.7	(1.5, 1.9)	**0.0002**	6	241
Disliking PA	1.7	(1.5, 1.8)	1.3	(1.1, 1.5)	**0.003**	3	244
Lack of safe environment	1.3	(1.2, 1.4)	1.2	(1.0, 1.3)	0.10	2	245
Lack of support from family	1.2	(1.1, 1.3)	1.1	(1.0, 1.2)	0.15	4	243
Fear of falls or injury	2.0	(1.8, 2.2)	1.5	(1.3, 1.7)	**0.001**	2	245
Lack of financial resources	1.3	(1.2, 1.4)	1.3	(1.1, 1.5)	0.91	3	244
Nausea	1.4	(1.3, 1.6)	1.2	(1.0, 1.3)	**0.01**	4	243
Tiredness or fatigue	3.1	(2.9, 3.2)	2.3	(2.0, 2.6)	**<.0001**	3	244
Pain	2.3	(2.1, 2.5)	1.8	(1.5, 2.1)	**0.006**	3	244
Side effects of treatment	2.4	(2.2, 2.6)	1.7	(1.5, 2.0)	**0.001**	7	240
Neuropathy	2.1	(1.9, 2.3)	1.7	(1.4, 2.0)	**0.03**	6	241
Sadness	1.6	(1.5, 1.7)	1.2	(1.1, 1.4)	**0.002**	3	244
Anxiety	1.5	(1.4, 1.6)	1.3	(1.1, 1.4)	**0.04**	4	243
Doctor or nurse advice not to exercise	1.1	(1.0, 1.1)	1.0	1.0	0.16	5	242

Note: Statistical significance (**bold**) is defined as $p<0.05$. For meeting strength guideline categories (meeting strength guideline, not meeting strength guideline), p-value is of pooled equal variances *t* test to assess whether there is a difference between the mean scores of the two groups.

CHAPTER 6: CONCLUSIONS & FUTURE DIRECTIONS

Summary of Results and Conclusions

The primary aim of this dissertation was to assess physical activity levels, changes in physical activity since diagnosis, and associations with quality of life among adults living with advanced cancer. In addition, investigating preferences for a multi-modal supportive care intervention among this population was a necessary next step in order to expand the knowledge base of ways to best address the needs of the growing population of adults living with advanced cancer. In Aim 1, I conducted a qualitative analysis using the Social Cognitive Theory to identify factors influencing physical activity among adults living with advanced cancer. Despite the numerous reported barriers to physical activity, adults living with advanced cancer were still engaging in some activity and interested in engaging in activities to meet their goals of gaining strength and maintaining independence. They also reported difficulties coping with changes in physical functioning due to fatigue, weakness, neuropathy, and pain. Conversations with providers were viewed as encouraging for pursuing activity and an important component of future interventions to help adults living with advanced cancer meet their goals.

In Aim 2, I fielded an original, mail-based survey to adults living with advanced cancer in Wisconsin to assess physical activity levels, including aerobic and strength training, and associations between activity with health-related quality of life outcomes. I found that most adults living with advanced cancer in our sample were insufficiently active (53%), engaging in light intensity activity (62%), and engaging in a lot less activity since their diagnosis (74%). Adults who were a lot less active had lower physical function scores and higher pain interference and fatigue scores than those a little less active or the same or more active since their diagnosis. I also found that adults engaging in a lot less activity reported lower, and clinically meaningful differences in, health-related quality of life compared to those adults engaging in the same or more activity since their diagnosis.

In Aim 3, I used the survey from Aim 2 among adults living with advanced cancer in Wisconsin to barriers to physical activity and supportive care intervention preferences by demographic and clinical characteristics. Numerous barriers to physical activity were reported with the highest barriers of weather issues in the winter, tiredness, and difficulty getting motivated reported among those who were considered insufficiently active compared to moderately active or active. In terms of supportive care intervention preferences, adults living with advanced cancer were most interested in an intervention designed to increase energy (88%) and improve physical health (86%) with physical therapy (73%), walking (72%), and resistance exercises (72%). Differences in programming and delivery preferences were most notable by gender and age group, while there were very few differences by cancer type and treatment status.

Strengths and Limitations

This dissertation has both important strengths and limitations to consider. The strengths of this study include a specific focus on the understudied and growing population of adults living with advanced cancer with an electronic medical record-verified diagnosis of advanced cancer. I included only those with a recent diagnosis of advanced cancer to increase the potential that patients were still alive, at a valid address, and able to recount recent/current treatment.

The limitations of this study include self-reported physical activity, which we know can lead to social desirability bias, i.e., overreporting of engaging in positive health behaviors like physical activity. However, recent research has suggested that the use of the Godin questions for physical activity assessment are similar in reporting to accelerometry in a breast cancer sample. In addition, I am not able to establish temporality or infer causality in these analyses due to the cross-sectional survey study design. This study is also at risk for healthy responder bias whereby patients who are healthier are more likely to respond to the survey and may not be representative of the target population of adults living with advanced cancer.

Importantly, all three aims of this dissertation lack a diverse representation of people with advanced cancer of different racial and ethnic identities or greatly different socioeconomic statuses. Also all patients in the study had access to medical treatment. After reviewing data from the survey and realizing that there was a lack of adults identifying as Hispanic and/or African American/Black in our sample, I reached out to the University of Wisconsin Carbone Cancer Center's (UWCCC) African American Community Advisory Board leadership to discuss ways that we could have better engaged our African American community members in this survey. They gave me some valuable insights for future work, which should include leaders who identify as African American and/or Black within the study team to best represent those people whose voices were missing from our survey and including other recruitment strategies to engage with members of the African American cancer community.

Future Directions

This dissertation investigates the numerous and varied barriers to physical activity faced by adults living with advanced cancer and illuminates potential pathways forward for designing interventions to meet their diverse needs and goals to improve physical function and quality of life. While existing research has focused on cancer survivors with curative disease, this dissertation focuses on the understudied and growing population of adults living with advanced cancer. Discussions in the field of cancer survivorship are active around ways to improve quality of life for those living longer with advanced cancer as our therapeutics continue to improve survival for many types of advanced cancer, including the types of cancer in this dissertation. If current trends in survival continue, this subset of the growing cancer survivor population will continue to live longer, and clinicians will need to adapt to the evolving quality of life concerns of this diverse and poorly understood population.

There are additional analyses that I would like to complete given the gleaned insights and generated dataset from my dissertation. I am interested in an assessment of physical activity level differences by cancer type and treatment type (on chemo/immune/hormonal therapy versus not), as I have not assessed differences by these clinical characteristics at present; however, existing knowledge would suggest that these factors may greatly impact physical activity among adults living with advanced cancer. There are also additional variables included in the survey that were not included in the dissertation chapters that I would like to explore further. Of particular interest is whether access to physical activity amenities in one's neighborhood environment may be an additional barrier to physical activity among our sample of adults living with advanced cancer. Although "safe environment for exercise" did not emerge as a barrier in my analyses, it is possible that other neighborhood factors, such as access to physical activity amenities in one’s neighborhood, may be more relevant to consider.

Clinical and Public Health Implications

Findings from Aim 1 of this dissertation shed light on the diverse factors that impact physical activity decision making of adults living with multiple types of advanced cancer in Wisconsin. These findings suggest critical future insights for clinicians and those working on developing physical activity interventions. Future work to support the needs of adults living with advanced cancer should consider their diverse barriers and future activity goals. Aims 2 and 3 add insight into the important relationship between physical activity and quality of life among the growing population of adults living with advanced cancer. A better characterization of this relationship among adults living with advanced cancer gives us a new understanding of the diverse barriers and current activity levels and quality of life of this population. Not only are adults with advanced cancer more likely to be on treatment for long periods of time, but they are also more likely to cycle on and off treatment, and face long-term toxicities associated with intensive treatments. Taken together, these experiences can greatly impact physical functioning and quality of life in the short- and long-term among this population. Results from Aim 2 suggest important differences in quality-of-life indicators, i.e., physical function, fatigue, and pain interference by changes in physical activity. Future research should take these considerations together with intervention preferences to determine ways to best support adults living with advanced cancer who are facing additional functional limitations as knowledge is growing that cancer survivors have more functional limitations than the general population. Aim 3 additionally gives us current estimates of barriers to physical activity and supportive care intervention preferences by a variety of demographic and clinical characteristics.

To best support adults living with advanced cancer in the future, it is necessary to listen to their needs and wants to develop interventions that break down barriers and incorporate their preferences. Importantly, future interventions need to better understand the needs of this growing and diverse population in terms of current limitations, such as lower physical functioning, and higher fatigue, and pain. Ensuring that adults living with advanced cancer can retain, and potentially improve, physical function and quality of life throughout their lives, interventions designed to best support them are critical next steps.

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APPENDICES

APPENDIX A1. ONLINE RESOURCE: INTERVIEW GUIDE AND SOCIAL COGNITIVE THEORY CONSTRUCTS

1. *Knowledge, attitudes, and self-efficacy*: Tell me about your experiences with physical activity.
2. *Attitudes and skills*: How has your cancer itself affected your physical activity level? (We will ask separately about the effect of treatment on your activity.)
3. Attitudes and skills: How has cancer treatment affected your physical activity level?
4. *Skills and expectations*: How would you describe your physical functioning, both now and prior to your diagnosis. (Physical functioning refers to fitness as well as factors like mobility and balance that affect your ability to engage in activities of daily living.)
5. *Social norms and knowledge*: What, if anything, have you been told by your providers about physical activity?
6. *Attitudes and expectations*: How do you feel physical activity might improve or worsen your health?
7. *Attitudes and expectations*: How do you feel physical activity might improve or worsen your well-being?
8. *Skills and expectations*: Do you have goals around physical activity? If so, what are they?
    a. What types of activity do you enjoy?
9. *Environmental factors*: If you decided to increase your activity level, what would help you to do that?
    a. What resources would you need or want? (Examples: coaching, access to a gym, the opportunity to participate in a group with other cancer survivors, an app)
10. *Social norms*: How would you feel about doing physical activity on your own vs. with other people?
    a. Do you have people in your life who you can be active with?
11. *Access in community*: Could you describe the neighborhood that you live in?
    a. How walkable is the neighborhood you live in?
        1. Sidewalks
        2. Traffic
        3. Safety
        4. Many things to walk to
12. *Access in community*: What types of exercise opportunities exist where you live? (Examples: sidewalks, walking/biking paths, gyms)
13. *Attitudes*: How important is your neighborhood in your decision to be active?
14. *Knowledge and expectations*: What information have you previously received about physical activity for cancer survivors? What would you like to know more about?

APPENDIX A2. STUDY INFORMATION SHEET

Study Information Sheet

Title of the Study: Understanding Physical Activity Needs and Concerns of Adults Living with Non-Curative Cancers

Principal Investigator: Lisa Cadmus-Bertram, Ph.D.
Phone: [redacted]
Email: lisa.bertram@wisc.edu

Mailing Address: 1300 University Ave. Madison, WI 53706

You are invited to participate in a research study that aims to understand how individuals with non-curative cancer think and feel about engaging in physical activity. This study will consist of interviews with adults living with multiple myeloma or with Stage 4 breast, colon, or prostate cancer.

If you choose to participate, you will be asked to complete a one-hour interview. During the interview, we will ask you about topics such as the types and amount of physical activity that you do, how your activity level has been affected by your cancer diagnosis and treatment, and your interests and goals for your activity level in the future. The interview will be held via Zoom (only audio recording) or phone and will be attended by one or two members of the study team. We will ask you not to mention your name or other identifying information during the interview. You will receive $40 in compensation for your time.

We will keep your answers confidential and will not share personal information about you with anyone outside the research team. You may choose not to answer any questions you do not wish to answer, and you can stop the interview at any time.

Audio recordings will be made of the interview. Only the researchers will have access to these recordings. The researchers or someone hired by the researchers will listen to the recording and write down what people said during the interview. The written copy is called a transcription. The transcription will be saved but the recording will be destroyed. No information that could identify you will be included in the transcription.

If you have questions or concerns about the study, please contact Lisa Cadmus-Bertram.

APPENDIX A3. PERMISSION TO CONTACT FORM

Permission to Contact for study

You may be eligible for a study about physical activity and exercise in individuals with non-curative cancer. Participating involves one phone or Zoom (only audio recording) interview, which takes about an hour. You will receive $40 compensation for your time. Can research staff reach out to you about this study?

The HIPAA Privacy Rule requires University of Wisconsin - Madison to obtain your written permission to release your name and phone number to Dr. Lisa Cadmus-Bertram and her research team at the University of Wisconsin-Madison so that they can contact you about taking part in this study. If you agree that we can share your name and telephone number, this information will only be used to contact you to provide more information about this study. Your name and telephone number will not be shared with anyone other than the UW research team. This permission for the researchers ends after the release of your health information to the researchers.

If you decide that you do not wish to take part in the research study after giving permission to provide the researchers with your name and telephone number, the UW researchers will destroy this information. Whenever possible, your health information will be kept confidential. However, if you have given permission to share your information with recipients who are not covered by federal health information privacy laws, the health information they receive may no longer be protected under those federal laws and the recipients may be permitted to further share your information without your permission. As noted before, there are no plans to share your name and contact information with anyone other than the UW researchers.

You do not have to give your name and contact information if you don't want to. If you don't want to provide your name and contact information, it will not affect your health care at this clinic.

By printing your name below and signing this form, you are giving permission for this clinic to give your name and telephone number to Dr. Lisa Cadmus-Bertram's research team to contact you about taking part in her study.

Your name: ___________________________

Your signature: ________________________ Date: ____________________

Preferred contact method (check one or both and fill in contact info below):

☐ Phone ☐ Email

Phone number: ________________________ Email address: ________________________

Best time to call: _______________________

Referring physician name: ____

Email is generally not a secure way to communicate sensitive or health related information as there are many ways for unauthorized users to access email. You should avoid sending sensitive, detailed personal information by email. Email should also not be used to convey information of an urgent nature. If you need to talk to someone immediately or would prefer not to receive study communication by email, please contact Megan Agnew, Research Staff, [redacted]

APPENDIX A4. TELEPHONE ELIGIBILITY SCREENER

Staff ID: _______
Date: _______

Telephone Screening Questionnaire

Hello, my name is ________ and I am calling from the University of Wisconsin – Madison. May I please speak with _________?

I'm calling regarding a new research study. We are contacting you because we are preparing to conduct paid interviews for a small number of patients with a cancer diagnosis. Is this a convenient time to speak to you?

If no, ask time for call back. If yes, continue:

The health benefits of physical activity are well known, however the physical activity needs may be different for adults with cancer. We are specifically interested in connecting with individuals with non-curative cancer, specifically Stage 4 breast, prostate, or colorectal cancer, or multiple myeloma to understand the factors that influence their interest or ability to engage in physical activity. The study is being conducted by Dr. Lisa Cadmus-Bertram, a faculty member in the Department of Kinesiology, in collaboration with cancer clinicians at the Carbone Cancer Center.

Would you like to hear more about the study?

If yes, continue:

This study consists of attending a single interview that will last approximately one hour. The interview will be recorded but no identifying information will be recorded from you. We will ask questions about your views and needs regarding physical activity and how these are affected by your diagnosis and treatment. Each participant will receive $40 to compensate for his or her time.

Does this research study sound like something you would be interested in?

If yes:

The first step is to complete a telephone-screening questionnaire, which takes less than 10 minutes. I will ask you some questions about your current lifestyle see if you are eligible for this study. Your responses will be kept in a password-protected database on a secure server and will be kept confidential to the extent provided by the law; no one except the researchers will see them and your name will not be given out without your consent. Your participation in all aspects of this research is voluntary and you may refuse to participate or withdraw at any time without affecting any relationship you may have with the UW – Madison or its affiliates. If you choose to enroll, your data will be kept as part of our study dataset. If you have any questions about your rights as a research participant at UW - Madison, you may contact the UWHC Patient Relations Representative at (608) 263-8009.

Do you have any questions about this research study? Would you like to go forward with the eligibility questions?

AGE

1. What is your current age? _______ years *Exclusion if <18 or >75*

2. If you decide to participate in this study, you would be asked to attend one interview via Zoom (audio recording only) or phone. Would you be willing and able to do this?
   ☐ Yes
   ☐ No *Exclusion*

3. Are you willing and able to talk about physical activity-related topics in an interview setting?
   ☐ Yes
   ☐ No *Exclusion*

4. Are you currently participating in any other research study related to physical activity?
   a. Yes (specify: ________________________) *Exclusion*
   b. No

END OF QUESTIONNAIRE

<u>If excluded</u>: Thank you for your time, but unfortunately, you do not qualify for this particular study.

<u>Eligible</u>: Thank you for their time in answering those questions. You do qualify for this study.

If the potential participant is interested in going forward:

- Complete contact information (next page)
- Collect information about schedule.
- Send appointment confirmation letter via e-mail (or postal mail if preferred). This packet will include confirmation of the interview, where it will be held, when it will be held, a map of the location and contact information for each of the study coordinators.

Answering machine script: My name is __________ and I am calling for _____________. I'm calling from the University of Wisconsin – Madison regarding a research study. If you would like to learn more about this study, please call us back at [redacted]

Leaving a message with a household member: My name is __________ and I am calling for _____________. I'm calling from the University of Wisconsin – Madison regarding a research study. If Ms. ___________ would like to learn more about this study, she can return my call at [redacted]

CONTACT INFORMATION

First name:		Last name:
Street address:		City & ZIP:
Home Phone: ( )		Cell: ( )
Work Phone: ( )		Preferred number & best time to reach:
Email:		DOB:
Preferred mode of contact:	☐ Phone ☐ Email	

APPENDIX A5. REPRESENTATIVE QUOTE TABLE

Major Themes	Representative Quotes
Positive early life experiences with physical activity (PA) impact current attitudes and behaviors	*"I have always had good physical activity. I worked a lot and played ball and whatnot all my life. [...] Well, softball, baseball."* (Participant 14) *"...I didn't have a lot of terrible side effects, but I was tired from it, and I lost some weight from it. So, I really just stopped doing any kind of regular working out during that time. I would say that probably lasted for five months where I kind of didn't feel like I wanted to work out. And then getting back into it, it was probably somewhat easier for me since I have been doing it my whole life, but I will say, that it kind of made me-- it went two ways, one was I knew I had to do it because it was good for me to do-- it would help my cancer diagnosis. And another was that I didn't know if my body was ready for it or not, so I started really slow and really easy."* (Participant 1) *"I guess I would say I've always been a high energy person. I've always been a very active person. There have been times in my past where I have participated in formal exercise. For quite a few years I went to the gym every morning at 6 o'clock in the morning and worked out for an hour."* (Participant 3) *"Once I retired, I noticed that the weight was coming on and, uh, the activity levels were slowing down. So, I always rode a bike intermittently since I was a kid, and then I figured 'I really like riding a bike, why don't I do it more, I have all the time in the world?' So, I switched to bike riding big time."* (Participant 6) *"I have a [FAMILY MEMBER] and she was always hiking, and she was always biking and all that kind of stuff. […] I'd go out there and she would go 'come on we are going to go hiking' and I was like 'ugh, really' because I was in my twenties and thirties and it's like, I don't want to do this, but the more I did it, you feel good, you feel better and all that. So that's how I got going."* (Participant 9) *"Well, I've always been active and athletic in my childhood days and my younger days. Um, I've always had physical jobs. […] lifting heavy parts [on] a daily basis, always active..."* (Participant 15) "*Okay, um, well I've actually always been, you know, physically active even as a kid. I mean, it's mostly just the general things like bike riding and we did a ton of walking."* (Participant 4)

	“*I grew up on a farm, so we did a lot of work and I still tried to stay active, you know, more or less with work. I didn’t get into running or jogging or nothing like that*.” (Participant 14) “*I wasn’t really active too much in the past 10 years, but we do have a swimming pool that we stay active at with the kids, the grandkids, and we just bought new bikes and I have been enjoying those tremendously and I’m hoping to get on it again this spring.*” (Participant 17) “*Um, well I guess I would say I’ve not been the most physically active person. I did, at a couple times, lost quite a bit of weight. And so, I guess it was in my mid-twenties, was doing a lot of aerobics and lost about eighty pounds...”* (Participant 13) **Physical and mental health benefits** *“…believe it or not, it’s relaxation to me. It clears my mind, makes my body feel better. It’s a goal that I want to continue reaching.”* (Participant 6) “*…[swimming] for me it’s almost like just a sign of meditation or kind of like a meditation*.” (Participant 4) *“Well, I certainly feel like it could improve my health. There’s no doubt about it, I would be stronger and safer, you know? I’d be happier mentally and I c[ould] do more things.”* (Participant 10) *“Oh, I feel like it would improve my health for sure, because I just feel better about myself. I’ve gained a lot of weight which I also somewhat attribute to the steroids, but also, it’s probably just having to deal with everything.”* (Participant 11) *“I just think that the more you exercise, the better you feel. I think it is all in the head a lot of times, so you just have to be motivated to do things that keep you going.”* (Participant 9) *“I don’t mind the physical activity. I can only do what I can do. I don’t try to overdo anything. I think it helps to keep you mentally sharp.”* (Participant 12) *“I think the little I do makes me feel like I can do things. Moving around gets you up there and sitting still and doing nothing I think would just be so depressing. You’ve got to get those*

	endorphins going, even though for me it is a lot of movement.” (Participant 2) “*For me it’s made a lot of difference, it has kept my attitude real positive. You know, I look forward to getting up in the morning and do[ing] whatever I’m going to do, and the first 6 months after diagnosis that’s a difficult time…”* (Participant 5)
Coping with changing physical abilities	**Treatment and cancer side effects** *“...I used to have a lot more stamina. But with the cancer and stuff and the strength-- so, I lost a lot of muscle mass and that’s hard to get used to, but I can still do it if I want to. It may take a little bit longer, you know, to find different ways to do things.”* (Participant 7) “…*it’s much more of a chore to go do something that I want to do than it was before. I can’t say that I don’t do the things that I like to do, it just takes me longer and I might not be everything exactly the way I used to*.” (Participant 13) “*I just get very out of breath. It’s just like I can’t do anymore. I just can’t push myself. And now I know that it is not me.”* (Participant 2) *“…shooting pains would come up my legs all the way to my hips and my arms, you know, from my hands all the way up my arms, you know? They would wake me up and I just couldn’t sleep.”* (Participant 15) *"But it was-- you know, the things with the fractured vertebrae and broken ribs, I was not doing a lot of anything because it hurt to move. I had to be dragged out of the chair. I couldn’t-- I was walking with a walker, barely. So that was certainly a big slow down and it was not because of the chemo, just because of the fractures.”* (Participant 10) *“I still get tired, but I have, you know, a few hours in there, where I can be quite busy and going and doing, but then by four or five o’clock, I have to stop. And that is not like me.”* (Participant 16) *"Well, I’m a hunter, you know. Like if I shoot a deer, I’m not allowed to pull it. I gotta rely on help because my back’s got the cancer. It could be, I don’t know what you want to call it, brittle, so I’ve got to be very careful. And it kind of takes a lot out of you."* (Participant 8)

	"*Well, I took the chemo and once I got admitted to the hospital and everything went downhill from there. I was basically stuck in the bed at the hospital for a month. And then I was re-learning-- I had to learn how to walk again because I was too weak to walk and do a lot of things."* (Participant 12) *"I would say that now I am at least equal to the time I was diagnosed, maybe a little bit better because I do a little more exercise."* (Participant 5) *"…right after the chemo treatments the tiredness sets in, so might be more sitting at home versus out running around but it depends what's gonna go on.*" (Participant 18) **Grappling with functional declines due to aging, cancer, treatment, or some combination of factors** "*I don't feel like I have the strength that I used to have. Once in a while, I am just like, wow, this isn't-- I just don't have the juice in my joints, but I guess I don't feel as though my cancer has affected my activity, it's more my age."* (Participant 3) "*Well, my activities are way down compared to what they used to be and that's probably more my fault. I just don't have the energy that I used to have and that's, I don't know if that's from the cancer drugs or what. I just don't have the drive. And maybe being older, might help, be a part of that.*" (Participant 8) *"And I don't know how much fatigue is from the cancer or just age. When I was first diagnosed, I was [AGE] and now I'm [AGE] so you start to approach [AGE] and you know you're going to have some natural decline in body function."* (Participant 5) *"…right after the chemo treatments the tiredness sets in, so might be more sitting at home versus out running around but it depends what's gonna go on.*" (Participant 18) *"As far as, you know, my balance and stuff, it was probably better when I was younger. But I did notice that a little bit. It's just 'cause I am more cautious 'cause you know a lot of it is I don't have the strength in my body, the core muscles anymore."* (Participant 7)
Provider recommendation to engage in physical	*"You don't know what to expect and, you know, you're thinking they told me you've got to keep active, you just gotta keep doing what you're doing, so that's what I kept doing."* (Participant 9)

activity is important and encouraging	“*Well, they tell me to do what I can, you know, to try to stay active, which I do. I try not to be a total coach potato here; I get up and do things. I try to do a lot of housework, you know, vacuuming and whatnot when I can*.” (Participant 14) *“They encourage me to-- both my nurse practitioner and my oncologist are like just if you even just walk every day, it will do wonders.”* (Participant 11) *“Well, they want me to get up and walk and be active and I’m trying to do that. You know, sometimes you’ve just gotta drive yourself to do it, like I said, and it’s hard, you know? But, like I said, I’m an outdoorsman. I have a yard, a big garden, I mean I’m always outside and putzing and doing something probably maybe not as physically demanding as it should be, but I go until I get tired and then I sit down.”* (Participant 8) "*Um, I think they encouraged me to be as active as you possibly can under the circumstances of your treatment, you know, whatever that is. Um, so they always encouraged you to eat well, that type of thing. But that’s about it.*" (Participant 4) *“…when I first started meeting with them and figuring out that this was stage four and what I was going to have to go through, they did say—the more active you can be the better.”* (Participant 1) **Recommended resources and referrals are needed** *“When I was first diagnosed, I said, ‘what should I do to help myself’, and she said, ‘keep yourself healthy’, and I said, ‘what would that mean for me? What would you suggest for me?’ and she said, ‘keep yourself healthy’. And I’ll never forget that because I thought that’s not enough.”* (Participant 3) “*And [physical therapy] was tremendously helpful, strengthening the core and helping with my back issues with the fractures and everything*.” (Participant 10) *“I was having some issues with my back and whatnot. ‘Cause I was seeing a physical therapist for a while. [My oncologist] sent me to the physical therapist. […] Yeah, I still do some of the exercises to try to improve my balance and stuff.”* (Participant 13)

	“[Physical therapy] was something that we talked about while I was in the hospital. It was a consensus between me and the doctors to help me out. […] it was something that I had to do to get better. It was no second thought with me […] I was going to try to do it.” (Participant 12) "*I enjoyed [LIVESTRONG] a lot. Um, in part because you’re assigned a personal trainer. It was like a personal trainer for every maybe three or four people. […] And then you got to try out different classes that were there, and that’s kind of how we got into the yoga class. It was a chair yoga, so it was more supportive, but still it was really quite beneficial."* (Participant 4)
Interventions should target activity goals	**Gaining strength and maintaining independence** *“I want to move and get around and go shopping when I need to go shopping and I can do it on my own. That’s good for me. I know there’s going to come a time when I can’t do that.”* (Participant 12) “*And so, my goal would probably be to continue doing what I’m doing so that I’m able to keep doing it. You know, if you don’t use it, you lose it. Even though I’ve lost so much, but I’m maintaining what I have, and that’s the goal to me...”* (Participant 7) *“…that was the kinda the impetus to do the yoga thing because at least that’s what it’s all about is balance and I can make myself stronger without killing myself saying like ‘oh I have to run even though it makes me feel miserable,’ so that was the biggest thing, but yeah, I definitely think it would help my mental and physical well-being to just be more in balance and have a better physical activity.”* (Participant 11) *“…‘cause I’m afraid that if I don’t keep moving and doing things, that it’ll just-- it’ll get worse, so I don’t want that to happen. You know, totally dependent on other people or something.”* (Participant 13) *“…that has always been my goal is to go out jogging-- going out and doing things. Stage four does not-- there is no expiration date. You could live for a long, long time.”* (Participant 2) "*I would like to get my upper body strength better because as I get older I want to be able to carry my own groceries and do my own things."* (Participant 3)

	"*I've never set a single goal. I just like to stay active and basically live my life the way I want to*." (Participant 18) **Other activity goals** "*…just to make [physical activity] a bigger part of my life. So, yeah, it was funny when they were like would you be willing to do this and I'm like well it is something that it is a goal of mine, but like as long as I don't have to be pretending that I do it. I'm not doing it right now, I'll be honest."* (Participant 11) "*My goal is to play with my grandchildren again, play in the pool with them, and play ball with them. And another goal is to ride my e-bike. I would love to be able to do that. [...] It would make me so happy to get on these trails on a warm night, biking around wherever we want."* (Participant 17) "*Well, mostly my goal is to go back to swimming laps and doing the water exercise, you know, that type of thing. Just because I think I can notice a difference now when I'm not swimming the laps, it's harder to go up and down the stairs, that type of thing. So, my goal is to eventually, you know, get back to that."* (Participant 4)
Importance of physical environment	*"I bike on roads because I live in [CITY] and there [are] no bike paths, so I go on a country road that is less traveled. I don't like going on highways of course, you know, with the busy travel."* (Participant 9) *"Oh, a ton of opportunities [for physical activity], there's always something to do out here. You know, we mow about 6 acres of land."* (Participant 7) *"It's really a great place to walk. It's a quiet neighborhood. There are lots of ways you can go. I do not have to cross any traffic lights or anything, there's an occasional car."* (Participant 10) "*To me, the neighborhood was not important. [...] I kinda value privacy and we wanted the acreage, so that was more important than having a neighborhood with sidewalks and stuff like that.*" (Participant 1) "*It really isn't [important] 'cause […] I put the bikes in the back of my truck and I drive to the bike trails so no, the neighborhood isn't conducive for walking the dog or biking. But when there's a will there's a way."* (Participant 6)

	"*Well, this is a pretty quiet neighborhood that we live in. I guess it's the older part of [CITY] and it's really quiet. So, it's no problem walking around, and everybody knows everybody, and everybody talks to everybody.*" (Participant 12) *"I have a gym. I have a really nice pool up at the high school that is accessible to me when I go to the gym at the school. I have a very nice quiet, country road to ride bikes and walk."* (Participant 3) **Sidewalks** *"I live on a country road that is not safe to walk on. […] There is no edge and a lot of traffic."* (Participant 16) *"Well, we just had, a couple years ago, they put sidewalks in. So, it's a very residential area, so there's lots of places to walk. There's a lot of parks. You know, I feel like it's a safe place to live."* (Participant 13) *"Uh, the one direction I don't go because the sidewalks are not very good. The other way, the sidewalk's a lot flatter and less cracks."* (Participant 15) "*I would not walk them on my road, only because there's no sidewalks*." (Participant 1) "*It's just the blacktop road down the bottom of the hill. I could walk forever if I wanted to*." (Participant 8) **Cold weather** *"I was thinking about joining a fitness club during the wintertime because it is getting colder and stuff like that just to work on my muscles. I got cardio down, but you know, the muscle part kind of worries me sometimes."* (Participant 9) Related to neuropathy: "*As far as physical activities, things aren't quite as sensitive. And they're not bad now, but like I said with the weather, it's really bad with the cold weather.*" (Participant 15) "*I really hate the cold like I don't like going outside in the cold and so that's like five months of the year*." (Participant 11)

	"Other than me going to the store or to school to pick up the kids or to the park, I don't go walking around through the park in the winter. I did in the summer when it was warm." (Participant 12) *"They used to have an open walking track and I would've loved to have done that in the winter."* (Participant 4)

APPENDIX A6. CODEBOOK STRUCTURE

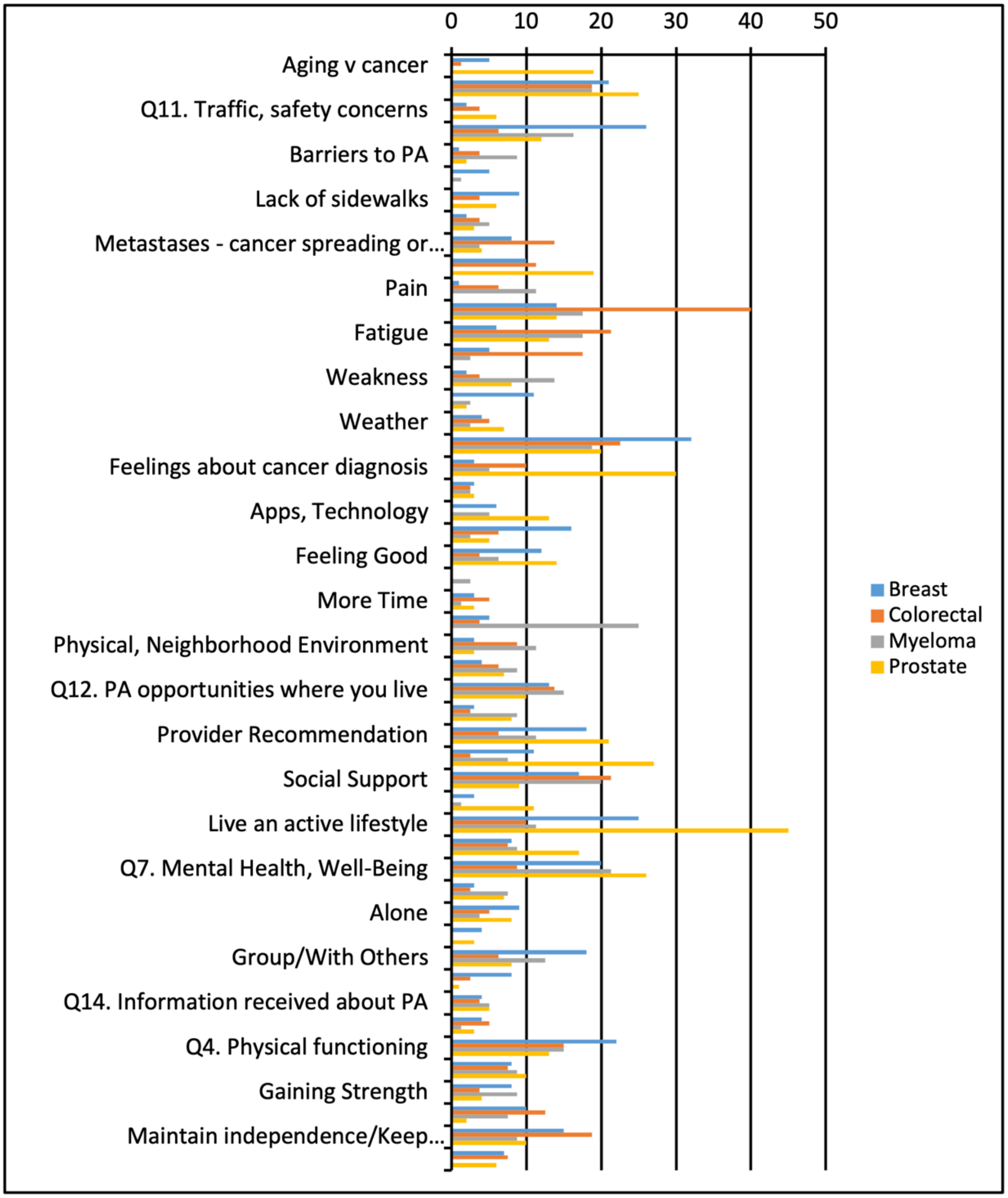
Theme	Code	Subcode
Aging v cancer		
Barriers to PA		
	Q11. Traffic, safety concerns	
	Q2. Symptoms of cancer	
		Out of breath
		Stamina
		Metastases - cancer spreading or affecting bones and lungs
	Q3. Symptoms of treatment	
		Fatigue
		Pain or neuropathy
		Weakness
	Weather	
	Covid concerns decreased activity	
	Too busy	
Cancer journey -- timeline		
	Before diagnosis	
	Diagnosis	
		Feelings about cancer diagnosis
	Treatment	
Facilitators of PA		
	Early life experience with PA	
	More time	
	Physical therapy	
	Community-based resources	
	Physical, neighborhood environment	
		Q12. PA opportunities where you live
		Q13. Importance of neighborhood in PA decision-making
		Low traffic, quiet
	Self-motivation	
	Provider recommendation	
	Apps, technology	

	Feeling good
	Social support
	Increased activity during pandemic
Positive experiences with PA	
	Live an active lifestyle
	Q6. Physical health
	Q7. Mental health, well-being
Q10. Preferences for PA	
	Alone
	Sense of solitude
	With others
Q14. Information received about PA	
	I'd like more information on…
Q4. Physical functioning	
Q8. Goals around PA	
	Gaining strength
	Keep doing what I'm doing…
	Get back to old activities
No provider recommendation	
Other support needed	

APPENDIX A7. NUMBER OF CODES BY CLINICAL AND DEMOGRAPHIC CHARACTERISTICS

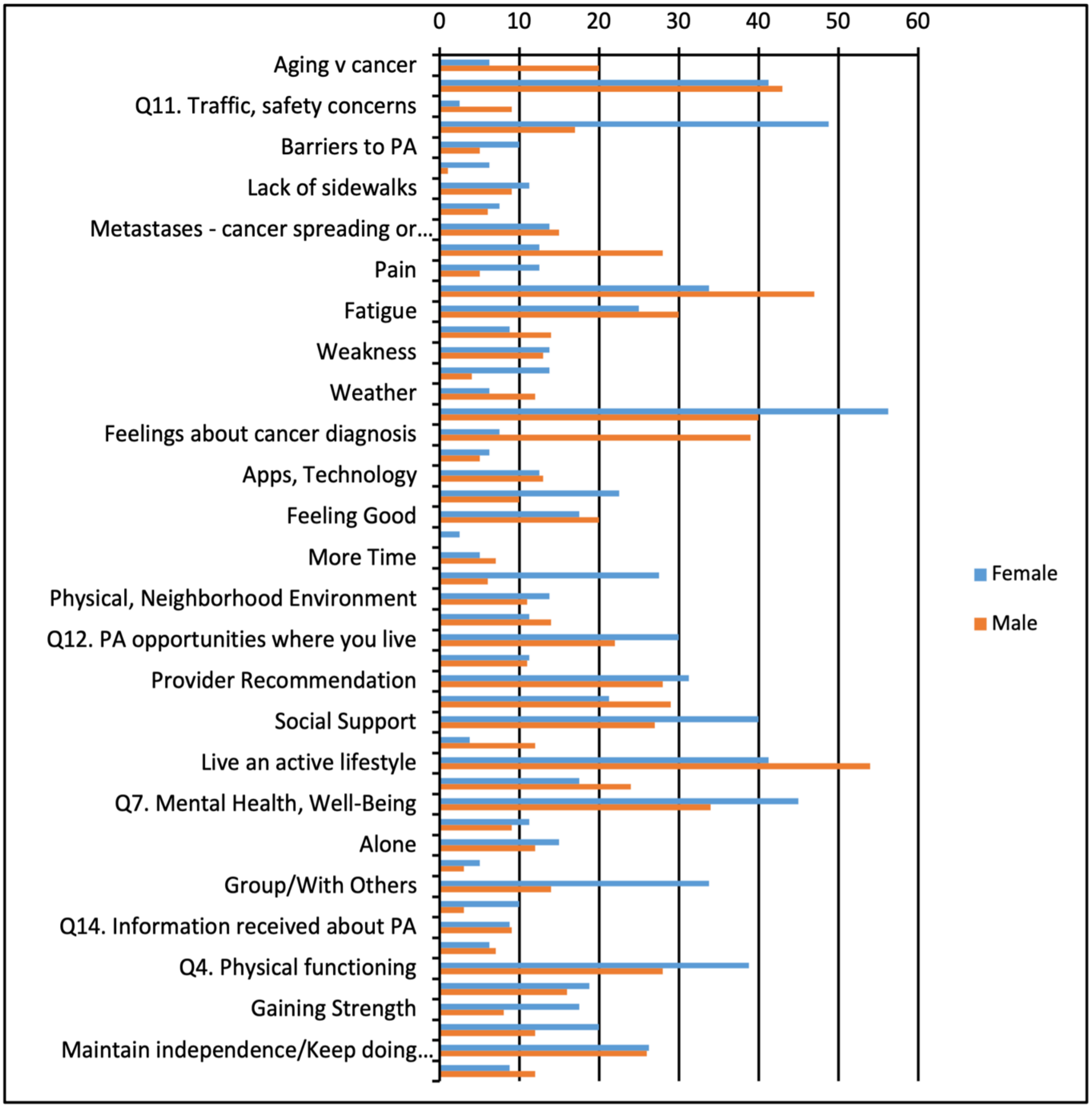
Code	Breast	Colorectal	Myeloma	Prostate
Aging v cancer	5	1.25	0	19
Early life experience with PA	21	18.75	18.75	25
Q11. Traffic, safety concerns	2	3.75	0	6
Other support needed - nutrition, coping, patient navigation	26	6.25	16.25	12
Barriers to PA	1	3.75	8.75	2
Covid concerns decreased activity	5	0	1.25	0
Lack of sidewalks	9	3.75	0	6
Q2. Symptoms of cancer	2	3.75	5	3
Metastases - cancer spreading or affecting bones and lungs	8	13.75	3.75	4
Out of breath or lack of stamina	10	11.25	0	19
Pain	1	6.25	11.25	0
Q3. Side effects of treatment	14	40	17.5	14
Fatigue	6	21.25	17.5	13
Neuropathy	5	17.5	2.5	0
Weakness	2	3.75	13.75	8
Too Busy	11	0	2.5	2
Weather	4	5	2.5	7
Cancer journey - timeline	32	22.5	18.75	20
Feelings about cancer diagnosis	3	10	5	30
Facilitators of PA	3	2.5	2.5	3
Apps, Technology	6	0	5	13
Community - Based Resources	16	6.25	2.5	5
Feeling Good	12	3.75	6.25	14
Increased Activity During Pandemic	0	0	2.5	0
More Time	3	5	1.25	3
Physical Therapy	5	3.75	25	0
Physical, Neighborhood Environment	3	8.75	11.25	3
Low Traffic, Quiet	4	6.25	8.75	7
Q12. PA opportunities where you live	13	13.75	15	10
Q13. Importance of neighborhood in PA decision-making	3	2.5	8.75	8
Provider Recommendation	18	6.25	11.25	21
Self-motivation	11	2.5	7.5	27
Social Support	17	21.25	20	9
Positive experiences with PA	3	0	1.25	11
Live an active lifestyle	25	10	11.25	45
Q6. Physical Health	8	7.5	8.75	17
Q7. Mental Health, Well-Being	20	8.75	21.25	26
Q10. Preferences for PA Program	3	2.5	7.5	7
Alone	9	5	3.75	8
Sense of Solitude	4	0	0	3

Group/With Others	18	6.25	12.5	8
Home-based activities	8	2.5	0	1
Q14. Information received about PA	4	3.75	5	5
I'd like more information on...	4	5	1.25	3
Q4. Physical functioning	22	15	15	13
Q8. Goals around PA	8	7.5	8.75	10
Gaining Strength	8	3.75	8.75	4
Get back to old activities	10	12.5	7.5	2
Maintain independence/Keep doing what I'm doing...	15	18.75	8.75	10
No provider recommendation	7	7.5	0	6



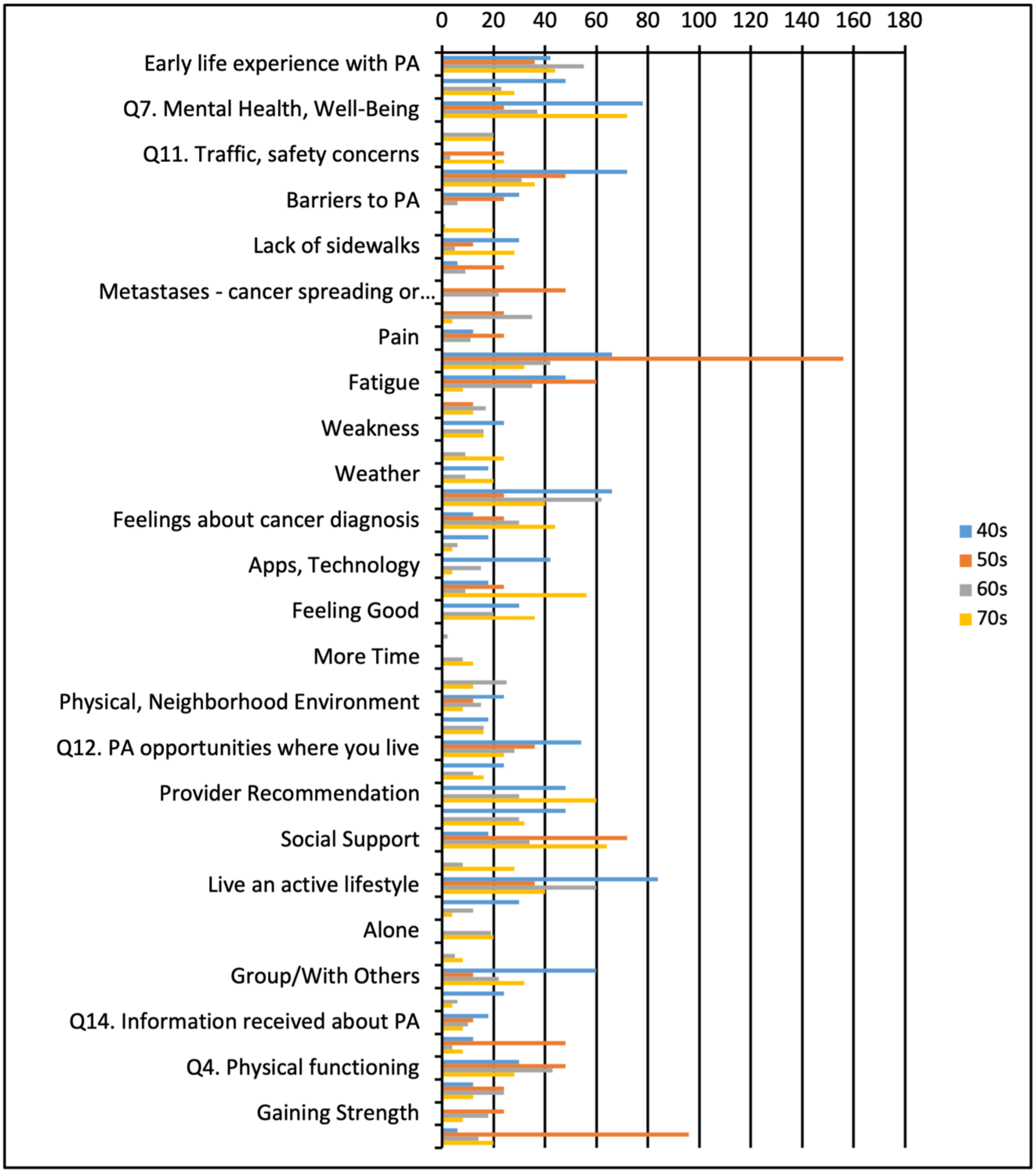
Code	Female	Male
Aging v cancer	6.25	20
Early life experience with PA	41.25	43
Q11. Traffic, safety concerns	2.5	9
Other support needed - nutrition, coping, patient navigation	48.75	17
Barriers to PA	10	5
Covid concerns decreased activity	6.25	1
Lack of sidewalks	11.25	9
Q2. Symptoms of cancer	7.5	6
Metastases - cancer spreading or affecting bones and lungs	13.75	15
Out of breath or lack of stamina	12.5	28
Pain	12.5	5
Q3. Side effects of treatment	33.75	47
Fatigue	25	30
Neuropathy	8.75	14
Weakness	13.75	13
Too Busy	13.75	4
Weather	6.25	12
Cancer journey - timeline	56.25	40
Feelings about cancer diagnosis	7.5	39
Facilitators of PA	6.25	5
Apps, Technology	12.5	13
Community - Based Resources	22.5	10
Feeling Good	17.5	20
Increased Activity During Pandemic	2.5	0
More Time	5	7
Physical Therapy	27.5	6
Physical, Neighborhood Environment	13.75	11
Low Traffic, Quiet	11.25	14
Q12. PA opportunities where you live	30	22
Q13. Importance of neighborhood in PA decision-making	11.25	11
Provider Recommendation	31.25	28
Self-motivation	21.25	29
Social Support	40	27
Positive experiences with PA	3.75	12
Live an active lifestyle	41.25	54
Q6. Physical Health	17.5	24
Q7. Mental Health, Well-Being	45	34
Q10. Preferences for PA Program	11.25	9
Alone	15	12
Sense of Solitude	5	3
Group/With Others	33.75	14
Home-based activities	10	3

Q14. Information received about PA	8.75	9
I'd like more information on...	6.25	7
Q4. Physical functioning	38.75	28
Q8. Goals around PA	18.75	16
Gaining Strength	17.5	8
Get back to old activities	20	12
Maintain independence/Keep doing what I'm doing...	26.25	26
No provider recommendation	8.75	12



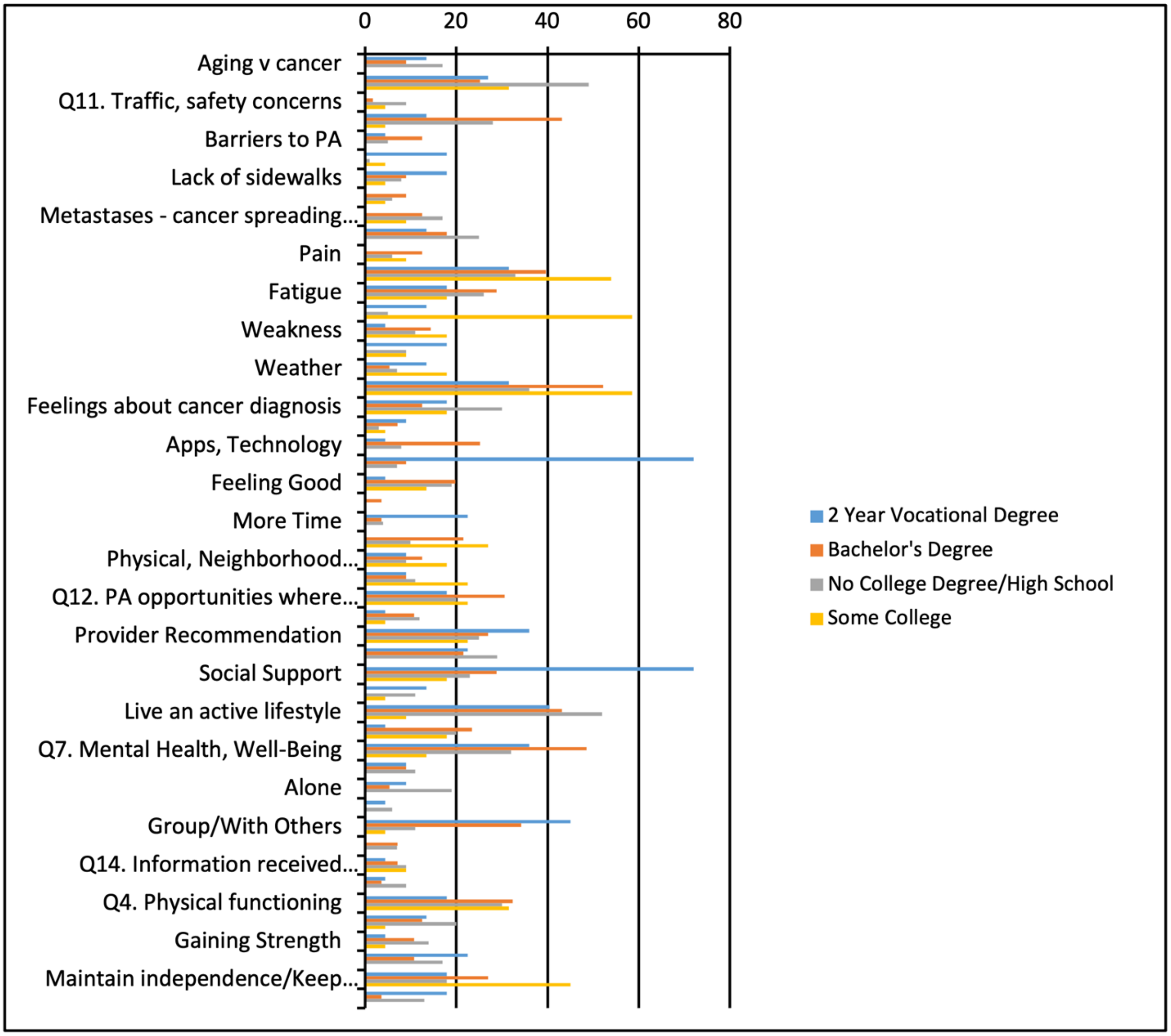
Code	40s	50s	60s	70s
Early life experience with PA	42	36	55	44
Q6. Physical Health	48	0	23	28
Q7. Mental Health, Well-Being	78	24	37	72
Aging v cancer	0	0	20	20
Q11. Traffic, safety concerns	0	24	3	24
Other support needed - nutrition, coping, patient navigation	72	48	31	36
Barriers to PA	30	24	6	0
Covid concerns decreased activity	0	0	1	20
Lack of sidewalks	30	12	5	28
Q2. Symptoms of cancer	6	24	9	0
Metastases - cancer spreading or affecting bones and lungs	0	48	22	0
Out of breath or lack of stamina	0	24	35	4
Pain	12	24	11	0
Q3. Side effects of treatment	66	156	42	32
Fatigue	48	60	35	8
Neuropathy	0	12	17	12
Weakness	24	0	16	16
Too Busy	0	0	9	24
Weather	18	0	9	20
Cancer journey - timeline	66	24	62	40
Feelings about cancer diagnosis	12	24	30	44
Facilitators of PA	18	0	6	4
Apps, Technology	42	0	15	4
Community - Based Resources	18	24	9	56
Feeling Good	30	0	20	36
Increased Activity During Pandemic	0	0	2	0
More Time	0	0	8	12
Physical Therapy	0	0	25	12
Physical, Neighborhood Environment	24	12	15	8
Low Traffic, Quiet	18	0	16	16
Q12. PA opportunities where you live	54	36	28	24
Q13. Importance of neighborhood in PA decision-making	24	0	12	16
Provider Recommendation	48	0	30	60
Self-motivation	48	0	30	32
Social Support	18	72	34	64
Positive experiences with PA	0	0	8	28
Live an active lifestyle	84	36	60	40
Q10. Preferences for PA Program	30	0	12	4
Alone	0	0	19	20
Sense of Solitude	0	0	5	8
Group/With Others	60	12	22	32
Home-based activities	24	0	6	4

Q14. Information received about PA	18	12	10	8
I'd like more information on...	12	48	4	8
Q4. Physical functioning	30	48	43	28
Q8. Goals around PA	12	24	24	12
Gaining Strength	0	24	18	8
Get back to old activities	6	96	14	20
Maintain independence/Keep doing what I'm doing...	12	12	39	20
No provider recommendation	0	24	14	12



Code	High School	2 Year Degree	Some College	Bachelor's Degree
Aging v cancer	17	13.5	0	9
Early life experience with PA	49	27	31.5	25.2
Q11. Traffic, safety concerns	9	0	4.5	1.8
Other support needed - nutrition, coping, patient navigation	28	13.5	4.5	43.2
Barriers to PA	5	4.5	0	12.6
Covid concerns decreased activity	1	18	4.5	0
Lack of sidewalks	8	18	4.5	9
Q2. Symptoms of cancer	6	0	4.5	9
Metastases - cancer spreading or affecting bones and lungs	17	0	9	12.6
Out of breath or lack of stamina	25	13.5	0	18
Pain	6	0	9	12.6
Q3. Side effects of treatment	33	31.5	54	39.6
Fatigue	26	18	18	28.8
Neuropathy	5	13.5	58.5	0
Weakness	11	4.5	18	14.4
Too Busy	9	18	9	0
Weather	7	13.5	18	5.4
Cancer journey - timeline	36	31.5	58.5	52.2
Feelings about cancer diagnosis	30	18	18	12.6
Facilitators of PA	3	9	4.5	7.2
Apps, Technology	8	4.5	0	25.2
Community - Based Resources	7	72	0	9
Feeling Good	19	4.5	13.5	19.8
Increased Activity During Pandemic	0	0	0	3.6
More Time	4	22.5	0	3.6
Physical Therapy	10	0	27	21.6
Physical, Neighborhood Environment	9	9	18	12.6
Low Traffic, Quiet	11	9	22.5	9
Q12. PA opportunities where you live	20	18	22.5	30.6
Q13. Importance of neighborhood in PA decision-making	12	4.5	4.5	10.8
Provider Recommendation	25	36	22.5	27
Self-motivation	29	22.5	0	21.6
Social Support	23	72	18	28.8
Positive experiences with PA	11	13.5	4.5	0
Live an active lifestyle	52	40.5	9	43.2
Q6. Physical Health	20	4.5	18	23.4
Q7. Mental Health, Well-Being	32	36	13.5	48.6

Q10. Preferences for PA Program	11	9	0	9
Alone	19	9	0	5.4
Sense of Solitude	6	4.5	0	0
Group/With Others	11	45	4.5	34.2
Home-based activities	7	0	0	7.2
Q14. Information received about PA	9	4.5	9	7.2
I'd like more information on...	9	4.5	0	3.6
Q4. Physical functioning	30	18	31.5	32.4
Q8. Goals around PA	20	13.5	4.5	12.6
Gaining Strength	14	4.5	4.5	10.8
Get back to old activities	17	22.5	0	10.8
Maintain independence/Keep doing what I'm doing...	18	18	45	27
No provider recommendation	13	18	0	3.6



APPENDIX B1. POSTCARD

Research Opportunity

You're invited to take part in a survey about your health!

- You will receive a survey in the mail in the next two weeks. Please complete it and mail it back to us.
- This survey is a partnership between the University of Wisconsin-Madison's Physical Activity Epidemiology Lab and the University of Wisconsin's Carbone Cancer Center.
- Your participation is completely voluntary. The information we receive is very valuable to our understanding of your health needs.
- Compensation is provided.

wisconsin physical activity epidemiology lab

WISCONSIN UNIVERSITY OF WISCONSIN–MADISON

Carbone Cancer Center UNIVERSITY OF WISCONSIN SCHOOL OF MEDICINE AND PUBLIC HEALTH

Thank you!

We greatly value your participation!

Questions?
To learn more or to opt out of the survey, please contact Megan via email or phone.
Email: bertramlab@education.wisc.edu
Phone: [redacted]

Email is generally not a secure way to communicate sensitive or health related information as there are many ways for unauthorized users to access email. You should avoid sending sensitive, detailed personal information by email. Email should also not be used to convey information of an urgent nature.

wisconsin physical activity epidemiology lab

WISCONSIN UNIVERSITY OF WISCONSIN–MADISON

Carbone Cancer Center UNIVERSITY OF WISCONSIN SCHOOL OF MEDICINE AND PUBLIC HEALTH

APPENDIX B2. COVER LETTER

Dear (first name, last name),

We are writing to invite you to participate in our research study titled "Survey of Health Needs and Preferences for Supportive Care Programs." The lead investigators of this study include Dr. Shaneda Warren Andersen, Assistant Professor of Population Health Sciences, and Megan Agnew, Researcher, from the University of Wisconsin-Madison. You are invited to participate in this study because you visited the UW Carbone Cancer Center in the past two years. Participation involves filling out the survey and returning it to us in the postage paid envelope.

During the survey, you will be asked about the following topics:

- your health and physical activity,
- your quality of life and lifestyle concerns, and
- your interest in supportive care programs.

Our goal is to understand how you think and feel about your health and your preferences for supportive care programs. We understand how valuable your time is and appreciate your assistance with the survey. We have enclosed $2.00 as a small token of our appreciation for your participation.

Your participation in this research study is completely voluntary. However, your assistance is very important to the success of the study. The "Study Information Sheet" with this letter has additional information about the study. You may choose not to answer any questions you do not wish to answer, and you can stop the survey at any time. There are no right or wrong responses to the following questions, we are interested in your open and honest feedback.

If you decide not to participate and wish to no longer receive any study materials, please contact Megan Agnew via phone at [redacted] or email at bertramlab@education.wisc.edu. If you do not contact the study team to tell them you do not want to participate, you will receive one additional survey and then you will not be contacted again. The money is yours to keep.

Participation in this study will not benefit you directly but will help our researchers identify ways to better support people living with cancer in our community. If you have any questions about this study, please do not hesitate to call Megan Agnew [redacted]).

Thank you for your time.

Members of the research team:

Shaneda Warren Andersen, PhD, MS
Assistant Professor of Population Health Sciences

Megan Agnew, MPH
Researcher and Doctoral Candidate,
Department of Population Health Sciences

Kris Kwekkeboom, PhD, RN, FAAN
Professor and Lillian S. Moehlman Bascom Professor of Nursing

Amy Trentham-Dietz, PhD
Professor of Population Health Sciences
Associate Director of Population Science, Carbone Cancer Center

Ronald Gangnon, PhD, MS
Professor of Population Health Sciences and Biostatistics & Medical Informatics

Meg Doherty Bea, PhD
Assistant Professor of Consumer Science

APPENDIX B3. STUDY INFORMATION SHEET

Study Information Sheet

Title of the Study: Survey of Health Needs and Preferences for Supportive Care Programs

Principal Investigator: Shaneda Warren Andersen, Ph.D.

Researcher: Megan Agnew, MPH
Email: bertramlab@education.wisc.edu
Phone: [redacted]

Invitation

You are invited to participate in a research study that aims to understand how you think and feel about your health needs and your preferences for supportive care programs.

The purpose of this information sheet is to give you the information you need to decide whether to be in the study. It also explains how health information will be used for this study and requests your authorization (permission) to use your health information.

Participation is voluntary. If you choose to participate, you will be asked to complete a survey which should take 15 - 20 minutes to complete. During the survey, you will be asked about topics such as the types of physical activity that you do, your quality of life, lifestyle concerns, and your interest in supportive care programs. We are including $2 as a token of our appreciation for completing the survey.

We will keep your answers confidential and will not share personal information about you with anyone outside the research team. You may choose not to answer any questions you do not wish to answer, and you can stop the survey at any time. Your survey responses will be saved. No information that could identify you will be included in any study presentations or reports.

If you have questions or concerns about the study, please contact Researcher, Megan Agnew via phone at [redacted] or email at bertramlab@education.wisc.edu.

Why are researchers doing this study?

The purpose of this research study is to survey people living with cancer to understand how we can better meet their unique needs. This study is being done at the University of Wisconsin-Madison. Funding for this study is provided by the Virginia Horne Henry Fund at the University of Wisconsin-Madison.

What will happen in this study?

If you decide to participate in this research study, the researchers will ask you to complete a single survey. You may skip any questions on the survey that you do not wish to answer.

Protected health information (PHI) used in this study

Protected health information, also called PHI, is information about your physical or mental health that includes identifiable information, such as your name. For the purposes of this study, we will only use the information you tell the researchers about your health in the survey.

Do I have to be in the study? What if I say "yes" now and change my mind later?

No, you do not have to be in this study. Taking part in research is voluntary. This means that you decide if you want to be in the study. If you decide now to take part, you can choose to leave the study at any time.

Let the researchers know if you choose to leave the study.

If you decide not to take part in the study, or if you choose to leave the study, your choice will not affect any treatment relationship you have with healthcare providers at UW-Madison, UW Health, or any affiliated organizations, or any services you receive from them. No matter what decision you make, and even if your decision changes, there will be no penalty to you. You will not lose medical care or any legal rights.

Your authorization for researchers to use your protected health information (PHI) does not have an end date. However:

- You can choose to take back your authorization for researchers to use your health information from the survey. You can do this at any time before or during your participation in the research.
- If you take back your authorization, you will not be able to take part in the research study.
- To take back your authorization, you will need to tell the researchers by writing to the Researcher, Megan Agnew at bertramlab@education.wisc.edu.

Will being in this study help me in any way?

Being in this study will not help you directly. Your participation in the study may benefit other people in the future.

Will I be paid or receive anything for being in this study?

As a token of our appreciation, we have included $2 for participating in this study. Payment in the form of cash is provided with the survey.

What are the risks?

There is a remote risk that your information could become known to someone not involved in this study.

How will researchers keep my research information confidential?

We have strict rules to protect your personal information and protected health information (PHI). We will limit who has access to your name, address, and phone number. We will also store this information securely. However, we cannot promise complete confidentiality. Federal or state laws may permit or require us to show information to university or government officials responsible for monitoring this study.

Authorizing the research team to use your PHI means that we can release it to the people or groups listed below for the purposes described in this form. Also, with appropriate institutional permissions and confidentiality protections, we might use information that we collect during this study for other research or share with other researchers without additional consent or authorization from you or your legally authorized representative.

Who at UW-Madison can use my information?

- Members of the research team
- Offices and committees responsible for the oversight of research

Who outside the UW-Madison may receive my information?

- Nobody outside of UW-Madison will receive your information.

What if I have questions?

If you have questions about this research or you feel you have been harmed by participating in this study, please contact the Researcher, Megan Agnew at 608-262-1167. If you have any questions about your rights as a research participant or have complaints about the research study or study team, call the confidential research compliance line at 1-833-652-2506. Staff will work with you to address concerns about research participation and assist in resolving problems.

APPENDIX B4. SURVEY INSTRUMENT

Title of the Study: Survey of Health Needs and Preferences for Supportive Care Programs

A. YOUR HEALTH

We are interested in learning more about your health history. The next several questions will ask about whether you have been diagnosed with cancer, any treatments received, and other health conditions.

1. Have you ever been told by a doctor or health care professional that you had cancer?
   - ☐ Yes
   - ☐ No. [***Please skip to Section F. Demographics on page 11***]

2. Please list the types of cancer you have had and the age and stage at which you were diagnosed with each type:

	Type of Cancer	Age at Diagnosis	Stage at Diagnosis
First Diagnosis			
Second Diagnosis			
Third Diagnosis			
Additional Diagnoses			

The next questions are about the treatments you are receiving for your cancer diagnosis.

3. **Currently**, which of the following types of treatment are you receiving for your cancer diagnosis? *Select all that apply.*
   - ☐ Medications (chemotherapy, immunotherapy, hormone therapy) I take at home
   - ☐ Medications (chemotherapy, immunotherapy, hormone therapy) at the hospital or clinic
   - ☐ Radiation therapy
   - ☐ Surgery (in the past 6 months)
   - ☐ Bone marrow transplant (in the past 6 months)
   - ☐ Other. Please describe:____
   - ☐ None at this time

4. **In the past**, which of the following treatments have you received for your cancer diagnosis? *Select all that apply.*
   - ☐ Medications (chemotherapy, immunotherapy, hormone therapy) I take at home
   - ☐ Medications (chemotherapy, immunotherapy, hormone therapy) at the hospital or clinic
   - ☐ Radiation therapy
   - ☐ Surgery (more than 6 months ago)
   - ☐ Bone marrow transplant (more than 6 months ago)

- ☐ Other. Please describe:____

5. How long ago did you receive your last treatment?
    - ☐ Less than one week ago
    - ☐ 1-2 weeks ago
    - ☐ More than 2 weeks, but less than 1 month ago
    - ☐ 1-3 months ago
    - ☐ More than 3 months ago

The next questions are about smoking cigarettes and other health conditions.

6. Have you smoked at least 100 cigarettes in your entire life? *One pack of commercial cigarettes contains twenty cigarettes.*
    - ☐ Yes
    - ☐ No [***Please skip below to Question 8***]

7. How often do you currently smoke cigarettes?
    - ☐ Everyday
    - ☐ Some days
    - ☐ Not at all

8. What is your current weight in pounds? __________ Pounds

9. What is your current height in feet and inches? ___________ Feet ___________ Inches

10. Have you been told by a health care provider that you have any of the following conditions?

Yes	**No**	**Medical Condition**
☐	☐	Angina
☐	☐	Anxiety or panic disorders
☐	☐	Arthritis (rheumatoid and osteoarthritis)
☐	☐	Asthma
☐	☐	Chronic obstructive pulmonary disease (COPD), acquired respiratory distress syndrome (ARDS), or emphysema
☐	☐	Congestive heart failure or heart disease
☐	☐	Diabetes types I and II
☐	☐	Degenerative disk disease
☐	☐	Depression
☐	☐	Heart attack
☐	☐	Hearing impairment
☐	☐	Neurological disease (such as multiple sclerosis or Parkinson’s)
☐	☐	Obesity
☐	☐	Osteoporosis
☐	☐	Peripheral vascular disease
☐	☐	Stroke or TIA
☐	☐	Upper gastrointestinal disease (ulcer, hernia, acid reflux)
☐	☐	Visual impairment
☐	☐	Other medical condition. Please describe: ________________________

The next few questions are about important topics discussed with your cancer care team, including your nurses and doctors, and your ongoing concerns about your health needs.

11. Which of the following topics has your cancer care team discussed with you during your clinic visits?

	Yes	**No**
Quality of life	☐	☐
Physical function	☐	☐
How much pain is interfering with your daily life	☐	☐
How much fatigue is interfering with your daily life	☐	☐
Cognitive function	☐	☐
Mental and emotional health impacts of your illness	☐	☐
Physical activity or exercise	☐	☐
Nutrition	☐	☐
Palliative care	☐	☐

12. Below is a list of health concerns that adults living with cancer might have. How concerned are you about each of the following?

	Not applicable	**Not concerned**	**Somewhat concerned**	**Very concerned**
Managing side effects from treatment	☐	☐	☐	☐
Having energy to make it through the day	☐	☐	☐	☐
Maintaining a proper diet	☐	☐	☐	☐
Maintaining a healthy weight	☐	☐	☐	☐
Getting enough physical activity	☐	☐	☐	☐
Managing prescribed medications	☐	☐	☐	☐
Managing doctor’s appointments	☐	☐	☐	☐
Getting/keeping health insurance	☐	☐	☐	☐
Getting the financial support you need	☐	☐	☐	☐

B. YOUR PHYSICAL ACTIVITY BELIEFS

The next questions ask about how content you are with your current physical activity, how important physical activity is to you, and your use of health tracking devices.

13. Compared to your physical activity level before your cancer diagnosis, how much physical activity are you doing **currently**?
    - ☐ A lot less activity
    - ☐ A little less activity
    - ☐ About the same amount of activity
    - ☐ A little more activity
    - ☐ A lot more activity

14. How satisfied are you with your **current** physical activity level?
    - ☐ Not at all satisfied
    - ☐ A little satisfied
    - ☐ Somewhat satisfied
    - ☐ Very satisfied

15. How important is physical activity to your **physical health**?
    - ☐ Not at all important
    - ☐ A little important
    - ☐ Somewhat important
    - ☐ Very important

16. How important is physical activity to your **mental health**?
    - ☐ Not at all important
    - ☐ A little important
    - ☐ Somewhat important
    - ☐ Very important

17. Have you ever used a personal device to track your health or activity such as a Fitbit or Apple watch?
    - ☐ Yes, I do currently
    - ☐ Yes, I have in the past, but do not currently
    - ☐ No

18. Would you be you interested in using a personal device to track your health or activity such as a Fitbit or Apple watch?
    - ☐ Yes
    - ☐ No

The next question asks how difficult it is for you to perform certain activities.

19. Please respond to each question by marking one box per row.

	Without any difficulty	**With a little difficulty**	**With some difficulty**	**With much difficulty**	**Unable to do**
Are you able to do chores such as vacuuming or yard work?	☐	☐	☐	☐	☐
Are you able to go up and down stairs at a normal pace?	☐	☐	☐	☐	☐
Are you able to go for a walk of at least 15 minutes?	☐	☐	☐	☐	☐
Are you able to run errands and shop?	☐	☐	☐	☐	☐

C. YOUR PHYSICAL ACTIVITY BARRIERS

Many people living with cancer find it hard to engage in physical activity. The next few questions will ask about whether certain factors make it less likely for you to engage in physical activity.

20. How much do these **factors** make it harder for you to be physically active?

	Not at all	**A little**	**Somewhat**	**Quite a bit**	**A great deal**
Lack of time or being too busy	☐	☐	☐	☐	☐
Difficulty getting motivated	☐	☐	☐	☐	☐
Weather issues in winter such as cold or snow	☐	☐	☐	☐	☐
Weather issues in summer such as heat or humidity	☐	☐	☐	☐	☐
Disliking physical activity	☐	☐	☐	☐	☐
Lack of safe environment to exercise	☐	☐	☐	☐	☐
Lack of support from spouse or family	☐	☐	☐	☐	☐
Fear of falls or injury	☐	☐	☐	☐	☐
Lack of financial resources to exercise	☐	☐	☐	☐	☐

21. How much do these **cancer-related factors** make it harder for you to be physically active?

	Not at all	**A little**	**Somewhat**	**Quite a bit**	**A great deal**
Nausea	☐	☐	☐	☐	☐
Tiredness or fatigue	☐	☐	☐	☐	☐
Pain	☐	☐	☐	☐	☐
Side effects of treatment	☐	☐	☐	☐	☐
Neuropathy (numbness or tingling)	☐	☐	☐	☐	☐
Surgical complications	☐	☐	☐	☐	☐
Sadness	☐	☐	☐	☐	☐
Anxiety	☐	☐	☐	☐	☐
Doctor or nurse’s advice not to exercise	☐	☐	☐	☐	☐

22. Please respond to each question or statement by marking one box per row.

In the **past 7 days…**

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
How much did pain interfere with your day-to-day activities?	☐	☐	☐	☐	☐
How much did pain interfere with work around the home?	☐	☐	☐	☐	☐
How much did pain interfere with your ability to participate in social activities?	☐	☐	☐	☐	☐
How much did pain interfere with your household chores?	☐	☐	☐	☐	☐
How run-down did you feel on average?	☐	☐	☐	☐	☐
How fatigued were you on average?	☐	☐	☐	☐	☐

I feel fatigued.	☐	☐	☐	☐	☐
I have trouble starting things because I am tired.	☐	☐	☐	☐	☐

AEROBIC PHYSICAL ACTIVITY

Now, we want you to recall your **current** leisure time physical activity (do not include work or household activities) during the **last 7 days**. When considering the number of times per week, please only include those times that you were physically active for **more than 15 minutes.**

The questions within this section relate to the physical activities that you perform during your leisure-time only. When we say leisure-time we mean your free-time and the activities that you perform that are NOT done as part of your work/job, transportation (moving to a different location), or as a part of household activities (chores).

During the **last 7 days** (week), how many times did you do the following kinds of exercise for **more than 15 minutes** during your free time?

23. **STRENUOUS EXERCISE (HEART BEATS RAPIDLY)** (e.g., running, jogging, hockey, football, soccer, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming, vigorous long-distance bicycling)
    _____Times per week

24. On average, what is the length of one of these sessions in minutes?
    _____Time in minutes

25. **MODERATE EXERCISE (NOT EXHAUSTING)** (e.g., fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing)
    _____Times per week

26. On average, what is the length of one of these sessions in minutes?
    _____Time in minutes

27. **LIGHT EXERCISE (MINIMAL EFFORT)** (e.g., archery, fishing from riverbank, bowling, horseshoes, golf, snow-mobiling, easy walking)
    _____Times per week

28. On average, what is the length of one of these sessions in minutes?
    _____Time in minutes

MUSCLE-STRENTHENING PHYSICAL ACTIVITY

The next questions are about your participation in muscle-strengthening exercise. The questions within this section relate to the physical activities that you perform during your leisure-time only. When we say leisure-time we mean your free-time and the activities that you perform that are NOT done as part of your work/job, transportation (moving to a different location), or as a part of household activities (chores).

The types of muscle-strengthening exercise modes that we are interested in include:

- Use of weight machines (typically in a gym or fitness center).
- Bodyweight exercises (including push-ups, sit-ups)
- Resistance exercises (using resistance bands or free weights like dumbbells).
- Holistic exercises (including Yoga, Tai-Chi and Pilates)

29. Do you usually do muscle-strengthening exercise?
    ☐ Yes
    ☐ No [***Please skip below to Question 33***]

30. How many days, in the **last 7 days**, did you do muscle-strengthening exercise?
    _____Days per week

31. In the **last 7 days**, please indicate how often you did each of the following types of muscle-strengthening exercise?

    Number of DAYS in the **last week**
    _____ Use weight machines (e.g. leg press, chest press, lat pulldown)
    _____ Body weight exercise (e.g. push-ups, sit-ups)
    _____ Use resistance bands or free weights (e.g. dumbbells)
    _____ Holistic exercise (including Yoga, Tai-chi and Pilates)

32. In the **last 7 days**, please indicate how long you spent doing each of the following types of muscle-strengthening exercise?

    MINUTES spent in a usual session
    _____ Use weight machines (e.g., leg press, chest press)
    _____ Body weight exercise (e.g., push-ups, sit-ups)
    _____ Use resistance bands or free weights (e.g., dumbbells)
    _____ Holistic exercise (including Yoga, Tai-chi and Pilates)

The next few questions ask about where you have performed your physical activity in the past 6 months and features of your current neighborhood.

33. Where have you done your physical activity in the past 6 months? *Select all that apply.*
    ☐ Inside my home (e.g., using weights, bands, or equipment at home)
    ☐ In the yard at my home (e.g., gardening, walking on property)
    ☐ In my neighborhood (e.g., walking on streets or sidewalks)
    ☐ In another neighborhood (e.g., walking on streets where you don't live)
    ☐ In an outdoor recreational space (e.g., parks or trails)
    ☐ In an indoor recreational space (e.g., gym, recreation center, indoor pool)

34. How would you describe the area you currently live in?
    - ☐ Urban
    - ☐ Suburban
    - ☐ Rural

35. Do you have access to the following types of amenities in your neighborhood?

	Yes, and I use it	**Yes, but I don't use it**	**No**	**Unsure**
Sidewalks	☐	☐	☐	☐
Bike paths	☐	☐	☐	☐
Trails or other nature areas	☐	☐	☐	☐
Gym	☐	☐	☐	☐
School	☐	☐	☐	☐
Local park	☐	☐	☐	☐
Community center	☐	☐	☐	☐

D. YOUR QUALITY OF LIFE

Below is a list of statements that other people with your illness have said are important.

36. Please mark one box per line to indicate your response as it applies to the **past 7 days**.

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
I have a lack of energy…	☐	☐	☐	☐	☐
I have nausea…	☐	☐	☐	☐	☐
Because of my physical condition, I have trouble meeting the needs of my family…	☐	☐	☐	☐	☐
I have pain…	☐	☐	☐	☐	☐
I am bothered by side effects of treatment…	☐	☐	☐	☐	☐
I feel ill…	☐	☐	☐	☐	☐
I am forced to spend time in bed…	☐	☐	☐	☐	☐

37. Please mark one box per line to indicate your response as it applies to the **past 7 days**.

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
I feel close to my friends…	☐	☐	☐	☐	☐
I get emotional support from my family…	☐	☐	☐	☐	☐
I get support from my friends…	☐	☐	☐	☐	☐
My family has accepted my illness…	☐	☐	☐	☐	☐
I am satisfied with family communication about my illness…	☐	☐	☐	☐	☐

I feel close to my partner or the person who is my main support…	☐	☐	☐	☐	☐
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ *and go to the next section.*					
I am satisfied with my sex life…	☐	☐	☐	☐	☐

38. Please mark one box per line to indicate your response as it applies to the **past 7 days**.

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
I feel sad…	☐	☐	☐	☐	☐
I am satisfied with how I am coping with my illness…	☐	☐	☐	☐	☐
I am losing hope in the fight against my illness…	☐	☐	☐	☐	☐
I feel nervous…	☐	☐	☐	☐	☐
I worry about dying…	☐	☐	☐	☐	☐
I worry that my condition will get worse…	☐	☐	☐	☐	☐

39. Please mark one box per line to indicate your response as it applies to the **past 7 days**.

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
I am able to work (include work at home)…	☐	☐	☐	☐	☐
My work (include work at home) is fulfilling…	☐	☐	☐	☐	☐
I am able to enjoy life…	☐	☐	☐	☐	☐
I have accepted my illness…	☐	☐	☐	☐	☐
I am sleeping well…	☐	☐	☐	☐	☐
I am enjoying the things I usually do for fun…	☐	☐	☐	☐	☐
I am content with the quality of my life right now…	☐	☐	☐	☐	☐

E. SUPPORTIVE CARE PROGRAM PREFERENCES

The next few questions ask about your personal preferences for participating in a **supportive care program**. Supportive care programs are designed to improve your overall health and quality of life as well as reduce side effects from cancer and its treatment. Supportive care programs can address a variety of needs including physical, practical, nutritional, and emotional. These services may be provided by specialists, doctors, and/or nurses.

40. How interested are you in participating in a supportive care program designed for people with cancer consisting of physical activity, nutrition, and/or coping support?
    ☐ Not at all interested
    ☐ A little interested
    ☐ Somewhat interested
    ☐ Very interested
    ☐ Extremely interested

41. When do you think it would be best to start a <u>supportive care program</u>?
    - ☐ At diagnosis
    - ☐ After diagnosis, but before treatment begins
    - ☐ During treatment
    - ☐ During a break from treatment
    - ☐ Other. Please tell us: ____

42. Which of the following reasons would make you want to join a <u>supportive care program</u>?

	Yes	No
To improve your physical health	☐	☐
To improve your mental health	☐	☐
To develop your muscle strength	☐	☐
To improve your balance	☐	☐
To increase your energy	☐	☐
To find support and motivation	☐	☐
Other. Please tell us: ____		

43. Which of the following types of physical activities would you prefer to have in a program?

	Yes	No
Physical therapy (e.g. to improve your ability to move your body)	☐	☐
Occupational therapy (e.g. to improve your ability to perform daily activities)	☐	☐
Walking	☐	☐
Using weight machines typically in a gym	☐	☐
Resistance exercises using resistance bands or free weights	☐	☐
Holistic exercises such as Yoga or Tai-Chi	☐	☐
Group aerobics class	☐	☐
Chair-based exercises	☐	☐
Other. Please tell us: ____		

44. Which of the following types of nutritional activities would you prefer to have in a program?

	Yes	No
Consult with a dietician	☐	☐
Cooking classes	☐	☐
Nutrition information and/or recipes for people with cancer	☐	☐
Other. Please tell us: ____		

45. Which of the following types of coping support activities would you prefer to have in a program?

	Yes	No
Individual therapy with a provider	☐	☐
Group therapy sessions for people with cancer	☐	☐
Mindfulness techniques for people with cancer	☐	☐

Other. Please tell us: ____

46. How would you like to participate in the <u>supportive care program</u>? *Select all that apply.*
    - ☐ In a group with other people with cancer
    - ☐ One-on-one with a provider
    - ☐ With a family member or friend
    - ☐ On your own
    - ☐ Other. Please tell us: ____

47. How would you like the <u>supportive care program</u> to be delivered? *Select all that apply.*
    - ☐ In person, at the cancer center before or after a clinic visit
    - ☐ In person, during a clinic visit (e.g., infusion)
    - ☐ In person, at a facility close to your home (e.g., YMCA)
    - ☐ Remotely, at your home
    - ☐ Other. Please tell us: ____

48. How would you like to get information about the <u>supportive care program</u>? *Select all that apply.*
    - ☐ Printed materials (e.g., brochures, handouts)
    - ☐ On the internet (e.g., website, online videos)
    - ☐ On an app (e.g., smartphone-based content)
    - ☐ Via phone call
    - ☐ Via video call
    - ☐ Other. Please tell us: ____

49. Do you have personal access to a smartphone or tablet computer?
    - ☐ Yes
    - ☐ No

50. Do you have Internet access at home?
    - ☐ Yes
    - ☐ No

F. DEMOGRAPHICS

The last set of questions will ask about personal characteristics.

51. What is your current age? _______ Age in years

52. What is your gender? _______ Gender

53. Are you of Hispanic or Latino origin?
    - ☐ Yes, Hispanic or Latino origin
    - ☐ No, not Hispanic or Latino origin

54. What is your racial identity? *Select all that apply.*
    - ☐ White
    - ☐ Black or African American
    - ☐ Asian

- ☐ American Indian or Alaska Native
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Other

55. Which of the following types of caregiver status describe you? *Select all that apply.*
    - ☐ Taking care of children under the age of 18
    - ☐ Taking care of adult children over the age of 18
    - ☐ Taking care of spouse, parents, or other adult family members
    - ☐ I am not a caregiver.
56. What is your current marital status?
    - ☐ Married or living with partner
    - ☐ Single
    - ☐ Separated or divorced
    - ☐ Widowed

57. What is your highest level of education attained?
    - ☐ Less than high school
    - ☐ High school or GED
    - ☐ Some college
    - ☐ Associate degree (2 years)
    - ☐ Bachelor's degree (4 years)
    - ☐ Graduate or professional degree (MBA, MPH, Master's or Doctoral degree)

58. What is your current employment status?
    - ☐ Full-time
    - ☐ Part-time
    - ☐ Not employed, retired
    - ☐ Not employed, on disability
    - ☐ Not employed, not retired/on disability

59. Which of the following categories represents your total household income in 2022?
    - ☐ Less than $25,000
    - ☐ Greater than $25,000, but less than $50,000
    - ☐ Greater than $50,000, but less than $75,000
    - ☐ Greater than $75,000, but less than $100,000
    - ☐ Greater than $100,000

We thank you for your time spent taking this survey!

We greatly appreciate you completing this survey to help us better understand your health. We are asking whether you would contribute to this study in one additional way:

60. Would you like to be put on a list to be contacted for future studies you may be eligible for?
    - ☐ Yes
    - ☐ No

61. Please tell us any general comments you may have regarding this survey or any other comments you may want to share regarding your health experiences.

If you have any questions about this study, please contact the study team at *bertramlab@education.wisc.edu* *or give us a call at* [redacted]

Please return your completed survey to us in the postage paid envelope provided.

Appendix B5. Multiple Imputation Analysis

Multiple Imputation Results of Association Between Leisure Score Index (LSI) and Health-related Quality of Life (*n*=278)

	Model 1[a]			**Model 2[b]**			**Model 3[c]**			**Model 4[d]**			
Parameter	**Est.**	**95% CI**		**Est.**	**95% CI**		**Est.**	**95% CI**		**Est.**	**95% CI**		**P-value**
Activity Level *(ref = Insufficiently active)* Active	10.3	5.80	14.77	9.30	4.68	13.93	8.02	3.33	12.71	8.17	3.51	12.84	**<.0001**
Moderately active	9.88	4.93	14.82	9.91	5.09	14.74	10.20	5.43	14.96	10.30	5.54	15.06	
Education Level *(ref = Bachelor's or higher)*													0.39
High school or less				1.93	-3.11	6.97	1.79	-3.50	7.08	2.44	-3.06	7.94	
Some college or Associate's				-1.41	-5.88	3.07	-0.92	-5.38	3.55	-0.44	-4.92	4.03	
Employment *(ref = Retired)* Full time or part time				2.11	-3.32	7.54	1.47	-3.94	6.89	1.30	-4.11	6.71	**0.001**
Not employed other				-8.83	-15.44	-2.21	-8.39	-15.0	-1.80	-8.43	-15.0	-1.85	
Gender *(ref = Man)* Woman				1.51	-2.58	5.59	1.95	-3.56	7.45	1.39	-4.14	6.91	0.95
Age *(ref = 70+ years old)* <60 years old				-9.47	-16.20	-2.74	-9.48	-16.4	-2.60	-9.48	-16.3	-2.62	**0.02**

60 to 70 years old				-1.63	-6.25	2.99	-1.49	-6.14	3.16	-0.86	-5.54	3.82	
Marital Status *(ref = Married or living with partner)*													**0.03**
Not married or living with partner				-5.53	-9.78	-1.28	-4.85	-9.06	-0.64	-5.01	-9.32	-0.70	
Comorbidities *(ref = No comorbidities)*													**0.02**
1 comorbidity							-6.18	-12.3	-0.08	-6.49	-12.6	-0.39	
2 comorbidities							-4.08	-9.98	1.83	-3.43	-9.35	2.48	
3 comorbidities							-8.77	-14.1	-3.45	-8.59	-13.9	-3.29	
Cancer Type *(ref = Prostate)*													
Breast							-1.93	-9.82	5.97	-1.58	-9.50	6.35	0.67
Colorectal							-0.39	-8.01	7.22	0.22	-7.39	7.83	
Lymphoma							2.12	-3.46	7.70	2.53	-3.13	8.19	
Myeloma							0.81	-5.86	7.47	1.06	-5.65	7.76	
Treatment Status *(ref = On treatment)*													
Not on treatment							2.38	-3.18	7.93	2.46	-3.07	8.00	0.19
Urbanicity *(ref = Urban)*													
Rural										0.25	-4.86	5.35	0.05
Suburban										4.15	-0.54	8.84	

Note: Est. = Beta estimate, 95% CI = 95% confidence interval, ref = Reference group; P-value is for the Type III tests of fixed effects for Imputation #19. Model 1[a] was unadjusted. Model 2[b] adjusted for: education, gender, age (categorical), and marital status. Model 3[c] was additionally adjusted for: cancer type, functional comorbidity index score (categorical), and on treatment status. Model 4[d] was additionally adjusted for: urbanicity.

APPENDIX B6. SENSITIVITY ANALYSES WITH FOUR-CATEGORY VARIABLE FOR ACTIVITY CHANGE

Association between Changes in Physical Activity Since Diagnosis and Health-related Quality of Life (*n*=247)

	Model 1[a]			**Model 2[b]**			**Model 3[c]**			**Model 4[d]**		
Parameter	**Beta Estimate**	**CI**	**P-value**	**Beta Estimate**	**CI**	**P-value**	**Beta Estimate**	**CI**	**P-value**	**Beta Estimate**	**CI**	**P-value**
Activity Change *(ref = Same activity)*			**<.0001**			**<.0001**			**<.0001**			**<.0001**
A little less	-8.3	(-13.4, -3.1)		-7.7	(-12.8, -2.7)		-7.4	(-12.5, -2.3)		-7.1	(-12.2, -2.0)	
A lot less	-20.5	(-25.5, -15.5)		-19.4	(-24.3, -14.5)		-19.0	(-23.9, -14.0)		-19.0	(-23.9, -14.0)	
More activity	-0.2	(-7.6, 7.1)		0.5	(-6.6, 7.6)		-0.6	(-7.8, 6.6)		-0.9	(-8.0, 6.3)	
Education Level *(ref = Bachelor's +)*												
High school or less				0.6	(-3.9, 5.1)	0.95	0.7	(-4.0, 5.4)	0.96	1.4	(-3.4, 6.3)	0.82
Some college or Associate's				-0.2	(-4.3, 3.9)		0.3	(-3.8, 4.4)		0.9	(-3.2, 5.0)	
Employment *(ref = Retired)*												
Full/part time				-0.2	(-5.3, 4.9)	**0.006**	-0.9	(-6.0, 4.2)	**0.01**	-0.9	(-6.0, 4.1)	**0.009**
Not employed other				-9.1	(-15.1, -3.1)		-8.8	(-14.7, -2.8)		-8.9	(-14.8, -3.0)	
Gender *(ref = Man)*												
Woman				0.7	(-3.1, 4.4)	0.72	0.03	(-5.1, 5.1)	0.99	-0.4	(-5.5, 4.7)	0.86
Age *(ref = 70+)*						**0.04**			0.05			**0.03**
<60 years				-6.9	(-13.1, -0.7)		-6.7	(-13.0, -0.4)		-6.6	(-12.8, -0.3)	
60 to 70 years				0.007	(-4.1, 4.2)		0.4	(-3.8, 4.5)		1.1	(-3.1, 5.2)	

Marital Status *(ref = Yes, married/living with partner)*										
No		-4.0	(-8.0, 0.01)	0.05	-3.4	(-7.4, 0.6)	0.09	-3.4	(-7.5, 0.6)	0.1
Comorbidities *(ref = No comorbidities)*										
1					-4.2	(-9.9, 1.5)	**0.02**	-4.5	(-10.2, 1.1)	**0.02**
2					-4.1	(-9.7, 1.5)		-3.4	(-9.0, 2.2)	
3+					-7.9	(-12.9, -3.0)		-7.7	(-12.6, -2.8)	
Cancer Type *(ref = Prostate)*										
Breast					-0.06	(-7.5, 7.3)	0.33	-0.2	(-7.4, 7.4)	0.32
Colorectal					-0.3	(-7.4, 6.8)		0.04	(-7.0, 7.1)	
Lymphoma					2.0	(-4.2, 8.2)		2.0	(-4.2, 8.2)	
Myeloma					4.4	(-0.9, 9.7)		4.6	(-0.8, 9.9)	
Treatment Status *(ref = On tx)*										
Not on treatment					-0.3	(-5.5, 5.0)	0.92	-0.2	(-5.3, 5.4)	0.95
Urbanicity *(ref = Urban)*										
Rural								0.7	(-4.0, 5.4)	0.05
Suburban								4.8	(0.4, 9.1)	

Note: CI = 95% confidence interval; ref = Reference group; Estimate = Beta estimate; P-value is for the Type III tests of fixed effects. Model 1[a] was unadjusted. Model 2[b] was adjusted for: education, gender, age (categorical), and marital status. Model 3[c] was additionally adjusted for: cancer type, functional comorbidity index score (categorical), and on treatment status. Model 4[d] was additionally adjusted for: urbanicity.

Univariate Analysis of the Health-related Quality of Life Measures by Changes in Activity Since Diagnosis (*n*=247)

Measure	***n***	**A lot less activity (Mean)**	**CI**	**A little less activity (Mean)**	**CI**	**Same activity (Mean)**	**CI**	**More activity (Mean)**	**CI**	**F-value**	**P-value**
FACT-G	247	70.3	(67.5, 73.1)	82.6	(79.5, 85.6)	90.8	(86.6, 95.0)	90.6	(84.6, 96.6)	29.4	**<.0001**
Physical	247	18.6	(17.8, 19.5)	23.2	(22.3, 24.2)	25.7	(24.5, 27.0)	25.7	(23.9, 27.6)	39.5	**<.0001**
Social	247	19.5	(18.5, 20.5)	21.9	(20.8, 23.1)	22.5	(21.0, 24.1)	22.9	(20.6, 25.1)	5.7	**0.0008**
Emotional	247	16.9	(16.0, 17.7)	18.2	(17.3, 19.1)	19.7	(18.4, 20.9)	19.4	(17.6, 21.3)	5.5	**0.0011**
Functional	247	15.3	(14.3, 16.4)	19.2	(18.1, 20.3)	22.9	(21.4, 24.4)	22.6	(20.4, 24.8)	28.0	**<.0001**
Physical Function[a]	245	40.3	(38.8, 41.8)	47.3	(45.6, 48.9)	51.6	(49.3, 53.9)	54.3	(51.0, 57.6)	35.2	**<.0001**
Fatigue[b]	244	59.3	(57.5, 61.1)	51.4	(49.4, 53.5)	42.2	(39.4, 45.0)	42.4	(38.4, 46.4)	43.6	**<.0001**
Pain Interference[c]	243	55.5	(53.8, 57.2)	48.8	(47.0, 50.7)	45.3	(42.7, 47.8)	46.2	(42.6, 49.9)	19.8	**<.0001**

[a]Missing *n*=2; [b]Missing *n*=3; [c]Missing *n*=4; *Note*: CI = 95% confidence interval of mean; P-values were generated using analysis of variance (ANOVA) tests to assess whether differences exist between the mean scores of the four groups.