

Preferences, Barriers and Facilitators to Exercise and Physical Activity in Cancer

Survivors of African, Caribbean, and Black descent in Nova Scotia

by

C. Joy Chiekwe

Submitted in partial fulfilment of the requirements

for the degree of Master of Science

at

Dalhousie University

Halifax, Nova Scotia

August 2022

© Copyright by C. Joy Chiekwe, 2022

Dedication Page

To those who encouraged me when I needed it the most.

Table of Contents

DEDICATION PAGE	ii
LIST OF TABLES	v
LIST OF FIGURES.....	vi
ABSTRACT.....	vii
LIST OF ABBREVIATIONS USED.....	viii
CHAPTER 1: INTRODUCTION	1
CHAPTER 2: REVIEW OF THE LITERATURE	4
IMPACT OF COMORBIDITY ON CANCER RELATED OUTCOMES	5
<i>Impact on treatment choice and outcomes.....</i>	6
<i>Impact on survival and recurrence</i>	7
BENEFITS OF PA AND EXERCISE FOR CANCER SURVIVORS	8
<i>PA and exercise as prehabilitation</i>	9
<i>On treatment (managing acute effects).....</i>	10
<i>Effects on fatigue.....</i>	10
<i>Effects on depression and anxiety</i>	11
<i>Off treatment.....</i>	11
PA PARTICIPATION AMONG ACB CANCER SURVIVORS	12
RESEARCH PURPOSE AND OBJECTIVES	14
CHAPTER 3: METHODOLOGY	15
DESIGN AND PROCEDURES	15
<i>Participant recruitment</i>	15
<i>Data Collection</i>	16
<i>Data Analysis</i>	17
<i>Researcher’s Rationale for Conducting this Study.....</i>	18
CHAPTER 4: RESULTS.....	20
PHASE 1	20
<i>Participant characteristics.....</i>	20
<i>Leisure-Time Physical Activity.....</i>	23
<i>Functional Assessment of Cancer Therapy Scale.....</i>	24
<i>Barriers, Facilitators, and Preferences.....</i>	24
PHASE 2	25
<i>Participant characteristics.....</i>	25
<i>Emerging Themes</i>	25
CHAPTER 5: DISCUSSION	36
<i>Survey</i>	36
<i>Interviews</i>	37
STRENGTHS AND LIMITATIONS	43
CONCLUSION AND RECOMMENDATIONS	44

REFERENCES	46
APPENDIX A: ONLINE SURVEY QUESTIONNAIRES.....	56
APPENDIX B: SEMI-STRUCTURED INTERVIEW GUIDE.....	79
APPENDIX C: AMENDED ONLINE CONSENT	81
APPENDIX D: ONLINE CONSENT VERSION 1	92
APPENDIX E: INTERVIEW CONSENT	112
APPENDIX F: RECRUITMENT POSTER.....	132

List of Tables

Table 1	Survey participant characteristics	21
Table 2	Survey participants cancer diagnoses.....	23
Table 3	Survey participant comorbidities.....	23
Table 4	FACT-G scores.....	26

List of Figures

Figure 1	Major qualitative themes and associated subthemes.....	29
----------	--	----

Abstract

Exercise and PA among Canadian ACB cancer survivors have not been studied. This study used a mixed-methods design (two-phase) to investigate the knowledge, preferences, barriers, and limitations to exercise and PA among ACB cancer survivors in Canada. Eighteen Canadian adult ACB survivors completed an online survey and eight ACB survivors from Nova Scotia were interviewed. The online survey found PA levels were not significantly related to QoL and ACB survivors did not show a preference to exercise types. An overarching theme of ‘No one Told Me’ emerged from the interviews, reflecting the limitations and barriers that contributed to four themes: (1) The Journey, (2) What’s There for Me?, (3) One Step at a Time and (4) See ME. The results from this study suggest that ACB cancer survivors are aware of the benefits of exercise and PA and want to feel welcomed and invited spaces that encourage exercise and PA.

List of Abbreviations Used

ACB – African, Caribbean, Black

ACCESS – Activating Cancer Communities through and Exercise Strategy for Survivors

ANSDPAD – African Nova Scotian Decade for People of African Descent Coalition

CEP – Clinical Exercise Physiologist

CS - Cancer survivor and/or cancer patient

EXCEL – Exercise for Cancer to Enhance Living well

FACT-G – Functional Assessment of Cancer Therapy – General

GLTEQ – Godin Leisure-Time Exercise

HAAC – Health Association of African Canadians

HRM – Halifax Regional Municipality

LSI – Leisure Score Index

LTPA – Leisure Time Physical Activity

METS – Metabolic equivalents

PA - Physical Activity

NS – Nova Scotia

QoL – Quality of Life

Chapter 1: Introduction

Cancer is the number one cause of death in Canada. The Canadian Cancer Registry estimated that 43% Canadians will develop cancer in their lifetime, and roughly one in four Canadians will die from the disease (Brenner et al., 2022). Though the Canadian Cancer Registry does not report findings based on race/ethnicity, data from the United States (US) has demonstrated that there are significant racial/ethnic disparities in both incidence and mortality rates. US-based research has shown that individuals of African descent bear the highest death rate and lowest survival rate of any racial and ethnic group of most cancers (Vo et al., 2021; Zavala et al., 2021; Chowdhury-Paulino et al., 2021; DeSantis et al., 2019; Rutter CM et al., 2021). African-, Caribbean-, and Black-American, (ACB) women in the US have a 42% higher breast cancer death rate and are twice as likely to die from cervical cancer than women of European descent. Prostate cancer has the largest cancer disparity, where ACB men face 78% higher incidence rate than non-Hispanic White men (Zavala et al., 2021). The risk of dying from low-grade prostate cancer is double that of men of other races (American Cancer Society for African Americans, 2019; Zavala et al., 2021).

It has been suggested that these racial disparities are the result of biological characteristics (e.g., genetic make-up, tumor biology), social inequalities, cultural barriers, fear of cancer, side-effects of treatment, lack of communication, and cultural sensitivity and distrust in the healthcare system resulting in delayed access and use of healthcare (e.g., reluctance to be tested). Notwithstanding these racial disparities, based on data from 2015-2017, there has been significant improvements in treatment modalities with as many as 64% of Canadians surviving five or more years post diagnosis; a significant jump from 55% in the early 1990's (CCS, 2021). With the number of survivors increasing, survivorship has become a vital component of a patient's overall cancer care. In survivorship, there has been a growing recognition of the adverse effects of cancer treatments (e.g., fatigue, pain, anxiety) in

conjunction with other comorbidities (e.g., cardio-respiratory issues) leading to an overall decrease in quality of life (QoL) (Beebe-Dimmer et al., 2020)

Importantly, a growing number of studies have demonstrated the benefits of embedding an exercise program as standard practice in cancer care. Exercise has been demonstrated to help mitigate adverse treatment related side-effects and manage comorbidities, including unmanageable weight gain, hypertension and diabetes which are highly prevalent among ACB populations, during treatment and into survivorship (Agyemang et al., 2009; Cormie et al., 2017). Emerging evidence also suggests that exercise and physical activity (PA) can not only reduce treatment related side-effects but may also reduce the risk of recurrence and premature cancer mortality (Yungeng et al., 2017). Yet, even with the established benefits of exercise and PA, cancer survivors, similar to the rest of the population, are not achieving activity levels sufficient enough to realize these benefits over the long-term (LeMasters et al., 2014). Despite the recent development of evidence-based guidelines, many health care providers and survivors are not only unfamiliar with these guidelines, but many also still lack an awareness and understanding of the benefits of exercise and PA for cancer survivors (Campbell et al., 2019). In addition, exercise has not been implemented as part of standard cancer care largely due to lack of resources, clinician knowledge, and exercise professionals specializing in oncology (Santa Mina et al., 2012).

To date, no study has explored exercise program participation in survivorship among African, Caribbean, and Black (ACB) cancer survivors in Canada and more specifically in Nova Scotia (NS) home to a large and distinct ACB population. NS is home to the oldest and largest historical Black population in Canada. NS's Black community is the largest racially visible group, representing 44% of the racial population (2.3%) in 2011. Although cancer incidences by race and ethnicity are not publicly noted in Canada, one of NS' historically Black communities, Shelburne, has seen an increase in cancer diagnoses and deaths raising

concern with local activists (The ENRICH Project | Exploring Toxic Legacies in Mi'kmaq and African Nova Scotian Communities).

Knowing the benefits of exercise and PA for cancer survivors and the higher advanced disease diagnoses and death rates among those of ACB descent, the primary objective of this study was to examine: 1) the trends of exercise participation of cancer survivors of ACB descent, 2) their perceived preferences, barriers, and facilitators to exercise, and 3) the relationship between PA and Qol . A mixed-method design was used to examine the knowledge, preferences, facilitators and barriers to participating in exercise for ACB cancer survivors across Canada with a deeper look into NS.

Chapter 2: Review of the Literature

The American Cancer Society (ACS) estimated that 111,990 ACB identifying men and 112,090 ACB identifying women would be diagnosed with cancer in 2022 (ACS, 2022). Prostate, lung, and bronchus cancers are most commonly diagnosed among ACB men. Breast, lung and colorectal cancers are the most common cancer diagnoses among ACB women. These cancers account for more than half of all new cancer diagnoses in this population (ACS 2022; Cancer Facts & Figures 2022). Compared to White people, ACB men have a 6% higher cancer incidence and a 19% higher risk of mortality. Of note, ACB women have an 8% lower cancer incidence rate than White women yet have a 12% higher mortality rate. This suggests that in the US, ACB individuals may not receive care in a timely manner, appropriate treatment options may not be accessible, or the level of care is not sufficient (Robbins et al., 2012).

Despite higher incidence and mortality rates in individuals of ACB descent, there has been an increase in the overall five-year survival rate in both Canada and the US (ACS 2022; CCS, 2021). In the US, the 5-year survival rate among ACB cancer patients increased from 27% to 63% between 1960 and 2017. Notwithstanding ACB cancer patients still have a significantly lower 5-year survival rate than their White counterparts overall (62% versus 68%) at every single stage of diagnosis for most cancer sites (ACS, 2022). The difference in survival rates have been attributed to many different characteristics. Zeng et al., (2014) found that many of these differences arise from socioeconomic barriers that limit access to timely and high-quality medical care, resulting in later stage diagnoses where treatment choices are limited. An encompassing contributor to these factors is structural racism that affects all aspects of life limiting overall standard of living through inequity. Of note, when controlling for socioeconomic factors and rapid access to care, these disparities still exist (Du et al.,

2011; Kish et al., 2014). Singh and Jemal (2017) found that within each socioeconomic group, ACB with cancer still have higher death rates compared to their White counterparts. Based on these findings, it is believed that disparities in cancer mortality may be attributed to the higher prevalence of underlying risk factors and pre-existing health conditions (i.e., comorbidities) in ACB cancer survivors and less frequent postdiagnosis surveillance (Beebe-Dimmer et al., 2020; Singh & Jemal, 2017)

Impact of Comorbidity on Cancer Related Outcomes

A comorbidity is the coexistence of various chronic illnesses in addition to the index disease (Houterman et al., 2004)). The prevalence of a comorbidity in cancer survivors' range between cancer types and individual age, while similar patterns are reported between males and females (Fowler et al., 2020; George et al., 2021). It is estimated that 75% of all cancer survivors have at least one comorbidity and at least 40% are among USA Medicare beneficiaries (individuals ages 65 years and older) (Panigrahi & Ambs, 2021; Safart et al., 2016). Prevalence of comorbidities among cancer-free individuals in the US is reported to be 31.8%, compared to breast (32.2%), and prostate cancer patients (30.5%) (Annual Report, 2010). Among the same cohort, lung cancer patients had the highest percentage of comorbidities (52.9%), followed by colorectal cancer patients (40.7%). Though these percentages reflect cancer survivors of all races/ethnicities, comorbidities do not affect all cancer survivors equally. When compared to other racial groups, ACB's and Native Americans have significantly higher rates of obesity, diabetes, chronic kidney disease, and hypertension (Panigrahi & Ambs, 2021). Further, women with breast cancer with pre-existing comorbidities are more likely to be ACB identifying; reflecting the prevalence of type 2 diabetes and hypertension in the ACB US population (Doose et al., 2021).

Many comorbidities share risk factors with cancer resulting in a co-occurrence/detection with cancer. Having one or more comorbidities may influence a cancer

survivors' quality of life (QoL), prognosis, and survival (Doose et al., 2021; George et al., 2021). In non-cancer studies, having a comorbidity is associated with poorer QoL. In the cancer literature, few studies report the direct impact of a comorbidity on a survivor's QoL (Sarfati et al., 2016). Independent of comorbidity type, patients with advanced non-small cell lung cancer reported lower QoL than those with zero comorbidities (Grønberg et al., 2010). In early-stage prostate cancer, those who reported a comorbidity at diagnosis had a lower QoL, though all survivors reported similar reduction in QoL throughout their cancer journey (Sarfati et al., 2016). Independent of sociodemographic factors and tumor characteristics, comorbidities have shown to be a strong predictor of survival in colorectal cancer survivors (Panigrahi & Ambs, 2021; Boakye et al., 2016). As a survivor's number and severity of comorbidities increase, its negative effect on their cancer outcomes tends to increase as well (Panigrahi & Ambs, 2021).

Impact on treatment choice and outcomes

Treatment choices are known to be affected in some way based on the presence of a comorbidity (Grønberg et al., 2010; Gross et al., 2007). Survivors with a comorbidity are less likely to receive curative treatment options than those living without (Sarfati et al., 2016). It is thought that clinicians may be concerned of additional conditions that will increase toxicity and adverse effects of treatment, adverse drug interactions, and that the treatments may be less effective, or that the life expectancy of patients is insufficient to justify the potential toxic agents (Kutner et al., 2000.; Newcomb & Carbone, 1993).

Among breast cancer patients, those diagnosed with cancer while dealing with pre-existing comorbidities are less likely to receive treatment based on the recommended guidelines (Ashing et al., 2014). In colorectal cancers, studies have shown a reduced offer and uptake of chemotherapy among survivors with a comorbidity, independent of age (Cronin et al., 2006; Gross et al., 2007; Sarfati et al., 2018). With surgery, some colorectal

cancer studies reported no association while others showed an inverse relationship between comorbidity, surgery choice and quality of post-surgical care (Janssen-Heijnen et al., 2005; Lemmens et al., 2005). While Gross et al., (2007) reported 55% of Black cancer patients received chemotherapy compared to 60% and 62% among White and other races, it is not clear if cancer survivors of ACB descent were included in the other comorbidity studies.

In contrast, there are findings that suggest that some patients with one or more comorbidities have their curative treatment unnecessarily modified. Bergman (1991) and colleagues researched whether treatment had an impact on survival among older prostate cancer patients with and without an existing comorbidity. Focusing on congestive heart failure, diabetes, and chronic airways disease, they found that among men with intermediate and high-risk prostate cancer, those who were treated had substantially better survival compared to those who were not, regardless of comorbidity status. Gross et al., (2007) found similar results and noted that the relative reduction in the risk of mortality associated with chemotherapy was similar between patients with chronic heart failure and patients without.

Impact on survival and recurrence

Depending on the number of comorbidities, their severity, and how the comorbidities are measured, the impact on survival can vary. However, the presence of a comorbidity has repeatedly shown to have a negative impact on survival from a cancer diagnosis (Tammemagi, 2005). As previously noted, cancer survivors living with a comorbidity often receive less active treatment than those without and may be more susceptible to higher levels of toxicity from various treatments, ultimately impacting their cancer-specific survival (Lee et al., 2011). Furthermore, it is likely that while undergoing cancer treatment, there may be a lack of attention to a patient's chronic disease management by both patient and physician (Sarfati et al., 2016). For example, mismanagement of blood glucose levels in diabetic patients, could be detrimental to overall health outcomes. Meyerhardt et al., (2003) found that

patients with diabetes had a 21% increased risk of recurrence. They concluded that the increased risk was due to hyperinsulinemia of diabetes, resulting in more rapid tumor progression. Piccirillo (2004) and group found when grouping comorbidity severity (none, mild, moderate, severe) based on the organ decomposition and prognostic impact, the chance of cancer recurrence increased with the higher comorbidity level.

In contrast, Kiderlen et al., (2013) found that among breast cancer patients, those with diabetes had a lower recurrence rate than those without diabetes. It was suggested that metformin, known for treating and curing type 2 diabetes, had a favorable impact that outweighed the adverse impact of diabetes itself. As an anti-cancer drug, metformin is known to decrease proliferation of cancer cells and when used alone or with radiotherapy, to reduce tumor growth (Kiderlen et al., 2013; Ma et al., 2020; Saraei et al., 2019).

As cancer survivorship improves within an aging population, more cancer survivors will continue to experience comorbidities, or cancer-related and treatment-related adverse effects that compromise overall QoL. Regular PA, along with a healthy diet and weight management have been recommended for cancer survivors to prevent, mitigate, and manage possible disease sequelae (Campbell et al., 2019).

Benefits of PA and Exercise for Cancer Survivors

PA is defined by the World Health Organization as an activity in which the body's large muscle groups move for a sustained period in a rhythmic manner (Bull et al., 2020). There is strong evidence showing that regular PA and exercise (i.e., the planned, structured, and intentional subcategory of PA) is associated with multiple health benefits such as, weight management, cardiorespiratory fitness, muscular strength, and endurance (Bull et al., 2020; Campbell et al., 2019; Garcia & Thomas 2014;). PA also plays an important role in primary and secondary prevention of chronic illness and premature death (Garcia & Thomson, 2014;

McTiernan et al., 2019; Warburton et al., 2011). In cancer survivors, PA and exercise have been shown to be a safe, feasible and effective method to alleviate the physiological and psychological side effects that may accompany a cancer diagnosis and its treatments (Meyerhardt et al., 2003).

PA and exercise as prehabilitation

Within oncology, prehabilitation is defined as the: “process on the continuum of care that occurs between the time of cancer diagnosis and the beginning of acute treatment, includes physical and psychological assessments that establish a baseline functional level, identifies impairments, and provides targeted interventions that improve a patient’s health to reduce the incidence and the severity of current and future impairments” (Silver & Baima, 2013). Although prehabilitation is not specific to cancer, it has been associated with surgery, where preoperative physiological health are well-established predictors of peri-and postoperative outcomes (Santa Mina et al., 2020).

In non-cancer related organ surgery patients, it was found that prehabilitation that included aerobic and/or resistance training led to improved postoperative pain, physical function and length of hospital stay. Those who are physically fit prior to non-cancer related surgery, have shown lower complication rates and experienced quicker recovery rates compared to less fit individuals (Chen et al., 2017). Surgery continues to be an important intervention for solid tumors. Prior to surgery, the diagnosis coupled with disease progression and interventions take a significant toll on the patients physical and mental health (Chen et al., 2017; Santa Mina et al., 2020). Further, antineoplastic therapies such as chemotherapy can reduce physical fitness resulting in a patient transitioning from lower to higher risk. Although the time between diagnosis and surgery may not be long, physical fitness adaptations can be made in little as two weeks (Silver & Baima, 2013).

Women with breast cancer who reported being active before surgery, had an 85% greater chance of reporting enhanced recovery to baseline 3 weeks post operation when compared to inactive women (Lahart et al., 2018). In addition, prehabilitation within oncology can significantly improve a patient's ability to cope with the possible effects of cancer treatments, including radiation, chemotherapy, immunotherapy and treatment for palliative care (Beebe-Dimmer et al., 2020; Brown et al., 2012; Campbell et al., 2019). While implementing an exercise routine during the prehabilitation stage continues to grow in the literature, the benefits of maintaining fitness and implementing activity during the therapy phase is well studied.

On treatment (managing acute effects)

Historically, cancer survivors were advised to rest and avoid PA and exercise upon diagnosis. It is now recommended that cancer survivors avoid *inactivity* upon diagnosis and after treatment to ease some of the most common treatment related side effects (e.g., fatigue, anxiety, depression, decreased QoL) (Campbell et al., 2019). Upon medical clearance, it is also recommended that cancer survivors participate in moderate intensity aerobic exercise at least 3 times per week for 30 minutes, to incorporate two or more days a week of resistance training, and implement daily stretching of major muscle groups (Campbell et al., 2019).

Effects on fatigue

The most commonly reported treatment related adverse effect is fatigue (Wang et al., 2014). Cancer-related fatigue affects up to 90% of survivors completing chemotherapy and radiation and continues to affect survivors for months, even years, after treatment completion even when there is no evidence of cancer (Tomlinson et al., 2014). A number of meta-analyses have shown PA and exercise as beneficial in managing and reducing cancer-related fatigue, both during and after completion of treatment (Campbell et al., 2019; Hilfiker et al., 2018; Mustian et al., 2017; Puetz & Herring, 2012; Tian et al., 2016). On top of impacting a

survivors physical, mental, and emotional functioning, cancer-related fatigue has been attributed to treatment noncompliance, treatment modification and early discontinuation of treatment (Van Vulpen et al., 2020). Improvement in cancer-related fatigue has been observed across several subgroups of cancer survivors, and the strongest effects on fatigue are observed in supervised exercise interventions (Van Vulpen et al., 2020; Mishra et al., 2012)

Effects on depression and anxiety

Nearly all cancer survivors experience psychological side effects related to their cancer and/or its treatments. Depression is associated with treatment noncompliance and reduced 5-year survival rate (Brown et al., 2012; Craft et al., 2012). PA and exercise are non-pharmacological therapies that have been shown to reduce depressive symptoms among individuals living with depression. In cancer survivors, meeting the recommended aerobic and strength training guidelines can significantly reduce depressive symptoms during and after cancer treatment (Campbell et al., 2019; Iwelunmor et al., 2014; Zyzniowska-Banaszak et al., 2021). Similarly, compliance to guidelines can reduce feelings of anxiety in this population (Ribeiro et al., 2020, Chen et al., 2015). Improvements in symptoms of depression and anxiety were greater in supervised training programs compared to unsupervised or home-based programs (Campbell et al., 2019).

Off treatment

A systematic review on cancer prevention and mortality showed a consistent inverse association between the amounts of PA after diagnosis and all-cause mortality (McTiernan et al., 2019). In breast cancer survivors, highest versus lowest levels of PA were associated with a 48% reduction in risk for all-cause mortality (Friedenreich et al., 2016). In prostate and colorectal cancers, data from two meta-analyses showed a 38% reduction in cancer-specific mortality with higher levels of total recreational, non-sedentary occupational, and vigorous

PA (Bonn et al., 2015; Wang et al., 2017). It was also shown that a greater number of metabolic equivalents (METs) hours per week one year post diagnosis was significantly related to reduced risk all-cause mortality (Bonn et al., 2015).

There continues to be emerging evidence showing PA and exercise having positive effects on lymphedema, bone health and health-related QoL (Campbell et al., 2019; Chen et al., 2017; Iwelunmor et al., 2014; Lahart et al., 2018). Regardless of cancer diagnosis, exercise interventions appear to be an effective way to improve these three areas during and long after treatments have finished (Ferrer et al., 2017). Yet, despite the established evidence of the effects and safety of PA and exercise and the recommended guidelines, many cancer survivors from all backgrounds are not meeting the recommended guidelines (Kennedy et al., 2021; Alderman et al., 2020; Garcia & Thomson, 2014).

PA Participation Among ACB Cancer Survivors

While comparable Canadian data is not available, it has been estimated that fewer than one-third of all ACB cancer survivors in the US meet the recommended exercise guidelines (Ray et al., 2018). Moreover, Beebe-Dimmer (2020) and colleagues reported that ACB survivors were far less likely to engage in any PA in comparison to non-Hispanic whites.

Recruitment of ACB cancer patients to exercise programs is consistently lower than other groups contributing to fewer than 3% of the study participant population (Owens et al., 2013; Nock et al., 2015; Pinto et al., 2011; Beebe-Dimmer et al., 2020; Halbert et al., 2008; Ray et al., 2018). The largest study to date (n=1500) examined the relationship between PA and QoL in ACB cancer survivors was conducted in Detroit. It was found that through a self-reported survey, regular participation in moderate-to-vigorous PA is associated with improved self-reported health-related QoL, less anxiety and depression among ACB cancer

survivors diagnosed with the four most common cancers (breast, prostate, colorectal and lung) (Beebe-Dimmer et al., 2020). It was also found that changes in the amount of PA from baseline to their one-year follow-up was also correlated with improvements in health-related QoL.

Paxton (2019) and colleague's systemic review of studies that focused on PA in only American ACB breast cancer survivors concluded that these women are willing and capable of adhering to PA interventions ranging from home-based unsupervised interventions to more complex web-based platforms. Of note, Piacentine (2018) found that using medical professionals to recruit ACB cancer survivors to exercise interventions within the individual's community with other ACB survivors with similar stories helped maintain engagement in the program. They also found that entering their exercise program, breast cancer survivors knew some benefits of exercise, but did not know the best ways to exercise. There are no comparable data found in Canadian studies that examine PA and exercise interventions in ACB cancer survivors of any kind.

In Halifax, Activating Cancer Communities through an Exercise Strategy for Survivors (ACCESS), a free 12-week exercise program for cancer survivors has consented over 300 patients and only two have identified as ACB descent. In addition, EXercise for Cancer to Enhance Living well (EXCEL), another free 12-week exercise program for cancer survivors based in rural and remote areas in Atlantic Canada has consented 200 participants to date. Of those 200 participants, one has identified as ACB descent. Both ACCESS and EXCEL welcome both clinician and self-referrals to the program and have completed programs online and in-person.

Because of the established benefits of PA and exercise observed in the literature, it is important to research the factors contributing to underrepresentation and low participation

rates of ACB cancer survivors in Canada. The literature suggests there is a need for tailored approaches in a clinical practice to address the needs and concerns of ACB cancer survivors and in doing so increase enrolment in all clinical trials in NS.

Research Purpose and Objectives

The objectives of this study were 1) to identify the ACB cancer survivor population in Nova Scotia and Canada; 2) to explore their knowledge and behaviours surrounding exercise and PA while living with a cancer diagnosis, 3) to identify preferences and barriers to being active. Specific research questions were: 1) do ACB cancer survivors know the benefits of exercise and PA while living with cancer? 2) what are the barriers ACB cancer survivors face surrounding exercise and PA? and 3) is there relationship between exercise and PA participation and QoL?

Chapter 3: Methodology

Design and Procedures

This study used a mixed-methods design (two-phase). In the first phase, quantitative data was collected using a web-based survey (REDCap). The second, qualitative phase was used to collect data through semi-structured interviews. For the purposes of this thesis, the web-based survey has been open since November 2021 and will remain open to allow additional participant recruitment for future research. Given the time constraints associated with the master's thesis, the survey data presented will represent the data collected between November 2021 – March 2022. In the second, qualitative phase, participants who agreed to be contacted for further participation in the initial web-based survey and resided in NS were selected and asked to complete a one-time audio-recorded interview through Zoom. As completion of the web-based survey was not a requirement for the interview interviews were conducted in tandem with the survey.

Participant recruitment

Participants for this study met the following inclusion criterion: 1) self-identified as ACB, 2) have/had a cancer diagnosis, 3) 19 years or older, 4) reside in Canada¹, and 4) were able to speak and understand English to engage in the consent form, survey questions, and interview. For the first phase, participants were recruited through weekly emails to Black-led organizations, including the Health Association of African Canadians (HAAC), African Nova Scotia Decade for People of African Descent Coalition (ANSDPAD), Black Physicians of Canada, and community centers and other trusted groups in the ACB community such as the Preston Township (Cherry Brook, Lake Loon , North Preston, East Preston). Relationships

¹ In February 2022, in response to a low response rate, an amendment was made to expand survey participation beyond ACB Nova Scotian residents, to include all ABC Canadian residents.

between ACB community leaders and the lead researcher/research team were also used to share flyers and a link to the online survey. Cancer survivor organizations were also contacted and asked to display study a recruitment poster inviting potential participants to contact the lead researcher for more information. Social media platforms such as Instagram and Facebook were used to reach potential participants through the researcher's personal accounts. For the second phase, survey participants who indicated interests in semi-structured interviews were contacted. Individuals who did not complete the survey but showed interest in being interviewed were also contacted.

Data Collection

Patient reported outcome measures included self-reported QoL using the Functional Assessment of Cancer Therapy – General (FACT-G) (Cella et al., 1993) and self-reported PA using the modified Godin Leisure Time Exercise Questionnaire (GLTEQ) (Godin & Shephard, 1985). The FACT-G is a validated and used questionnaire to assess health-related QoL of cancer patients across four areas (physical, social, emotional, and functional well-being) (Cella et al., 1993). The GLTEQ is a validated 3-item self-reported questionnaire that is used to assess leisure-time PA (Godin & Shephard, 1985). The GLTEQ is commonly used in exercise oncology research (Amireault et al., 2015). Participants were also asked to list their knowledge, beliefs, preferences, barriers, and facilitators, to exercise and PA after being diagnosed (Appendix A)

The semi-structured interview guide included four sections: 1) cancer diagnosis and treatment history/plan, 2) current knowledge of PA and exercise, 3) barriers and facilitators to PA and exercise in their community, and 4) thoughts and ideas on exercise trials for cancer patients/survivors in NS. Interview questions were curated to expand on survey answers that did not allow for nuance through text (Appendix B). Participant interviews lasted between 12

to 32 minutes and were conducted by the lead researcher. Interviews were transcribed verbatim by transcriptionist. Participants were recruited until data saturation was achieved.

Data Analysis

IBM SPSS Statistics Version 27 was used to summarize descriptive statistics. Summaries included frequency distributions, means and ranges of demographics, cancer and health history, PA, QoL, and exercise barriers and facilitators, and preferences.

QoL of was measured using the FACT-G. The FACT-G includes four subscales: physical (7-items, score range 0-28), social (7-items, score range 0-28), emotional (6-items, score range 0-24), and functional (7-items, score range 0-28). An overall score can be generated per individual provided more than 50% of the items in a subscale are answered. Missing values were replaced with the mean of the subscale, an acceptable method of imputing missing data in the FACT when more than 50% of the items are answered (Webster et al., 2003). Higher scores for the scales and subscales indicate a higher QoL.

PA levels were scored using the GLTEQ. The GLTEQ includes questions gaining information on the number of times an individual engaged in mild, moderate, and strenuous leisure-time PA (LTPA) in bout of at least 15 minutes. The leisure score index (LSI), was derived by multiplying the number of bouts at each intensity by 3 (mild), 5 (moderate), and 9 (strenuous) METS per week and then summed. LSI scores were used to rank individuals from low to high PA levels. Further, moderate and strenuous scores were used to categorize individuals as either sufficiently active (LSI score \geq to 24) and insufficiently active (LSI score \leq to 23) in accordance to the public health guidelines for healthy adults (Amireault et al., 2015; Public Health Agency of Canada, 2011).

Transcribed interviews were analyzed using an inductive thematic analysis as described by Braun and Clark (2009). Phase 1 included familiarization with the data by

reading interview transcripts three times and making notes along the way. In phase 2, a coding system was generated to identify relevant information. Phase 3 included identifying emerging themes by reviewing the coded data, followed by reviewing potential themes for quality and relevance to the data in phase 4. In phase 5, themes were clearly defined and then reported in phase 6. To ensure rigour, all transcripts were reviewed and coded by the lead researcher and co-supervisor. Together, the lead researcher and co-supervisor discussed patterns and topics that were identified as appropriate themes. Participants were offered to read their transcripts and emerging themes to ensure their thoughts and feelings were conveyed appropriately, however none chose to do so.

Researcher's Rationale for Conducting this Study

My undergraduate degree in Kinesiology opened my world to the important roles exercise and PA play on overall health outside of sport. I became interested in the prevention and management of chronic disease through movement and using exercise as a form of medicine. I was lucky enough to begin working as a clinical exercise physiologist (CEP) on clinical research projects involving cancer survivors and exercise. During the last 3.5 years I have been in this position, I've noticed patterns among the participants I consented and worked with. Specifically, the majority of the participants that were being referred or who had referred themselves were all White, near retirement and had no barriers transporting to the lab. I had also noticed similar patterns when working in other areas dealing with chronic diseases.

As the Black Lives Matter movement gained mainstream attention and a lot of self-reflection being done, I knew the demographic patterns I have seen daily at work had to change. My perception of healthcare, research and exercise shifted drastically and became interested in health-equity and proper patient-oriented research. To understand why I was not seeing people who looked like me, Black faces, being referred to a free program for cancer

survivors I knew I had to ask questions to Black survivors. Being the daughter of two Nigerian immigrants and repeatedly forgotten when speaking of Black Nova Scotians, I wanted to make sure all Black faces were involved rather than those indigenous to NS and Canada.

Chapter 4: Results

Phase 1

Participant characteristics

A total 55 individuals responded to the online survey. Of these, 50 identified as ACB. Of the 50 ACB respondents 21 did not meet all inclusion criteria and 11 had partial responses. Of the 18 respondents with complete data, the mean age was 61.5 years, most were female (67%), most identified as either African or African Nova Scotian (58.8%) and resided within the Halifax Regional Municipality (HRM) (61.1%). Detailed participant demographics are presented in Table 1. Breast cancer was the most prevalent cancer diagnosis (29.4%). Five participants reported additional comorbidities with hypertension being reported by all five. Cancer and comorbid disease history is presented in Tables 2 and 3, respectively.

Table 1

Survey participant characteristics (N = 18)

Mean age (range)	61.5 years (39-70)
Sex n (%)	
Male	6 (33)
Female	12 (67)
Ethnicity n (%)	
African & African Nova	11 (61.1)
Scotian	
Black	5 (27.8)
Caribbean & Other	2 (11.1)
Residence n (%)	
HRM	11(61.1)
Outside HRM	4 (22.2)
Prefer not to say	3 (16.7)
Education n (%)	
Highschool (or less)	4 (13.8)
Diploma	5 (17.2)
Bachelor's	6 (20.7)
Education n (%)	
Graduate	2 (6.9)
Prefer not to say	1 (3.4)
Income n (%)	
Less than \$74,999	3 (10.3)

Income n (%)	
\$75,000-\$99,000	3 (10.3)
\$100,000-149,000	4 (13.8)
\$150,000-199,000	2 (6.9)
Not sure/prefer not to say	6 (17.2)

Employment n (%)

Full-Time	8 (27.6)
Retired	9 (31.0)
Part-Time	1 (3.4)

Note: HRM = Halifax Regional Municipality

Table 2

Cancer Diagnoses N=18

Cancer	N(%)
Breast	5 (29.4)
Prostate	4 (23.5)
NHL	2 (11.8)
Gynecological	3 (17.6)
Other	4 (17.6)

Note. NHL = Non-Hodgkin's Lymphoma.

Table 3

Comorbidities among participants N=5

Comorbidities	N(%)
Hypertension	5 (100)
Type 2 diabetes	2 (11.8)
Arthritis	2 (11.8)

Leisure-Time Physical Activity

LTPA was measured using the GLTEQ with LSI as the main scoring category. After removing outliers and incomplete responses 13 scores were analyzed. Based off LSI, six participants were categorized as sufficiently active and seven were categorized as insufficiently active. Five (38.5%) participants averaged 0-2 sessions/week, another five

(38.5%) averaged 3-6 sessions/week and three (23%) averaging 7+ sessions/week. Most of the participants (53.8%) listed their average PA durations above 60 minutes.

Functional Assessment of Cancer Therapy Scale

Normative scores for the FACT-G are 80.1; 22.7 for physical, 19.2 for social, 18.5 for functional and 19.9 for emotional (Webster et al., 2003). Table 4 shows the participants in this study reported QoL scores scored within normal ranges. There were no significant correlations between QoL and PA to note within this cohort.

Table 4

Quality of Life Descriptive Statistics

	Minimum	Maximum	Mean	Std. Deviation	Normative Mean
Physical	14.00	28.00	22.67	4.00	22.7
Social	.00	28.00	19.72	6.74	19.2
Emotional	12.00	24.00	19.11	4.04	19.9
Functional	14.00	27.00	20.44	4.38	18.5
FACTG total	54.00	103.00	81.94	12.97	80.1

Note: FACTG = Functional Assessment of Cancer Therapy - General

Barriers, Facilitators, and Preferences.

No single variables were seen as significant barriers or facilitators to PA and exercise among the participants responses. Enjoyment (29.4%), equipment availability (29.4%) and access to space/facilities (23.5%) were considered mild barriers. Highest rated facilitators to participation included good for health (47.1%), improved fitness (47.1%), family/friend support (35.3%) and confidence (41.2%). Participants did not report any substantial

preferences between having a tailored program for ACB survivors (35.3), compared to a program for all races and ethnicities (29.4%). Participants reported they felt confident they could take part in an individual or group-based exercise program (52.9%). Respondents preferred walking, strength/resistance training and flexibility training equally (58.8%) with little preference towards aerobic training (23.5%). Two participants were aware of existing exercise programs for cancer survivors because they took part in ACCESS and all participants reported e-mail as a preferred mode of receiving study and program information.

Phase 2

Participant characteristics

A total of eight interviews were conducted (females $n = 4$). All participants were current residents of NS and met all other eligibility criteria. Most of the participants resided within the HRM and the Preston Township. Cancer diagnoses were varied, and some participants had more than one diagnosis. Cancer diagnoses included: prostate, pancreas, bone marrow, endocrine, lymphoma, breast, liver, bowel, lung, and thyroid. Participants were selected based on shown interest from the online survey and from those who contacted the lead researcher directly.

Emerging Themes

An overarching storyline titled ‘No One Told Me’ was produced from the qualitative data. This storyline reflects the limitations and barriers that contributed to four themes. Theme 1, ‘The Journey’, relates to the knowledge sharing between survivor and healthcare provider based on unique daily challenges while navigating the cancer continuum. Theme 2, ‘What’s There for Me?’ unravels participants knowledge of available support systems and guidance to maintain and/or improve wellbeing through PA and exercise. Theme 3, ‘One Step at a Time’ focuses on the internal thoughts and perceived notions of participating in activities that positively affect a survivor’s health. Finally, Theme 4, ‘See ME’, discusses

recommendations to increase awareness and participation in exercise trials/programs and the importance of safe and welcoming spaces for all cancer survivors. To protect the identity of participants, they will be referred to as B1, B2, B3,B4 and W1, W2, W3, W4.

Figure 1

Major themes and associated subthemes



No One Told Me

Despite the length of active surveillance after being diagnosed, participants commonly identified themes during the entirety of the cancer journey that hindered their ability to fully feel aware and confident of what was happening and what was available to them. Some participants identified that information shared was limited to their diagnosis and treatment plan, with little information provided on the ways their daily lives may be affected.

Participants were aware of positive activities to improve their wellbeing while going through their journey, but were not told about them, therefore felt hesitant in participating. The themes will be presented in the following order “The Journey”, “What’s There for Me?”, “One Step at a Time”, and finally “ See ME”.

The Journey

Participants noted the need to continually adapt each day to their new life as a cancer survivor and the lack of information and guidance by their oncologist and other members of the health care team surrounding PA, exercise, and nutrition: Participant W2 stated “My hematologist never told me about like going out and like staying active, like after my chemo like go for walks or eat healthy and stuff like that, they never really told me anything about that”. W2 is reflecting on their desire to want to do more and live better but did not feel the information and the importance of exercising was shared with them.

Participants also expressed a lack of knowledge and supportive information about elements that could positively and negatively impact their journey and daily changes to their ‘old’ life. W4 recalling their surgery remembered that “after my surgery I was kind of left to my own devices and I went back to what I was doing previously and what that did was it stretched my scarring, it affected my scar tissue”. This participant did not seem to receive any information about what they should or shouldn’t do. This resulted in W4 having a longer recovery period because of their scar and discouraged them from being as active as they were previously.

What’s There for Me?

It was made evident that participants believed PA and exercise was good for their overall wellbeing prior to and after being diagnosed with cancer. B2 explores how they understand PA stating, “you know it just means continually being involved in different type

of participation whether it be exercise, walking, golfing, any activity that keeps the juices flowing, right”. It seems B2 understood the importance of PA and did their best to keep active. However, when they were diagnosed, the importance of PA was not discussed by health professions. Additionally, B1 expressed their understanding of PA as:

“Well, you’re able to, to breathe better you know. You expand your lung capacity, you’re able to do more such as you know walking, jogging, that sort of thing, you’re able to extend how long you can do it. And just overall good and wellbeing”- B1

Several participants also understood the benefits of PA and exercise and were able to differentiate between the two. B3 provided examples of PA in relation to housework:

“Physical activity can take any form, it can be cleaning your house, it could be out doing your gardening, it can be mowing your lawn. Exercise to me is more of there’s a specific purpose to the exercise that you’re doing. So, if I’m going to the gym, I’m going to the gym because I want to work on certain things but overall physical activity can work on all of those things all at once” – B3

Moreover, B4 saw PA as “something that you do daily, like it’s a daily activity that you do to keep your mind occupied.” Incorporating PA into your daily routines, was one way in which B4 was able to stay active and focused on something other than their health.

Although participants were able to differentiate the two, certain participants were less aware of the variety of benefits PA and exercise, associating exercise with weight loss, sport, and as a means to improve health while ill only. B1, B2, and B4 expressed how they perceive or participate in exercise. B4 said they “think with exercise you’re trying to like basically lose weight type thing. Like you’re looking to lose a certain amount of pounds”. Relating PA to sport, B2 mentioned they played rugby for 45 years. After doing all that, going to practice, playing games, I kind of like my retirement”. Finally, B1 related being active to their diagnosis and treatment “the farther away I am from the treatment, the less exercising that I’m doing, but I just like you know puttering around the house is my activity now.” PA and exercise were associated with physical and psychological benefits, and some noted its

importance to remain positive throughout their cancer journey. Both W4 and B1 talked about the benefits of exercise and PA to their mental health:

“When I am physically active, I feel more mobile and I have just like more confidence in what my body can take on. My mental health, so even just moving my body a little bit, provides, I think it’s like a serotonin bomb, I immediately have an improvement in my mood” – W4

“Well, I mean I know my physical activity, I’m sure keeps me mentally strong, you know as much as it works to keep your body in condition, it also keeps your mind active and keeps you I don’t know, it can help keep you somewhat sane sometimes, especially going through treatment” – B1

The focus on their mental health and reference to the importance of keeping mentally strong in order to keep sane is shared by several participants.

Despite knowing the benefits of PA and exercise, many participants felt unsure of what was safe to do while going through treatment and into survivorship. Nearly all participants mentioned that nowhere along their cancer journey did their health care providers mention benefits of maintaining an active lifestyle unless brought up by the survivor themselves. W2 talked about how “while I was doing my chemo and stuff, they never really told me to be active or anything”.

There was no discussion with W2 and their health care providers about the benefits of exercise and PA for individuals diagnosed with cancer. Unlike W2, B4 who was active after asking a question to their physician was encouraged to continue to do what they like:

“Once I was able to go back to the gym, like my last surgery and stuff when I went to have my check-up I asked the guy I talked to if I could go to the gym and he said you can do anything you want” -B4

B4, although approved to keep active was not informed by their caregivers about the benefits of PA and exercise as a cancer survivor. There were expressions of lack of guidance and knowledge sharing. W4 experienced the opposite of B2 but still without direction from their care providers:

“I have kind of like saggy areas now and I went to my surgeon and she was like well you shouldn’t have been lifting weights, and I’m like nobody said that to me. We all knew that that’s what I did beforehand, but no one said to stop doing it afterwards” - W4

The journey for many of the cancer survivors was not an easy one. For some it was two steps forward, one step back and several felt alone as they look their first step into being a cancer survivor.

One Step at a Time

Barriers and facilitators to participating in PA and exercise rose as participants navigated through their cancer journeys. Participants noted decrease in overall wellbeing when they were no longer able to do what they used to:

“My old perception of exercise and physical activity was like pretty intense, hard core, pushing myself to my limits consistently. And I just could not do that after my cancer diagnosis from so many perspectives. Physically I couldn’t do what I could do before. Mentally, I wasn’t sure I wanted to be pushing that way anymore” – W4

And although they were aware of its benefits, it was mentioned that their treatment side effects, physical limitations and other priorities were common reasons why they are not as active as they may think they should be. Several participants shared their struggle with PA:

“Well now that I’m finally feeling a little bit better after my chemo, I just want to relax. Like I don’t want to do anything, I don’t want to leave the house or anything. So I found it put a big barrier on me being physical and stuff like that because I just don’t, didn’t want to do anything, like it literally drains your body like so when you do get the energy, by the time I got the energy back it was time to get my kids and then three days later after I had my kids then it’s time to go back to my chemo”- W3

“I’ve got bad knees, I’ve got sore joints, you know and that’s what I find is really stopped me from wanting to go out and exercise any more cause my knees, my joints, all that arthritis in them now and all that they say these drugs could be a factor” -B1

“The frustrating thing is side effects and how it can affect whether I’m going to go out and do something. So with one of the side effects, if I go out and it’s cold my brain plays tricks on me, so it tells me that my hands are burning or my throat is burning or my toes are burning. So when I go out it’s not fun and if I’m feeling nausea or if I have heartburn, which I’ve had the last week, I wasn’t up to doing any kind of physical activity”-W4

Participants discuss unwanted results from medication such as weight gain, fatigue, and some side effects from medication. Participants recognized these as barriers to PA and exercise and appeared limited in what they could do to reverse some of these symptoms.

Despite these perceived barriers, three participants mentioned their current environment as a barrier to be active:

“Well I find it’s very hard in my neighborhood because of the fact that there’s no sidewalks within the community so it’s, I mean it’s safe in a some type of instance but then at the same time it’s not. Like when I take my kids out and stuff you have to walk in the middle of the road and then if we see a car coming we have to stop and go over to the side of the road just for safety reasons” – W2

W2 identified the difficulty to just walk in their community. In contrast, many participants were aware of the potential their environments had to facilitate outdoor activities and did not see their current neighborhood as a barrier to be active outside. For instance, W4 and B4 find it easy to walk in their communities:

“I’m really fortunate, it is easy cause I’m like, well there’s no sidewalks which is unfortunate, but I’m really close to a path so there’s a path in my neighborhood that’s close to my house that I have access to that goes along a lake. And I also have a backyard which I can do activity in” -W4

“I don’t think there’s anything, well what could probably make it harder for some who don’t have money to do it, but then you don’t really need money because you can go outside and go for a walk. You can do pretty much anything, you can do anything in your house or outside if you want to” B4

“Well, I guess walking wise I live in North End Halifax, so from the point of view of just getting out and walking that’s my own right? You know there’s nothing in the area to prevent you, in the immediate area” – B1

These three participants were able to express the convenience of walking and also make the connection between walking as a feasible mode to be active for health, while understanding other modes may be limited through situational barriers.

Further, six participants were also aware of facilities and programs that were being offered to the general public pertaining to PA support and exercise programs within their own communities, yet none were enrolled in the programs being offered. A sub theme of *One Step*

at a Time was “*to tell or not to tell*” this theme identified a key reason for individuals to not participate in these programs. This subtheme revolves around the constant need of re-telling their cancer story, creating mental and emotional hardships; a direct cause of non-cancer specific programming and/or trained individuals in this field, which is reflected by W1, W3 and B1:

“And I just, I’m always constantly having to reiterate what I’m going through. And it’s all so emotionally and mentally straining. What I’m looking for is somewhere that I feel safe, comfortable, and if someone who is trained to train cancer patients so that if something happens, they’ll know what to do and they’ll understand what I’m feeling” -W1

“I want people there that would like be able to tell us o.k. you’re not pushing, don’t push yourself too hard, like you could go harder, whatever, like stuff like that, like just to help, like because they would know like and especially if we were able to say o.k. this is the type of cancer we had, this is what affected us during the cancer”- W3

“there’s all kinds of programs at the community center that promote it you know, but not cancer. I did the exercises and guidance when I was going through the treatments. I did like the encouragement from the PREP program and you know just once I start something, I like to finish it, so once I got into the program I kept doing it until I got to the end of. But there isn’t anything like that now. I don’t know” - B1

These participants identify a desire to engage in exercise programs, but additionally note they are not aware of programs where they would feel fully understood as a cancer survivor. The sentiment of feeling left out is covered in the next theme “*See ME*”.

See ME

All participants expressed that they had no prior knowledge of programs that encouraged cancer survivors to be active within or outside of current communities. W4 expressed “if someone had said go to this group with other survivors and people who had just had surgery, I definitely would have done that because I really needed the guidance”.

Although without given any information, W4 recognized the benefits a program like this could provide. Similarly, in agreement, B1 mentioned “if there was a program there that was set up for people with that cancer, I mean I would try to take advantage of that, of course”.

These two participants demonstrate an interest in a program for cancer survivors.

Additionally, a subtheme of the importance of feeling welcomed was relevant for all eight participants. Participants expressed feelings of feeling seen and represented in some capacity is important and that “for someone from the Black community it may be the importance of wanting to feel welcome in the recreational activity because most activities that I participate in there are very few people that look like me there” – W4. Alongside, feelings of encouragement from instructors were mentioned as important qualities, with W3 mentioning they are “not uncomfortable with colour, like I wouldn’t care if you were purple, blue or green, but it would be more like motivation”. Participants continued to note that an instructor who is there for the right reasons, is knowledgeable in the field and sees the individual along with their cancer diagnosis is an important when joining and adhering to an exercise program tailored for cancer survivors:

“Having a program that the instructor can like focus, I mean not just focus on me, like focus on other individuals, but focus on me, make sure I’m doing what I’m doing properly and then they know what exercises to do. Like say don’t do that, do this instead. Just someone who’s invested, who’s not just going to like, someone who’s not just there for a pay cheque, you know what I mean?” - W1

“It’s a lot. Because I don’t get remission like some cancer patients do and I don’t have a cure, they don’t have a cure for me, so I’m like dealing with this for the rest of my life, you know what I mean? So to find something for me, I’ll say for me, kind of selfish but, find something for me would be so amazing” - W2

In summary, an individual’s cancer journey will always be unique. There will be daily challenges, changes, and obstacles that with positive guidance and knowledge sharing can help overcome or adapt these situations. Increasing awareness, availability and support of PA and exercise programs within the ACB community is a positive mechanism to improve QoL while navigating the cancer continuum. Encouraging safe, welcoming, and uplifting spaces is important to increase participation in exercise programs.

Connecting the Two Phases

Due to recruitment struggles and a short timeline, a sequential mixed-methods approach, where the qualitative data is meant to enhance the quantitative data already collected, was not done. As the online survey and interviews were done in tandem, and with different populations, it is important to discuss their overlap.

Participants who completed the survey included few ACB survivors from outside of the HRM. Participant demographics were varied, all economic and educational statuses were represented, and multiple cancer diagnoses were reported. Just over half of the survey participants were not sufficiently active, and as a group they reported normal levels of QoL and had no preferences and mild barriers to exercise and PA. Essentially, the survey results alone did not showcase substantial evidence to fully answer this study's objectives.

Although the survey responses included few participants from outside of the HRM, many of the respondents were within. This is notable, as all interview participants resided in Nova Scotia with the majority currently living in the HRM. The interview data showed ACB cancer survivors are aware of the benefits of exercise and PA and its effects on QoL. In contrast to the survey data, where no significant relations between QoL and exercise and PA levels were noted, the interview data found that being active had a notably positive effect on all four subareas of QoL covered in the FACT-G. In addition, interview data showed when participants were not able to be as active as they were prior to their cancer journey, they felt a decrease in QoL.

The differences between the survey and interview data may be due to the populations studied. As many survey participants reported low frequencies of activity in a week, their preferences and barriers may be skewed as they may not be as versed in the various modes of activity. Furthermore, they may not be active enough to experience the long-term benefits of exercise and PA on health related QoL. The interview group had the opportunity to mention

their activity patterns prior to their cancer diagnosis and how it had been affected by their cancer journeys. This group seemed to be more open to various modes of activity and active long enough to notice and maintain the benefits of being active.

Interview participants mentioned knowing of community programs that offer exercise programs but were not currently participating. Similar to the most survey respondents, they also noted that they did not know of any existing cancer specific exercise programs. Both groups reported they were willing to participate in community exercise programs that were tailored for cancer survivors, no matter the race/ethnicity of the other participants and instructors. This showed that no matter their activity levels, how exercise and PA affected their QoL, participants in this study were not made aware of the benefits of exercise and PA while navigating their cancer journey and how to participate in on-going programs.

Chapter 5: Discussion

Survey

This study aimed to use a mixed methods design to capture the current participation trends and knowledge of the benefits of PA and exercise after a diagnosis. To my knowledge, this was the first study to explore the knowledge, barriers, limitations and preferences to PA and exercise in Canadian cancer survivors who identify as ACB. The findings from this study uncovered a gap in program outreach and awareness towards ACB individuals. Despite having knowledge of community programs, being aware of the benefits of PA and exercise, reporting mild barriers, and no specific preferences to being active, participants acknowledged an improvement in efforts of inclusion should be mandatory to increase participation of all cancer survivors in exercise programs, specifically underrepresented groups in NS. Since PA and exercise maintenance have been associated with reduce morbidity, mortality, recurrence, and improved QoL, it is important to maximize efforts within the current programs to create a more welcoming and inviting spaces, regardless of race (Beebe-Dimmer et al., 2020)

It was observed that 46% of ACB cancer survivors reported PA patterns that were categorized as sufficiently active, this percentage is higher than what is typically seen in the literature among, including other ACB survivors (Alderman et al., 2020; Beebe-Dimmer et al., 2020; Black et al., 2018; Campbell et al., 2019; Paxton et al., 2012). Although the literature notes walking and other forms of aerobic training as the most preferred exercise option, participants in this study reported aerobic training as highly unfavored with strength training and walking equally preferred.

Improved QoL is a frequently reported outcome in cancer exercise trials with higher levels of PA typically being associated with higher QoL. Of note, no significant association between PA and QoL was found in the current study. The lack of an association may be a

reflection of a small sample, however a recent meta-analysis by Cormie et al., (2017) found no evidence to report a positive effect of exercise on QoL among lung, colorectal or gynecological cancers. Notwithstanding, significant improvements were seen in breast cancers, which was the majority in this study's population. There is the possibility that other factors improve QoL among the breast cancer participants in this study, such as religion and spirituality which were not assessed. Additional study in this area is warranted.

Even though, only 29.4% of survey respondents reported living with another medical condition, the literature has suggested that the discrepancies in higher incidences and poorer survival rates can be attributed to the presence of these pre-existing conditions (Beebe-Dimmer et al., 2020). In this study's population, hypertension was reported among all participants living with another medical condition, though not shocking due to 40% of Canadians over 25 years having hypertension (Hypertension Canada 2016). It is unclear whether participants were diagnosed pre- or post-cancer diagnosis and treatment therefore difficult to infer the implications this comorbidity may have.

Interviews

This findings of the second phase of this study illustrated internal and external barriers, as well as facilitators for ACB cancer survivors to be active and reach the recommended exercise guidelines. Despite having the knowledge, access, and competencies to be active, participants continued to acknowledge a lack of knowledge sharing and welcoming environments suited for them.

The Journey

The literature defines the cancer journey to span across the time of diagnosis to the completion of treatment and long into survivorship (Garcia & Thomson, 2014). Addressing information needs for cancer survivors at different stages of their cancer journey can help

survivors cope and digest the challenges of their diagnosis and any obstacles they may face (Li et al., 2017; Tran et al., 2019)(Tran; Li). Tran and colleagues surveyed over 72 000 cancer survivors, ages 16 and older, to obtain patient experience and overall satisfaction of their care during their cancer journey. They found that survivors valued an abundance of information early on in their journey. Information about their care and possible adverse effects were associated with better survivor satisfaction and perceived control of their wellbeing. Similarly, Li (2017) and colleagues reported improvements in survivor health outcomes, improved symptoms, physical functioning, physiological status, and pain with proper survivor-provider communication.

Some studies have reported disproportionate survivor-provider communication satisfaction between survivors of ACB descent compared to survivors of European descent (Song et al., 2012; Matthews et al., 2012). Song et al., (2012), performed a qualitative study of the experiences of American ACB survivors where their studies participants reported low satisfaction in levels of communication from healthcare providers through the entirety of their cancer journeys. The communication areas included, cancer information, shared decision making, empathy and understanding, and respect. The participants in this study attributed their negative survivorship experience to this low satisfaction.

There continues to be barriers to maintain an effective survivor-provider communication pathway. Knowledge and information should be translated accordingly and at a convenient time that reflects the survivor's journey to lessen the impact on ACB survivors' mental strength.

What's there for me?

A significant proportion of healthcare professionals do not discuss the importance of PA and exercise with their cancer patients (Alderman et al., 2020). Although this conversation is not happening consistently, survivors are still aware of the benefits of PA and exercise on their wellbeing. Data from Caperchione et al., (2021) national survey, showed most of their cancer survivors agreed that exercise was safe and beneficial during and after their cancer treatment. Notably, although they saw it as a positive, half of their survivors would not consider participating. They believed the provided exercise recommendations from the oncologist may not be aligned with the survivors' perceptions of exercise. Further, their results suggested that half of the survivors would prefer receiving on-going exercise recommendations and counselling from an exercise specialist who is part of the oncology team. These findings could lead to a system where oncologists and nurses can provide insight on the safety of exercising in tandem with a referral to an exercise specialist to facilitate further adherence.

One step at a time

The participants in this study reported post-treatment symptoms, bone/joint pain, feeling unsure and lack of guidance as mild barriers to being active in their communities. Contrary to the literature, personal barriers such as lack of time and knowledge of PA and exercise did not seem to be a significant proponent to initiating activity in this group. Piacentine (2018) and colleagues, found through a focus group with American ACB breast cancer survivors, that despite knowing the benefits of PA and exercise, it was never made a priority and took a back seat to other daily responsibilities (family, work, etc). The participants in the focus group also reported that exercise was not part of their treatment phase and noted their healthcare team emphasized proper nutrition, but not the importance of exercise. Other barriers to exercise for ACB cancer survivors noted in the literature included

lack of equipment, self-efficacy, safety concerns and reconstruction surgery, similar to few participants in this study (Burse et al., 2020).

A unique limitation among the participants in this study that was not noted in the literature, was the burden of retelling their cancer journey. As healthcare providers in Canada continue to use various databases to store health records, individuals continue to carry the burden of reiterating their medical journey when faced with a new provider (Persaud, 2019). Although not all exercise programs are in a clinical setting or physician-referred, a form of harmonized medical records may be beneficial in clinical research settings for recruitment and consenting potential participants to minimize distress of reliving difficult moments.

See ME

Despite the racial disparities and prevalence of comorbidities, there is limited data on ACB survivors' participation in exercise trials and programs. Participants in this current study reported an increase in awareness to specific cancer programs essential to increase participation. Black et al., (2018), found integrating ACB survivors' preferences and in needs into programming is mandatory to improve participation. They concluded that the program should support efforts to maintain PA and exercise throughout the cancer journey, instructors should understand the physical and emotional impact of cancer, face-to-face communication and share strategies to cope with potential adverse effects from treatment and other potential lifestyle barriers. In NS, Evans and colleagues (2005) explored the perceptions and experiences of ACB breast and prostate cancer survivors. In their study, focus group participants expressed feelings of being disenfranchised from health care due to distance to treatment services, difficulty in transportation and racist attitudes of health professionals. These disparities may be factors influencing low enrollment rates in current exercise trials for cancer survivors in NS.

Researcher's Reflection It is hard to say I am fully pleased with the outcomes of this study. Based off the last 3.5 years with ACCESS and EXCEL, and only consenting three survivors that have identified as ACB, I knew it would be difficult to recruit cancer survivors and especially hard to recruit ACB cancer survivors for this study. I had hoped that the relationships I had created a couple of years prior with community leaders through the creation of the Black Wellness Co-Op would have helped get the importance of the study to more individuals. As a lover of action and implementation, I must value the data collection process that feeds certain programming and funding to improve equity in all areas. But I found myself constantly debating if this area of research and the questions I was asking were even worth it. As I continued to immerse myself in the literature, I began to feel the pressure of how a study like this is only the tip of the research iceberg.

When the study eligibility was widened to all of Canada, I expected there to be an increase in survey responses, but there was not. Although the responses would not have been completely representative of Nova Scotia, it would have been significant to get feedback from other ACB survivors and their experiences with exercise and PA to improve services provided or uncover the lack of services provided. A larger survey response would have also been significant to showcase the amount of ACB survivors in Canada as data is not made easily accessible.

As this was my first study with a qualitative piece and as a lead researcher, I thoroughly enjoyed the process of interviewing participants. With no real template of how to conduct these interviews, I came quick to realize the importance of the patient- and community-oriented research and the pressure that lies in accurately interpreting and sharing sentiments and beliefs. I also came to fully understand how deep rooted the distrust in

research and healthcare among ACB living in Nova Scotia is. Despite the informed consent, it almost felt as if prior to beginning the interview, I was interviewed to ensure what participants would say would not be altered, would remain anonymous and would truly be used for the betterment of the community. Even with the pre-interview of me, I could feel some participants holding back, uncovering my novice experience in this area with my inability to dig deeper, even when I wanted to.

When I say I am not fully pleased with the outcomes of this study, I am reacting to my own efforts as a lead researcher. As I continued to immerse myself in the literature, and lack thereof, I realized the questions I was asking may have been a few steps ahead of where we need to begin. I relate this to my own privilege as an ACB identifying woman who is educated in the importance of exercise and PA for chronic diseases and works in a healthcare setting.

My old thoughts of 'exercise can mend all' quickly shifted to a lens of health equity among all populations and diseases in Canada. I acknowledge this is the first study, that I know of, to be done in this field and it holds great importance for future researchers, program/research coordinators and policy makers. I hope we can continue to put efforts into widening demographics represented in research and asking questions with health equity in mind.

Strengths and Limitations

This is the first study to explore PA and exercise patterns in ACB cancer survivors in Canada, and to further explore knowledge, preferences, and barriers of ACB survivors in NS. Although not sequential, a strength of the research was the mixed-methods design uncovered that there remains to be gaps in the knowledge sharing between healthcare providers and survivors pertaining to appropriate mechanisms to maintain QoL throughout the cancer journey through PA and exercise. This study showed ACB cancer survivors are aware of the benefits of PA and exercise and improved outreach efforts to recruit in exercise programs would be beneficial.

Due to a small sample size of survey responses, the results of phase 1 may not be representative of the larger group of cancer survivors who identify as ACB in Canada; this was identified as a limitation. However, although there is no clear sample size, qualitative data saturation was reached. Due to online and anonymous survey responses, quantitative data may have been skewed with improper inputting of data by the survivors (e.g., moderate-vigorous total activity minutes). In addition, the individuals who chose to participate in this study may already have had an interest in PA and exercise prior to their diagnosis or have adopted a new behaviour more recently.

As participants recruited were only cancer survivors, data from healthcare providers who engage in oncology care was not collected. Recruiting this population may have given more insight on where the greatest knowledge gaps were encountered and the providers beliefs and knowledge of PA and exercise for their patients.

Another consideration of this study was the failure to correlate between the two phases. Time and participants recruited did not allow for a sequential mixed methods where the qualitative data could strengthen the quantitative data cohesively.

Conclusion and Recommendations

This study offers insight on the PA and exercise patterns and knowledge among ACB survivors in Canada. Participants reported perceived barriers and limitations to PA and exercise found in the literature may not be the defining characteristics to lack of participation in trials and programs. Participants discussed improvements in components that limit access, awareness and sentiments of inclusion can alleviate the current gap in recruitment. The major themes of: What's There for Me and One Step at a Time, illustrate the unique experience and narrative of ACB survivors navigating their cancer journeys. Key findings from this study include:

1. ACB survivors are aware of the benefits of being active throughout the cancer journey;
2. Proper outreach tactics (e.g., community networking, continued education for healthcare providers on the benefits of exercise, inclusive marketing materials) and welcoming spaces may be essential in improving diversity in exercise programs and trials; and
3. Collaborative medical record storage is an important aspect to minimize participant burden of re-telling their cancer journey.

Future researchers can build on this study as a starting point and guide for digging deeper into asking the right questions to uncover how to improve representation in clinical exercise studies and community programming. This study illustrated a gap in knowledge translation between healthcare providers and patient. It also left room to investigate healthcare providers knowledge of exercise and PA for cancer survivors and their willingness to prescribe exercise and PA or refer to ongoing programs in Canada. Future research should

also consider survivorship timelines, treatment plans, and cancer specific preferences and barriers.

This study showed that specific outreach of underrepresented communities is a suitable way to improve participation. Outreach tactics should include creating trusting relationships with community leaders who can further disseminate study and program details. Community programming should highlight the psycho-social benefits of exercise and PA while living with a cancer diagnosis.

As for policy, I recommend consideration of practices to increase exercise and PA participation among cancer survivors of all backgrounds. This should involve a collaborative effort between physicians, academic researchers, exercise science professionals, cancer survivors and other healthcare teams that are involved in the cancer journey. Further, exercise and PA education for all healthcare teams should be integrated in continued learning sessions as an effort to integrate exercise and PA counselling as part of standard oncology care in Canada. This in-turn should continue into accessible community-based programming to enhance and encourage life-long exercise participation.

References

- Alderman, G., Semple, S., Cesnik, R., & Toohey, K. (2020). Health Care Professionals' Knowledge and Attitudes Toward Physical Activity in Cancer Patients: A Systematic Review. *Seminars in Oncology Nursing, 36*(5), 151070.
<https://doi.org/10.1016/j.soncn.2020.151070>
- Amireault, S., Godin, G., Lacombe, J., & Sabiston, C. M. (2015). The use of the Godin-Shephard Leisure-Time Physical Activity Questionnaire in oncology research: A systematic review. *BMC Medical Research Methodology, 15*(1), 60.
<https://doi.org/10.1186/s12874-015-0045-7>
- Beebe-Dimmer, J. L., Ruterbusch, J. J., Harper, F. W. K., Baird, T. M., Finlay, D. G., Rundle, A. G., Pandolfi, S. S., Hastert, T. A., Schwartz, K. L., Bepler, G., Simon, M. S., Mantey, J., Abrams, J., Albrecht, T. L., & Schwartz, A. G. (2020). Physical activity and quality of life in African American cancer survivors: The Detroit Research on Cancer Survivors study. *Cancer, 126*(9), 1987–1994.
<https://doi.org/10.1002/cncr.32725>
- Black, K. Z., Johnson, L.-S., Samuel-Hodge, C. D., Gupta, L., Sundaresan, A., & Nicholson, W. K. (2018). Perceived barriers and preferred components for physical activity interventions in African-American survivors of breast or endometrial cancer with type 2 diabetes: The S.U.C.C.E.S.S. framework. *Supportive Care in Cancer, 26*(1), 231–240. <https://doi.org/10.1007/s00520-017-3839-9>
- Brenner, D. R., Poirier, A., Woods, R. R., Ellison, L. F., Billette, J.-M., Demers, A. A., Zhang, S. X., Yao, C., Finley, C., Fitzgerald, N., Saint-Jacques, N., Shack, L., Turner, D., & Holmes, E. (2022). Projected estimates of cancer in Canada in 2022. *Canadian*

Medical Association Journal, 194(17), E601–E607.

<https://doi.org/10.1503/cmaj.212097>

Brown, J. C., Huedo-Medina, T. B., Pescatello, L. S., Ryan, S. M., Pescatello, S. M., Moker, E., LaCroix, J. M., Ferrer, R. A., & Johnson, B. T. (2012). The Efficacy of Exercise in Reducing Depressive Symptoms among Cancer Survivors: A Meta-Analysis. *PLoS One*, 7(1), e30955.

<http://dx.doi.org.ezproxy.library.dal.ca/10.1371/journal.pone.0030955>

Bull, F. C., Al-Ansari, S. S., Biddle, S., Borodulin, K., Buman, M. P., Cardon, G., Carty, C., Chaput, J.-P., Chastin, S., Chou, R., Dempsey, P. C., DiPietro, L., Ekelund, U., Firth, J., Friedenreich, C. M., Garcia, L., Gichu, M., Jago, R., Katzmarzyk, P. T., ... Willumsen, J. F. (2020). World Health Organization 2020 guidelines on physical activity and sedentary behaviour. *British Journal of Sports Medicine*, 54(24), 1451–1462. <https://doi.org/10.1136/bjsports-2020-102955>

Burse, N. R., Bhuiyan, N., Mama, S. K., & Schmitz, K. H. (2020). Physical activity barriers and resources among black women with a history of breast and endometrial cancer: A systematic review. *Journal of Cancer Survivorship*, 14(4), 556–577.

<https://doi.org/10.1007/s11764-020-00873-z>

Campbell, K. L., Winters-Stone, K. M., Wiskemann, J., May, A. M., Schwartz, A. L., Courneya, K. S., Zucker, D. S., Matthews, C. E., Ligibel, J. A., Gerber, L. H., Morris, G. S., Patel, A. V., Hue, T. F., Perna, F. M., & Schmitz, K. H. (2019). Exercise Guidelines for Cancer Survivors: Consensus Statement from International Multidisciplinary Roundtable. *Medicine & Science in Sports & Exercise*, 51(11), 2375–2390. <https://doi.org/10.1249/MSS.0000000000002116>

Cancer Facts & Figures 2022. (1930). 80.

- Cella, D. F., Tulskey, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., Silberman, M., Yellen, S. B., Winicour, P., & Brannon, J. (1993). The Functional Assessment of Cancer Therapy scale: Development and validation of the general measure. *Journal of Clinical Oncology*, *11*(3), 570–579. <https://doi.org/10.1200/JCO.1993.11.3.570>
- Chen, B. P., Awasthi, R., Sweet, S. N., Minnella, E. M., Bergdahl, A., Santa Mina, D., Carli, F., & Scheede-Bergdahl, C. (2017). Four-week prehabilitation program is sufficient to modify exercise behaviors and improve preoperative functional walking capacity in patients with colorectal cancer. *Supportive Care in Cancer*, *25*(1), 33–40. <https://doi.org/10.1007/s00520-016-3379-8>
- Cronin, D. P., Harlan, L. C., Potosky, A. L., Clegg, L. X., Stevens, J. L., & Mooney, M. M. (2006). Patterns of care for adjuvant therapy in a random population-based sample of patients diagnosed with colorectal cancer. *The American Journal of Gastroenterology*, *101*(10), 2308–2318. <https://doi.org/10.1111/j.1572-0241.2006.00775.x>
- Du, X. L., Lin, C. C., Johnson, N. J., & Altekruse, S. (2011). Effects of Individual-Level Socioeconomic Factors on Racial Disparities in Cancer Treatment and Survival: Findings from the National Longitudinal Mortality Study, 1979–2003. *Cancer*, *117*(14), 3242–3251. <https://doi.org/10.1002/cncr.25854>
- Garcia, D. O., & Thomson, C. A. (2014). Physical Activity and Cancer Survivorship. *Nutrition in Clinical Practice : Official Publication of the American Society for Parenteral and Enteral Nutrition*, *29*(6), 768–779. <https://doi.org/10.1177/0884533614551969>
- Godin, G., & Shephard, R. J. (1985). A simple method to assess exercise behavior in the community. *Canadian Journal of Applied Sport Sciences. Journal Canadien Des Sciences Appliquees Au Sport*, *10*(3), 141–146.

- Grønberg, B. H., Sundstrøm, S., Kaasa, S., Bremnes, R. M., Fløtten, Ø., Amundsen, T., Hjelde, H. H., Plessen, C. von, & Jordhøy, M. (2010). Influence of comorbidity on survival, toxicity and health-related quality of life in patients with advanced non-small-cell lung cancer receiving platinum-doublet chemotherapy. *European Journal of Cancer, 46*(12), 2225–2234. <https://doi.org/10.1016/j.ejca.2010.04.009>
- Gross, C. P., McAvay, G. J., Guo, Z., & Tinetti, M. E. (2007). The impact of chronic illnesses on the use and effectiveness of adjuvant chemotherapy for colon cancer. *Cancer, 109*(12), 2410–2419. <https://doi.org/10.1002/cncr.22726>
- Halbert, C. H., Weathers, B., Esteve, R., Audrain-McGovern, J., Kumanyika, S., DeMichele, A., & Barg, F. (2008). Experiences with weight change in African-American breast cancer survivors. *The Breast Journal, 14*(2), 182–187. <https://doi.org/10.1111/j.1524-4741.2007.00551.x>
- Hilfiker, R., Meichtry, A., Eicher, M., Nilsson Balfe, L., Knols, R. H., Verra, M. L., & Taeymans, J. (2018). Exercise and other non-pharmaceutical interventions for cancer-related fatigue in patients during or after cancer treatment: A systematic review incorporating an indirect-comparisons meta-analysis. *British Journal of Sports Medicine, 52*(10), 651–658. <https://doi.org/10.1136/bjsports-2016-096422>
- Houterman, S., Janssen-Heijnen, M. L. G., Verheij, C. D. G. W., Louwman, W. J., Vreugdenhil, G., van der Sangen, M. J. C., & Coebergh, J. W. W. (2004). Comorbidity has negligible impact on treatment and complications but influences survival in breast cancer patients. *British Journal of Cancer, 90*(12), 2332–2337. <https://doi.org/10.1038/sj.bjc.6601844>
- Iwelunmor, J., Newsome, V., & Airhihenbuwa, C. O. (2014). Framing the impact of culture on health: A systematic review of the PEN-3 cultural model and its application in

public health research and interventions. *Ethnicity & Health*, 19(1), 20–46.

<https://doi.org/10.1080/13557858.2013.857768>

Janssen-Heijnen, M. L. G., Houterman, S., Lemmens, V. E. P. P., Louwman, M. W. J., Maas, H. A. A. M., & Coebergh, J. W. W. (2005). Prognostic impact of increasing age and co-morbidity in cancer patients: A population-based approach. *Critical Reviews in Oncology/Hematology*, 55(3), 231–240.

<https://doi.org/10.1016/j.critrevonc.2005.04.008>

Kiderlen, M., de Glas, N. A., Bastiaannet, E., Engels, C. C., van de Water, W., de Craen, A. J. M., Portielje, J. E. A., van de Velde, C. J. H., & Liefers, G. J. (2013). Diabetes in relation to breast cancer relapse and all-cause mortality in elderly breast cancer patients: A FOCUS study analysis. *Annals of Oncology*, 24(12), 3011–3016.

<https://doi.org/10.1093/annonc/mdt367>

Kish, J. K., Yu, M., Percy-Laurry, A., & Altekruse, S. F. (2014). Racial and Ethnic Disparities in Cancer Survival by Neighborhood Socioeconomic Status in Surveillance, Epidemiology, and End Results (SEER) Registries. *Journal of the National Cancer Institute. Monographs*, 2014(49), 236–243.

<https://doi.org/10.1093/jncimonographs/lgu020>

Kutner, J. (n.d.). *Patient Age and Cancer Treatment Decisions—Kutner—2000—Cancer Practice—Wiley Online Library*. Retrieved April 2, 2022, from <https://onlinelibrary-wiley-com.ezproxy.library.dal.ca/doi/abs/10.1046/j.1523-5394.2000.83004.x?sid=nlm%3Apubmed>

Lahart, I. M., Metsios, G. S., Nevill, A. M., & Carmichael, A. R. (2018). Physical activity for women with breast cancer after adjuvant therapy. *The Cochrane Database of Systematic Reviews*, 1, CD011292. <https://doi.org/10.1002/14651858.CD011292.pub2>

- Lee, L., Cheung, W. Y., Atkinson, E., & Krzyzanowska, M. K. (2011). Impact of Comorbidity on Chemotherapy Use and Outcomes in Solid Tumors: A Systematic Review. *Journal of Clinical Oncology*, *29*(1), 106–117.
<https://doi.org/10.1200/JCO.2010.31.3049>
- Lemmens, V. E. P. P., Janssen-Heijnen, M. L. G., Verheij, C. D. G. W., Houterman, S., Repelaer van Driel, O. J., & Coebergh, J. W. W. (2005). Co-morbidity leads to altered treatment and worse survival of elderly patients with colorectal cancer. *The British Journal of Surgery*, *92*(5), 615–623. <https://doi.org/10.1002/bjs.4913>
- Li, C.-C., Matthews, A. K., Dossaji, M., & Fullam, F. (2017). The Relationship of Patient–Provider Communication on Quality of Life among African-American and White Cancer Survivors. *Journal of Health Communication*, *22*(7), 584–592.
<https://doi.org/10.1080/10810730.2017.1324540>
- Ma, R., Yi, B., Riker, A. I., & Xi, Y. (2020). Metformin and cancer immunity. *Acta Pharmacologica Sinica*, *41*(11), 1403–1409. <https://doi.org/10.1038/s41401-020-00508-0>
- McTiernan, A., Friedenreich, C. M., Katzmarzyk, P. T., Powell, K. E., Macko, R., Buchner, D., Pescatello, L. S., Bloodgood, B., Tennant, B., Vaux-Bjerke, A., George, S. M., Troiano, R. P., & Piercy, K. L. (2019). Physical Activity in Cancer Prevention and Survival: A Systematic Review. *Medicine and Science in Sports and Exercise*, *51*(6), 1252–1261. <https://doi.org/10.1249/MSS.0000000000001937>
- Mustian, K. M., Alfano, C. M., Heckler, C., Kleckner, A. S., Kleckner, I. R., Leach, C. R., Mohr, D., Palesh, O. G., Peppone, L. J., Piper, B. F., Scarpato, J., Smith, T., Sprod, L. K., & Miller, S. M. (2017). Comparison of Pharmaceutical, Psychological, and Exercise Treatments for Cancer-Related Fatigue: A Meta-analysis. *JAMA Oncology*, *3*(7), 961–968. <https://doi.org/10.1001/jamaoncol.2016.6914>

- Newcomb, P. A., & Carbone, P. P. (1993). Cancer Treatment and Age: Patient Perspectives. *JNCI: Journal of the National Cancer Institute*, *85*(19), 1580–1584.
<https://doi.org/10.1093/jnci/85.19.1580>
- Paxton, R. J., Phillips, K. L., Jones, L. A., Chang, S., Taylor, W. C., Courneya, K. S., & Pierce, J. P. (2012). Associations among physical activity, body mass index, and health-related quality of life by race/ethnicity in a diverse sample of breast cancer survivors. *Cancer*, *118*(16), 4024–4031. <https://doi.org/10.1002/cncr.27389>
- Persaud, N. (2019). A national electronic health record for primary care. *Canadian Medical Association Journal*, *191*(2), E28–E29. <https://doi.org/10.1503/cmaj.181647>
- Public Health Agency of Canada. (2011). *Tips to get active: Physical activity tips for ...*
- Puetz, T. W., & Herring, M. P. (2012). Differential effects of exercise on cancer-related fatigue during and following treatment: A meta-analysis. *American Journal of Preventive Medicine*, *43*(2), e1-24. <https://doi.org/10.1016/j.amepre.2012.04.027>
- Ray, A. D., Twarozek, A. M., Williams, B. T., Erwin, D. O., Underwood, W., & Mahoney, M. C. (2018). Exercise in African American and White Colorectal Cancer Survivors: A Mixed Methods Approach. *Rehabilitation Oncology (American Physical Therapy Association. Oncology Section)*, *36*(4), 188–197.
<https://doi.org/10.1097/01.REO.00000000000000125>
- Robbins, A. S., Siegel, R. L., & Jemal, A. (2012). Racial Disparities in Stage-Specific Colorectal Cancer Mortality Rates From 1985 to 2008. *Journal of Clinical Oncology*, *30*(4), 401–405. <https://doi.org/10.1200/JCO.2011.37.5527>
- Santa Mina, D., van Rooijen, S. J., Minnella, E. M., Alibhai, S. M. H., Brahmabhatt, P., Dalton, S. O., Gillis, C., Grocott, M. P. W., Howell, D., Randall, I. M., Sabiston, C. M., Silver, J. K., Slooter, G., West, M., Jack, S., & Carli, F. (2020). Multiphasic Prehabilitation Across the Cancer Continuum: A Narrative Review and Conceptual

Framework. *Frontiers in Oncology*, *10*, 598425.

<https://doi.org/10.3389/fonc.2020.598425>

Saraei, P., Asadi, I., Kakar, M. A., & Moradi-Kor, N. (2019). The beneficial effects of metformin on cancer prevention and therapy: A comprehensive review of recent advances. *Cancer Management and Research*, *11*, 3295–3313.

<https://doi.org/10.2147/CMAR.S200059>

Sarfati, D., Koczwara, B., & Jackson, C. (2016). The impact of comorbidity on cancer and its treatment. *CA: A Cancer Journal for Clinicians*, *66*(4), 337–350.

<https://doi.org/10.3322/caac.21342>

Silver, J. K., & Baima, J. (2013). Cancer prehabilitation: An opportunity to decrease treatment-related morbidity, increase cancer treatment options, and improve physical and psychological health outcomes. *American Journal of Physical Medicine & Rehabilitation*, *92*(8), 715–727. <https://doi.org/10.1097/PHM.0b013e31829b4afe>

Singh, G. K., & Jemal, A. (2017). Socioeconomic and Racial/Ethnic Disparities in Cancer Mortality, Incidence, and Survival in the United States, 1950–2014: Over Six Decades of Changing Patterns and Widening Inequalities. *Journal of Environmental and Public Health*, *2017*. <https://doi.org/10.1155/2017/2819372>

Tammemagi, C. M. (2005). Comorbidity and Survival Disparities Among Black and White Patients With Breast Cancer. *JAMA*, *294*(14), 1765.

<https://doi.org/10.1001/jama.294.14.1765>

The ENRICH Project | Exploring Toxic Legacies in Mi'kmaq and African Nova Scotian Communities. (n.d.). Retrieved June 22, 2022, from <https://www.enrichproject.org/>

Tian, L., Lu, H. J., Lin, L., & Hu, Y. (2016). Effects of aerobic exercise on cancer-related fatigue: A meta-analysis of randomized controlled trials. *Supportive Care in Cancer*:

Official Journal of the Multinational Association of Supportive Care in Cancer, 24(2), 969–983. <https://doi.org/10.1007/s00520-015-2953-9>

- Tomlinson, D., Diorio, C., Beyene, J., & Sung, L. (2014). Effect of Exercise on Cancer-Related Fatigue: A Meta-analysis. *American Journal of Physical Medicine & Rehabilitation*, 93(8), 675–686. <https://doi.org/10.1097/PHM.0000000000000083>
- Tran, Y., Lamprell, K., Nic Giolla Easpaig, B., Arnolda, G., & Braithwaite, J. (2019). What information do patients want across their cancer journeys? A network analysis of cancer patients' information needs. *Cancer Medicine*, 8(1), 155–164. <https://doi.org/10.1002/cam4.1915>
- Van Vulpen, J. K., Sweegers, M. G., Peeters, P. H. M., Courneya, K. S., Newton, R. U., Aaronson, N. K., Jacobsen, P. B., Galvao, D. A., Chinapaw, M. J., Steindorf, K., Irwin, M. L., Stuiver, M. M., Hayes, S., Griffith, K. A., Mesters, I., Knoop, H., Goedendorp, M. M., Mutrie, N., Daley, A. J., ... Buffart, L. M. (2020). Moderators of Exercise Effects on Cancer-related Fatigue: A Meta-analysis of Individual Patient Data. *Medicine & Science in Sports & Exercise*, 52(2), 303–314. <https://doi.org/10.1249/MSS.00000000000002154>
- Wang, X. S., Zhao, F., Fisch, M. J., O'Mara, A. M., Cella, D., Mendoza, T. R., & Cleeland, C. S. (2014). Prevalence and characteristics of moderate-to-severe fatigue: A multicenter study in cancer patients and survivors. *Cancer*, 120(3), 425–432. <https://doi.org/10.1002/cncr.28434>
- Warburton, D. E. R., Gledhill, N., Jamnik, V. K., Bredin, S. S. D., McKenzie, D. C., Stone, J., Charlesworth, S., & Shephard, R. J. (2011). Evidence-based risk assessment and recommendations for physical activity clearance: Consensus Document 2011 ¹ This paper is one of a selection of papers published in this Special Issue, entitled Evidence-based risk assessment and recommendations for physical activity clearance, and has

undergone the Journal's usual peer review process. *Applied Physiology, Nutrition, and Metabolism*, 36(S1), S266–S298. <https://doi.org/10.1139/h11-062>

Webster, K., Cella, D., & Yost, K. (2003). The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: Properties, applications, and interpretation. *Health and Quality of Life Outcomes*, 1, 79. <https://doi.org/10.1186/1477-7525-1-79>

Zyzniewska-Banaszak, E., Kucharska-Mazur, J., & Mazur, A. (2021). Physiotherapy and Physical Activity as Factors Improving the Psychological State of Patients With Cancer. *Frontiers in Psychiatry*, 12, 772694. <https://doi.org/10.3389/fpsy.2021.772694>

Appendix A: Online Survey Questionnaires

Questionnaire

Screening Questions

1. Do you identify as a person of African descent? (African, African Nova Scotian, African Canadian, Black, Caribbean?) Yes No
 - a. If yes, go to #2
 - b. If no, we thank you for your interest, but you are not eligible to participate in this study.

2. Which do you identify with the most?
 - African
 - African Nova Scotian
 - African Canadian
 - Caribbean
 - Black
 - Other (please specify):

3. Are you 19 years of age or older? Yes No
 - a. If yes, go to question #3
 - b. If no, we thank you for your interest, but you are not eligible to participate in this study

4. Have you ever had a cancer diagnosis? Yes No
 - a. If yes, proceed to Informed Consent document

- b. If no, we thank you for your interest, but you are not eligible to participate in this study

***Informed Consent Form

GETTING TO KNOW YOU

The information within this section is needed to help understand the characteristics of the people participating in this study. For this reason, it is very important information. **Be assured that it will remain confidential**

1. Current age (years):

2. Where do you currently live?

Cherry Brook

East Preston

Lake Loon

North Preston

Other (please specify):

Prefer not to say

3. Which gender identity do you most identify?

Female

- Male
- Transgender Female
- Transgender Male
- Prefer to self-describe:
- Prefer not to answer

4. What is the highest degree or level of education you have completed?

- Highschool (or less)
- Trade, technical or vocational school
- Diploma from a community college or non-university certificate
- University certificate below Bachelor's level
- Bachelor's degree
- Graduate degree (MSc, MBA, MD, PhD, etc.)
- Prefer not to answer

5. What is your employment status? (tick the box that best describes you):

- Full-time Self-employed Unemployed Retired Part-time

Homemaker

- On disability leave Doing unpaid or volunteer work Student

6. The next question asks about your household income. We understand that this information is very private, but the question is important as it helps us to understand whether the study includes a wide variety of participants. All answers will be kept anonymous and strictly confidential. Which category best describes the total income of all household members, before taxes, for last year?

- Less than \$24,999
- \$25,000-\$49,999
- \$50,000-\$74,999
- \$75,000-\$99,999
- \$100,000-\$149,999
- \$150,000-\$199,999
- \$200,000 or more
- Don't know
- Prefer not to answer

7. How would you rate your general health overall?

- Excellent
- Very good
- Good
- Fair
- Poor
- Prefer not to answer

CANCER HISTORY

What type of cancer were you diagnosed with (select all that apply)?

- Bladder
- Brain/Central Nervous System
- Breast
- Cervix
- Colorectal
- Hodgkin's Lymphoma
- Kidney
- Leukemia
- Liver
- Lung
- Melanoma
- Multiple myeloma
- Non-Hodgkin's Lymphoma
- Oral
- Ovarian
- Pancreas
- Prostate
- Uterine
- Other (please specify):

How old were you when you were first diagnosed with cancer? (age in years):

Are you currently receiving cancer treatment: Yes No

Please indicate which treatments you are currently receiving or have received in the past
(select all that apply):

Chemotherapy

Radiation therapy

Hormone therapy

Biological therapy

No treatment

Denied treatment

Other (please specify):

Don't know

Do you currently have any other chronic medical conditions? Yes No

If yes, what health conditions are you currently living with (select all that apply):

- Arthritis

- Chronic obstructive pulmonary disease (COPD)

- Diabetes

- Heart disease

- Hypertension

- Mood and/or anxiety disorder

- Stroke

- Other (please specify):

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

Please circle or mark one number per line to indicate your response as it applies to the past 7 days. If you feel that an item is not applicable, please select “Not at all”.

PHYSICAL WELL-BEING		Not at all	A little bit	Some -what a bit	Quite a bit	Very much
		0	1	2	3	4
G	I have a lack of energy	0	1	2	3	4
P						
1						
G	I have nausea	0	1	2	3	4
P						
2						
G	Because of my physical condition, I have trouble meeting					
P	the needs of my family	0	1	2	3	4
3						
G	I have pain	0	1	2	3	4
P						
4						
G	I am bothered by side effects of treatment	0	1	2	3	4
P						
5						

G	I feel ill	0	1	2	3	4
P						
6						
G	I am forced to spend time in bed	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING

		Not at all	A little bit	Some -what	Quite a bit	Very much
G	I feel close to my friends	0	1	2	3	4
S						
1						
G	I get emotional support from my family	0	1	2	3	4
S						
2						
G	I get support from my friends	0	1	2	3	4
S						
3						
G	My family has accepted my illness	0	1	2	3	4
S						
4						
G	I am satisfied with family communication about my illness	0	1	2	3	4
S						
5						

G	I feel close to my partner (or the person who is my main					
S	support)	0	1	2	3	4
6						
Q	Regardless of your current level of sexual activity, please					
1	answer the following question. If you prefer not to answer					
	<input type="checkbox"/>					
G	I am satisfied with my sex life	0	1	2	3	4

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

EMOTIONAL WELL-BEING		Not	A little	Some	Quite	Very
		at all	bit	-what	a bit	much
		0	1	2	3	4
G	I feel sad					
E						
1						
G	I am satisfied with how I am coping with my illness	0	1	2	3	4
E						
2						
G	I am losing hope in the fight against my illness	0	1	2	3	4
E						
3						

G	I feel nervous	0	1	2	3	4
E						
4						
G	I worry about dying	0	1	2	3	4
E						
5						
G	I worry that my condition will get worse	0	1	2	3	4

FUNCTIONAL WELL-BEING

		Not at all	A little bit	Some -what	Quite a bit	Very much
G	I am able to work (include work at home)	0	1	2	3	4
F						
1						
G	My work (include work at home) is fulfilling	0	1	2	3	4
F						
2						
G	I am able to enjoy life	0	1	2	3	4
F						
3						

G	I have accepted my illness	0	1	2	3	4
F						
4						
G	I am sleeping well	0	1	2	3	4
F						
5						
G	I am enjoying the things I usually do for fun	0	1	2	3	4
F						
6						
G	I am content with the quality of my life right now	0	1	2	3	4

Physical Activity & Exercise

The following section of this survey will ask you to recall your *average* weekly level of physical activity over the *last 7 days*. Please include *all* exercise/physical activity that you do.

Godin Leisure-Time Exercise Questionnaire

1. During a typical **7-Day period** (a week), **how many times** on the average do you do the following kinds of exercise for **and for how long** during your free time (write on each line the appropriate number).

Frequency

Time in

a) 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)

MODERATE EXERCISE

(NOT EXHAUSTING) _____

(e.g., fast walking, baseball, tennis, easy bicycling,

volleyball, badminton, easy swimming, alpine skiing,

popular and folk dancing)

b) MILD EXERCISE

(MINIMAL EFFORT) _____

(e.g., yoga, archery, fishing from river bank, bowling,

horseshoes, golf, snow-mobiling, easy walking)

Exercise and Physical Activity Beliefs

In this section we want to explore your current beliefs surrounding physical activity and exercise. Please answer all to the best of your abilities, there are no wrong or right answers.

Behavioral Beliefs

As an individual living with cancer, what do you believe are the advantages/benefits of being physically active? List your top 5 advantages below:

- a. _____
- b. _____
- c. _____
- d. _____
- e. _____

As an individual living with cancer, what do you believe are the disadvantages/potential harms of being physically active? List your top 5 disadvantages/harms below:

- a. _____
- b. _____
- c. _____
- d. _____
- e. _____

Normative Beliefs

Since your cancer diagnosis, who are the most important individuals or groups in supporting you in getting/staying physically active (e.g., spouse, physician, fitness professional, children etc.)?

- a. _____
- b. _____
- c. _____
- d. _____

e. _____

Since your cancer diagnosis, are there any individuals or groups that would disapprove of your getting/staying physically active?

- a. _____
- b. _____
- c. _____
- d. _____
- e. _____

Barriers and Facilitators

In this section we want to explore your current barriers and facilitators to participating in physical activity.

The following are common barriers to physical activity (i.e., factors or circumstances that make being physically active difficult or impossible). Please indicate which of the following barriers that prevent you from being active.

Barrier	Not at all	A little bit	Somewhat	Quite a bit	Very much
Lack of self-discipline	1	2	3	4	5
Lack of time	1	2	3	4	5
Lack of energy/too tired	1	2	3	4	5
Lack of interest/motivation	1	2	3	4	5
Lack of company/activity buddy	1	2	3	4	5
Lack of enjoyment	1	2	3	4	5
Discouragement	1	2	3	4	5

Lack of equipment	1	2	3	4	5
Poor weather	1	2	3	4	5
Lack of skills	1	2	3	4	5
Lack of facilities or space	1	2	3	4	5
Lack of knowledge of how to exercise	1	2	3	4	5
Lack of good health	1	2	3	4	5
Lack of confidence	1	2	3	4	5
Fear of injury	1	2	3	4	5
Effects of cancer treatment	1	2	3	4	5
Cost	1	2	3	4	5
Family responsibilities	1	2	3	4	5

Lack of transportation	1	2	3	4	5
Other (please specify)	1	2	3	4	5
Other (please specify)	1	2	3	4	5

The following are common facilitators that help overcome barriers to physical activity. Please indicate which of the following enable you to get and remain active.

Facilitator	Not at all	A little bit	Somewhat	Quite a bit	Very much
Good for my health	1	2	3	4	5
Improved fitness	1	2	3	4	5
Less tired/more energy	1	2	3	4	5
Family/friend support	1	2	3	4	5

Belonging to a group of other individuals living with a cancer diagnosis	1	2	3	4	5
Belonging to a group of a similar race or ethnic background	1	2	3	4	5
Enjoyment/fun	1	2	3	4	5
Confidence	1	2	3	4	5
Access	1	2	3	4	5
Faith/spirituality	1	2	3	4	5
Other (please specify)	1	2	3	4	5
Other (please specify)	1	2	3	4	5

Exercise Preferences

Please read the following questions and select a box that best represents your preferences.

Are you interested in participating in an exercise program tailored to individuals of ABC descent living with a cancer diagnosis?

Yes No Not sure

Do you feel you could take part in an individually tailored, group-based exercise program?

Yes No Not sure

What type of activities/exercise would you be most interested in?

Walking Strength/resistance exercises Flexibility exercises Aerobic exercises

Other (please specify): No preference

What intensity (how hard) would you like to exercise at?

Light Moderate Light-to-moderate Moderate-to-vigorous Vigorous No preference

How often would you be interested in attending an exercise program?

- Once a week
- Twice a week
- Three times a week
- More than three times a week
- No preference

What time of day would you prefer to have an exercise program?

- Morning
- Afternoon
- Morning or afternoon
- Evening
- No preference

Who would you prefer to exercise with?

- Alone
- Other cancer survivors of ABC descent
- Other cancer survivors (general public)
- General public
- Family
- Friends

No preference

Other (please specify):

Who would you like your exercise program to be delivered by:

Physiotherapist of ABC descent

Physiotherapist (general public)

Trained fitness professional of ABC descent

Trained fitness professional (general public)

Other health care professional of ABC descent

Other health care professional (general public)

No preference

Other (please specify):

Where would you prefer that the exercise program take place?

Home

Cancer center

Community center

No preference

Other (please specify):

Who would you like to receive information on available exercise programs for individuals of ABC descent living with cancer?

- Oncologist
- Nurse
- Physiotherapist
- Family physician
- Other health care professional
- No preference
- Other (please specify):

Are you currently aware of any community exercise programs for individuals living with a cancer diagnosis in your area?

- Yes No

If yes, how/where did you learn about the program(s)?

If no, how would you like to be informed about these types of programs (e.g., mail, flyer, social media, health care professional, etc.)

We thank you for taking the time to complete this survey.

Appendix B: Semi-structured interview guide

Semi-structured interview guide

Introduction: Hello, my name is Joy Chiekwe and I want to thank you for taking the time to met with me today. As a reminder, I am interested in learning more about your preferences and facilitators relating to being physically active and exercising with a cancer diagnosis. I am also interested in learning about if there any potential barriers and if there are ways to improve your barriers to physical activity and exercise at any level. Participants in this study all identify as African, Black or Caribbean and reside in Nova Scotia and have all been diagnosed with cancer.

As a Black health professional and someone who works with cancer patients and survivors every day, I have become interested in exploring the views and beliefs of ABC patients regarding exercise as a means of managing the impact of a cancer diagnosis on quality of life.

Section 1: Background

1. What community do you currently reside in?
2. How many years have you been there?
3. Cancer Dx
4. Month and year of Cancer Dx
5. Cancer treatment history

Section 2: Exploring PA and exercise knowledge

1. Can you describe to me in your own words what PA means to you? Is it the same as exercise?
2. Are you aware of the benefits of PA on your overall health? Can you list 3 benefits.

3. Has a HCP ever told you about the benefits of PA after a cancer diagnosis? What did they say?
4. How much PA and exercise should someone do each day? In a week?

Section 3: Barriers and facilitator to PA and exercise

1. Is it easy to be physically active in your neighborhood? What makes it easy? What makes it hard?
2. Are there any groups or programs in your neighborhood that promote health and PA?
 - a. If no, do you think you would participate if there were programs?
 - b. If yes, do you participate?
3. Has your cancer diagnosis impacted your view on being physically active and exercise? How so?

Section 4: Exercise trials

1. Would you be more inclined to exercise if there was an exercise program for cancer patients/survivors? Why or why not?

Thank you for taking the time to answer my questions, we are all done. Your answers and suggestions very valued.

Appendix C: Amended Online Consent

RMU2021_058R - preferences, barriers and facilitators to exercise ABC cancer survivors

Page 1

Noninterventional Consent 2

Record ID

STUDY TITLE: Exercise preferences, barriers and facilitators to exercise in cancer survivors of African, Black, and Caribbean descent: A mixed-methods approach

PRINCIPAL INVESTIGATOR: C. Joy Chiekwe, Dalhousie University, School of Health and Human Performance, 6230 South St, 902-473-2035

NS HEALTH REB FILE NUMBER: 1027043, **Version 4, January 27 2022**

1. Introduction

You have been invited to take part in a research study being conducted by Joy Chiekwe, a Masters student at Dalhousie University. A research study is a way of gathering information on a treatment, procedure or medical device or to answer a question about something that is not well understood. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study. You may take as much time as you wish to decide whether or not to participate. Feel free to discuss it with your friends and family, family doctor, or health care provider.

Please ask the research team or the principal investigator to clarify anything you do not understand or would like to know more about. Make sure all your questions are answered to your satisfaction before deciding whether to participate in this research study.

The researchers will:

- Discuss the study with you
- Answer your questions
- Be available during the study to deal with problems and answer questions

You are being asked to consider participating in this study because you are a cancer patient/survivor of African, Black and/or Caribbean (ABC) descent. If you decide not to take part or if you leave the study early, your cancer treatment and/or your usual health care will not be affected.

In addition, at the end of the survey, you will be asked the following things:

- Submit your contact information in order to be entered into a draw for Sportcheck gift cards and a fitness consultation.

- Permission to contact you at a later date to participate in an interview and/or focus groups.

Your contact information will not be linked to your survey results and will be destroyed after the prize draw/ after the interview/focus groups.

Providing your contact information is completely voluntary and is not required to participate in this survey.

This study is voluntary. I do not have to take part or can leave the study at any time and my usual health care will not be affected.

- True
 False

TRUE: You do not have to take part in this study

- Continue
 No thanks, I am not interested

2. Why Is There A Need For This Study?

Cancer remains the leading cause of death among Canadians, however the extent of cancer burden for patients/survivors of ABC descent is unclear because Canadian cancer statistics are not yet stratified by ethnicity/race. Despite the improvements in treatment therapies and improved survival rates, cancer survivors of ABC descent in the United States have the lowest survival rate of any racial or ethnic group for most cancers.

It is well known that exercise and physical activity have many benefits on the overall quality of life of the general population. It is also known that those diagnosed with cancer and long into survivorship benefit by being physically active. These benefits include improvements of mental health, physical function, as well as increase in survival.

Although these benefits are clear, the enrolment of ABC cancer survivors in physical activity and exercise programs is low and there is a need for tailored approaches to increase enrolment in exercise trials in Canada. Therefore, the purpose of this study is to explore the attitudes, beliefs, barriers, and facilitators to exercise in cancer patients and survivors of ABC descent in Canada.

3. How Long Will I Be In The Study?

Your participation in this study will last approximately 30 minutes to 1.5 hours depending on what you choose to participate in.

4. How Many People Will Take Part In This Study?

It is anticipated that about 100-200 people will participate in the online survey. However, the survey will remain open for 2 months allowing as many individuals who may wish to participate time to complete the survey. Between 8-12 participants who complete the survey will also be invited to take part in a telephone/video conference interview.

5. How Is The Study Being Done?

Adult (19 years of age and older) cancer patients and survivors who self-identify as either African, Black or Caribbean and currently **reside in Canada** will be recruited through various platforms to participate in this study. Once you have been screened and consent to participate, a member of the research team will send you a link to an online survey through a confidential database called REDCap where you will be asked to acknowledge your consent to participate.

Upon completion of the survey, you will be asked if you would be willing to participate in an individual interview. If you choose to participate, a member of the research team will contact you to set up an interview time.

6. What Will Happen If I Take Part In This Study?

If you consent to participate in this study, you will be asked to complete several surveys (e.g., knowledge of exercise, current exercise behaviours, activity preferences, quality of life, etc.) and provide basic information about yourself (e.g., age, sex, occupation, household income, brief cancer and health history). It will take approximately 20-35 minutes to complete the online surveys. You may skip any questions that you are uncomfortable answering. You can complete the survey through a secure web-based application known as REDCap. REDCap is an application designed exclusively to support data capture for research studies and is licensed to Nova Scotia Health (NSH). The application and data are housed on secure servers located at NSH. All web-based information transmission is encrypted.

If you agree to participate in an interview, you will be asked to answer additional questions about potential barriers and facilitators to exercising in your community. This will be done at another time and may take up to 1.5 hours.

Similar to the online surveys, you may skip any questions that you are uncomfortable answering.

7. Are There Risks To The Study?

You will be asked to complete an online survey. The survey will ask you questions about your knowledge of benefits of physical activity, barriers and facilitators to exercising, lifestyle behaviors (e.g., physical activity) and overall quality of life. If you are uncomfortable in responding to any of these questions you can leave them blank, refuse to answer, or you are free to withdraw from the study at any time without penalty. You will be told about any new information that might reasonably affect your willingness to continue to participate in this study as soon as the information becomes available to the research team.

8. Are There Benefits Of Participating In This Study?

You may or may not benefit directly from this study. Potential benefits include the collection of raced-based data within oncology care to improve underrepresentation in exercise oncology trials. Your participation also may or may not help the design of an exercise program tailored to African, Black and Caribbean cancer patients/survivors.

I might not benefit from this research but my contribution may benefit others in the future.

- T
 r
 u
 e
 F
 a
 l
 s
 e

9. What Happens at the End of the Study?

If you would like a summary of the results, please notify the research team and a summary will be mailed or emailed to you upon completion of the study. It is anticipated that the results of this study will be published and or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

10. What Are My Responsibilities?

As a participant of the study you will be expected to read the consent form and complete the online survey. You will also have the option of completing a one-time interview.

11. Can My Participation in this Study End Early?

The Nova Scotia Health (NSH) Research Ethics Board (REB) and the principal investigator have the right to stop patient recruitment or cancel the study at any time.

You can also choose to end your participation at any time. If you choose to withdraw from this study by informing the research team, your decision will have no effect on your current or future medical treatment and healthcare.

If you withdraw your consent, the information about you that was collected before you left the

study will still be used. No new information about you will be collected without your permission. If you

to



withdraw from the study, please inform the research team.

Once I submit this consent form, I can't withdraw or be removed from the study.

- True
 False

You may stop taking part in the study at any time.

- Continue
 No thanks, I am not interested

12. Will It Cost Me Anything?

It will not cost you anything to participate. Participants will be offered an opportunity to enter a one-time draw for one of two \$50 Sport Check gift cards and a free one-on-one personal training consultation (\$150 value) with Ms. Joy Chiekwe, Clinical Exercise Physiologist. The draw will be made upon the closing of the online survey.

Research Related Injury

If you become injured (privacy breach) as a direct result of allowing access to your information the following will apply. Your completion of this form indicates that you have understood to your satisfaction the information regarding your participation in this research study. In no way does this waive your legal rights nor release the principal investigator, the research team, the study sponsor or involved institutions from their legal and professional responsibilities.

13. What About My Privacy and Confidentiality

Protecting your privacy is an important part of this study and every effort to protect your privacy will be made. To help protect your privacy, we will not keep your name on any study data. Instead, we will use a unique study identifier. If the results of this study are presented to the public, nobody will be able to tell that you were in the study. However, complete privacy cannot be guaranteed. For example, the principal investigator may be required by law to allow access to research records.

When the study is published, people will know I was a part of the study.

- True
 False

14. Declaration of Financial Interest

This study is unfunded. The Principal Investigator has no vested financial interest in conducting this study.

15. What About Questions or Problems?

For further information about the study you may call the Principal Investigator who is the person in charge of this study and/or any other research team member listed below.

Joy Chiekwe, Clinical Exercise Physiologist, MSc Student joy.chiekwe@dal.ca

16. What Are My Rights?

You have the right to all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study and your rights as a research participant, and to have them answered to your satisfaction before you make any decision. You also have the right to ask questions and to receive answers throughout this study. You have the right to withdraw your consent at any time.

If you have questions about your rights as a research participant, and/or concerns or complaints about this research study, you can contact:

The Nova Scotia Health Research Ethics Board manager (cell:902-222-9263; email:ResearchEthics@nshealth.ca) Patient Relations at (902) 473-2133 or 1-855-799-0990 or healthcareexperience@nshealth.ca.

In the next part you will be asked if you agree (consent) to join this study. If the answer is "yes", please submit the form.

17. Consent

The NS Health REB advises that the PI sign the consent form within a two week period from the date that the patient consented so that the PI is aware that a particular patient is interested in participating in the study.

I have reviewed all of the information in this consent form related to the study called:

Exercise preferences, barriers and facilitators to exercise in cancer survivors or African, Black, and Caribbean descent: A mixed-methods approach.

And I have been given the opportunity to discuss this study with a research team member. All of my questions have been answered to my satisfaction.

D
 i
s
a
g
r
e
e
A
g
r
e
e

By submitting this e-consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time without affecting my future health care.

Date:



Principal Investigator signature:

Signature:

First name:

Last name:

Date:

Appendix D: Online Consent Version 1

Non-Interventional Consent

Please read this consent form

carefully before signing Thank you!

STUDY TITLE: Exercise preferences, barriers and facilitators to exercise in cancer survivors of African, Black, and Caribbean descent: A mixed-methods approach

PRINCIPAL INVESTIGATOR: C. Joy Chiekwe, Dalhousie University, School of Health and Human Performance, 6230 South St, 902-473-2035

NS HEALTH REB FILE NUMBER: 1027043, Version 3 August 27th 2021

1. Introduction

You have been invited to take part in a research study. A research study is a way of gathering information on a treatment, procedure or medical device or to answer a question about something that is not well understood. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study. You may take as much time as you wish to decide whether or not to participate. Feel free to discuss it with your friends and family, family doctor, or health care provider.

Please ask the research team or the principal investigator to clarify anything you do not understand or would like to know more about. Make sure all your questions are answered to your satisfaction before deciding whether to participate in this research study.

The researchers will:

- Discuss the study with you
- Answer your questions
- Be available during the study to deal with problems and answer questions.

You are being asked to consider participating in this study because you are a cancer patient/survivor of African, Black and/or Caribbean (ABC) descent. If you decide not to take part or if you leave the study early, your cancer treatment and/or your usual health care will not be affected.

This study is voluntary. I do not have to take part or can leave the study at any time and my usual health care will not be affected.



T
r
u
e
F
a
i

s
e

TRUE: You do not have to take part in this study

Continue

No thanks, I am not interested

2. Why Is There A Need For This Study?

Cancer remains the leading cause of death among Canadians, however the extent of cancer burden for patients/survivors of ABC descent is unclear because Canadian cancer statistics are not yet stratified by ethnicity/race. Despite the improvements in treatment therapies and improved survival rates, cancer survivors of ABC descent in the United States have the lowest survival rate of any racial or ethnic group for most cancers.

It is well known that exercise and physical activity have many benefits on the overall quality of life of the general population. It is also known that those diagnosed with cancer and long into survivorship benefit by being physically active. These benefits include improvements of mental health, physical function, as well as increase in survival.

Although these benefits are clear, the enrolment of ABC cancer survivors in physical activity and exercise programs is low and there is a need for tailored approaches to increase enrolment in exercise trials in Nova Scotia. Therefore, the purpose of this study is to explore the attitudes, beliefs, barriers, and facilitators to exercise in cancer patients and survivors of ABC descent in Nova Scotia.

3. How Long Will I Be In The Study?

Your participation in this study will last approximately 2 hours.

4. How Many People Will Take Place In This Study?

It is anticipated that about 100-200 people will participate in the online survey. However, the survey will remain open for 2 months allowing as many individuals who may wish to participate time to complete the survey. Between 8-12 participants who complete the survey will also be invited to take part in a telephone/video conference interview.

5. How Is The Study Being Done?

Adult (19 years of age and older) cancer patients and survivors who self-identify as either African, Black or Caribbean and currently reside in Nova Scotia will be recruited through various platforms to participate in this study. Once you have been screened and consent to participate, a member of the research team will send you a link to an online survey through a confidential database called REDCap where you will be asked to acknowledge your consent to participate.

Upon completion of the survey, you will be asked if you would be willing to participate in an individual interview. If you choose to participate, a member of the research team will contact you to set up an interview time.

6. What Will Happen If I Take Part In This Study?

If you consent to participate in this study, you will be asked to complete several surveys (e.g., knowledge of exercise, current exercise behaviours, activity preferences, quality of life, etc.) and provide basic information about yourself (e.g., age, sex, occupation, household income, brief cancer and health history). It will take approximately 30-45 minutes to complete the online surveys. You may skip any questions that you are uncomfortable answering. You can complete the survey through a secure web-based application known as REDCap. REDCap is an application designed exclusively to support data capture for research studies and is licensed to Nova Scotia Health (NSH). The application and data are housed on secure servers located at NSH. All web-based information transmission is encrypted.

If you agree to participate in an interview, you will be asked to answer additional questions about potential barriers and facilitators to exercising in your community. Similar to the online surveys, you may skip any questions that you are uncomfortable answering.

7. Are There Risks To The Study?

You will be asked to complete an online survey. The survey will ask you questions about your knowledge of benefits of physical activity, barriers and facilitators to exercising, lifestyle behaviors (e.g., physical activity) and overall quality of life. If you are uncomfortable in responding to any of these questions you can leave them blank, refuse to answer, or you are free to withdraw from the study at any time without penalty. You will be told about any new information that might reasonably affect your willingness to continue to participate in this study as soon as the information becomes available to the research team.

8. Are There Benefits Of Participating In This Study?

You may or may not benefit directly from this study. Potential benefits include the collection of raced-based data within oncology care to improve underrepresentation in exercise oncology trials. Your participation also may or may not help the design of an exercise program tailored to African, Black and Caribbean cancer patients/survivors.

I might not benefit from this research but my contribution may benefit others in the future.

- True
- False

9. What Happens at the End of the Study?

If you would like a summary of the results, please notify the research team and a summary will be mailed or emailed to you upon completion of the study. It is anticipated that the results of this study will be published and or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

10. What Are My Responsibilities?

As a participant of the study you will be expected to read and sign the consent form and complete online survey. You will also have the option of completing a one-time interview.

11. Can My Participation in this Study End Early?

The Nova Scotia Health (NSH) Research Ethics Board (REB) and the principal investigator have the right to stop patient recruitment or cancel the study at any time.

You can also choose to end your participation at any time. If you choose to withdraw from this study by informing the research team, your decision will have no effect on your current or future medical treatment and healthcare.

If you withdraw your consent, the information about you that was collected before you left the study will still be used. No new information about you will be collected without your permission. If you chose to withdraw from the study, please inform the research team.

Once this consent form is signed, I can't withdraw or be removed from the study.

- True
 False

FALSE: You may stop taking part in the study at any time.

- Continue
 No thanks, I am not interested

12. Will It Cost Me Anything?

It will not cost you anything to participate. Participants will be offered an opportunity to enter a one-time draw for one of two \$50 Sport Check gift cards and a free one-on-one personal training consultation (\$150 value) with Ms. Joy Chiekwe, Clinical Exercise Physiologist. The draw will be made upon the closing of the online survey.

Research Related Injury

If you become injured (privacy breach) as a direct result of allowing access to your information the following will apply. Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in this research study. In no way does this waive your legal rights nor release the principal investigator, the research team, the study sponsor or involved institutions from their legal and professional responsibilities.

13. What About My Privacy and Confidentiality

Protecting your privacy is an important part of this study and every effort to protect your privacy will be made. To help protect your privacy, we will not keep your name on any study data. Instead, we will use a unique study identifier. If the results of this study are presented to the public, nobody will be able to tell that you were in the study. However, complete privacy cannot be guaranteed. For example, the principal investigator may be required by law to allow access to research records.

When the study is published, people will know I was a part of the study.

- True
- False

14. Declaration of Financial Interest

This study is unfunded. The Principal Investigator has no vested financial interest in conducting this study.

15. What About Questions or Problems?

For further information about the study you may call the Principal Investigator who is the person in charge of this study and/or any other research team member listed below.

Joy Chiekwe, Clinical Exercise Physiologist, MSc Candidate joy.chiekwe@dal.ca

16. What Are My Rights?

You have the right to all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study and your rights as a research participant, and to have them answered to your satisfaction before you make any decision. You also have the right to ask questions and to receive answers throughout this study. You have the right to withdraw your consent at any time.

If you have questions about your rights as a research participant, and/or concerns or complaints about this research study, you can contact:

The Nova Scotia Health Research Ethics Board manager (cell:902-222-9263; email:ResearchEthics@nshealth.ca)
Patient Relations at (902) 473-2133 or 1-855-799-0990 or healthcareexperience@nshealth.ca.

In the next part you will be asked if you agree (consent) to join this study. If the answer is “yes”, please sign the form.

17. Consent And Signatures

The NS Health REB advises that the PI sign the consent form within a two week period from the date that the patient signed the consent form so that the PI is aware that the particular patient is interested in participating in the study.

I have reviewed all of the information in this consent form related to the study called:

Exercise preferences, barriers and facilitators to exercise in cancer survivors or African, Black, and Caribbean descent: A mixed-methods approach.

And I have been given the opportunity to discuss this study with a research team member. All of my questions have been answered to my satisfaction.

- Disagree
 Agree

I authorize access to my personal health information, and research study data as explained in this form

- Yes
 No

Email and texting can be used by a member or members of the research team to communicate with you while you are in this study. All communication you will receive will only be through an NS Health email account (nshealth.ca), or text by a phone issued to a research member through NS Health. All efforts are made to keep information sent or received private, but it is possible other people may be able to see, read, and change messages sent to or from NS Health.

- I give my permission to be contacted by a member or members of the research team from an NS Health Webmail account or an NS Health cell phone by research staff to communicate during this study.
 I do not wish to be contacted by email or text message, unless I otherwise give permission at another time during this study.
 Not applicable

Providing my name, date, electronic signature and submitting this e-consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time without affecting my future health care.

Initial:

Date:

Email:

Phone:

Participant signature:

Signature:

First name:

Last name:

Date:



Principal Investigator signature:

Signature:

First name:

Last name:

Date:

Appendix E: Interview Consent

Non-Interventional Consent

Please read this consent form

carefully before signing Thank you!

STUDY TITLE: Exercise preferences, barriers and facilitators to exercise in cancer survivors of African, Black, and Caribbean descent: A mixed-methods approach

PRINCIPAL INVESTIGATOR: C. Joy Chiekwe, Dalhousie University, School of Health and Human Performance, 6230 South St, 902-473-2035

NS HEALTH REB FILE NUMBER: 1027043, Version1 July 29th 2021

1. Introduction

You have been invited to take part in a research study. A research study is a way of gathering information on a treatment, procedure or medical device or to answer a question about something that is not well understood. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study. You may take as much time as you wish to decide whether or not to participate. Feel free to discuss it with your friends and family, family doctor, or health care provider.

Please ask the research team or the principal investigator to clarify anything you do not understand or would like to know more about. Make sure all your questions are answered to your satisfaction before deciding whether to participate in this research study.

The researchers will:

- Discuss the study with you
- Answer your questions
- Be available during the study to deal with problems and answer questions.

You are being asked to consider participating in this study because you are a cancer patient/survivor of African, Black and/or Caribbean (ABC) descent. If you decide not to take part or if you leave the study early, your cancer treatment and/or your usual health care will not be affected.

This study is voluntary. I do not have to take part or can leave the study at any time and my usual health care will not be affected.



T
r
u
e
F

a
l
s
e

TRUE: You do not have to take part in this study

- Continue
- No thanks, I am not interested

2. Why Is There A Need For This Study?

Cancer remains the leading cause of death among Canadians, however the extent of cancer burden for patients/survivors of ABC descent is unclear because Canadian cancer statistics are not yet stratified by ethnicity/race. Despite the improvements in treatment therapies and improved survival rates, cancer survivors of ABC descent in the United States have the lowest survival rate of any racial or ethnic group for most cancers.

It is well known that exercise and physical activity have many benefits on the overall quality of life of the general population. It is also known that those diagnosed with cancer and long into survivorship benefit by being physically active. These benefits include improvements of mental health, physical function, as well as increase in survival.

Although these benefits are clear, the enrolment of ABC cancer survivors in physical activity and exercise programs is low and there is a need for tailored approaches to increase enrolment in exercise trials in Nova Scotia. Therefore, the purpose of this study is to explore the attitudes, beliefs, barriers, and facilitators to exercise in cancer patients and survivors of ABC descent in Nova Scotia.

3. How Long Will I Be In The Study?

Your participation in this study will last approximately 30 minutes.

4. How Many People Will Take Place In This Study?

Between 8-12 participants who completed the initial survey will also be invited to take part in this telephone/video conference interview.

5. How Is The Study Being Done?

Adult (19 years of age and older) cancer patients and survivors who self-identify as either African, Black or Caribbean and currently reside in Nova Scotia have been recruited through various platforms to participate in this study. Those who have consented to be recontacted to participate in an individual interview will be chosen.

6. What Will Happen If I Take Part In This Study?

You will be asked to answer questions about potential barriers and facilitators to exercising in your community with a cancer diagnosis. Similar to the online surveys, you may skip any questions that you are uncomfortable answering.

7. Are There Risks To The Study?

If you are uncomfortable in responding to any of the questions you can ask to skip to the next one, refuse to answer, or you are free to withdraw from the study at any time without penalty. You will be told about any new information that might reasonably affect your willingness to continue to participate in this study as soon as the information becomes available to the research team.

8. Are There Benefits Of Participating In This Study?

You may or may not benefit directly from this study. Potential benefits include the collection of raced-based data within oncology care to improve underrepresentation in exercise oncology trials. Your participation also may or may not help the design of an exercise program tailored to African, Black and Caribbean cancer patients/survivors.

I might not benefit from this research but my contribution may benefit others in the future.

- True
- False

9. What Happens at the End of the Study?

If you would like a summary of the results, please notify the research team and a summary will be mailed or emailed to you upon completion of the study. It is anticipated that the results of this study will be published and or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

10. What Are My Responsibilities?

As a participant of the study you will be expected to read and sign the consent form and complete the interview to the best of your abilities.

11. Can My Participation in this Study End Early?

The Nova Scotia Health (NSH) Research Ethics Board (REB) and the principal investigator have the right to stop patient recruitment or cancel the study at any time.

You can also choose to end your participation at any time. If you choose to withdraw from this study by informing the research team, your decision will have no effect on your current or future medical treatment and healthcare.

If you withdraw your consent, the information about you that was collected before you left the study will still be used. No new information about you will be collected without your permission. If you chose to withdraw from the study, please inform the research team.

Once this consent form is signed, I can't withdraw or be removed from the study.

- True
 False

FALSE: You may stop taking part in the study at any time.

- Continue
 No thanks, I am not interested

14. Will It Cost Me Anything?

It will not cost you anything to participate. Participants will be offered an opportunity to enter a one-time draw for one of two \$50 Sport Check gift cards and a free one-on-one personal training consultation (\$150 value) with Ms. Joy Chiekwe, Clinical Exercise Physiologist. The draw will be made upon the closing of the online survey.

Research Related Injury

If you become injured (privacy breach) as a direct result of allowing access to your information the following will apply. Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in this research study. In no way does this waive your legal rights nor release the principal investigator, the research team, the study sponsor or involved institutions from their legal and professional responsibilities.

15. What About My Privacy and Confidentiality

Protecting your privacy is an important part of this study and every effort to protect your privacy will be made. To help protect your privacy, we will not keep your name on any study data. Instead, we will use a unique study identifier. If the results of this study are presented to the public, nobody will be able to tell that you were in the study. However, complete privacy cannot be guaranteed. For example, the principal investigator may be required by law to allow access to research records.

When the study is published, people will know I was a part of the study.

- True
- False

16. Declaration of Financial Interest

This study is unfunded. The Principal Investigator has no vested financial interest in conducting this study.

17. What About Questions or Problems?

For further information about the study you may call the Principal Investigator who is the person in charge of this study and/or any other research team member listed below.

Joy Chiekwe, Clinical Exercise Physiologist, MSc Candidate joy.chiekwe@dal.ca

18. What Are My Rights?

You have the right to all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study and your rights as a research participant, and to have them answered to your satisfaction before you make any decision. You also have the right to ask questions and to receive answers throughout this study. You have the right to withdraw your consent at any time.

If you have questions about your rights as a research participant, and/or concerns or complaints about this research study, you can contact:

The Nova Scotia Health Research Ethics Board manager (cell:902-222-9263; email:ResearchEthics@nshealth.ca)
Patient Relations at (902) 473-2133 or 1-855-799-0990 or healthcareexperience@nshealth.ca.

In the next part you will be asked if you agree (consent) to join this study. If the answer is “yes”, please sign the form.

19. Consent And Signatures

The NS Health REB advises that the PI sign the consent form within a two week period from the date that the patient signed the consent form so that the PI is aware that the particular patient is interested in participating in the study.

I have reviewed all of the information in this consent form related to the study called:

Exercise preferences, barriers and facilitators to exercise in cancer survivors or African, Black, and Caribbean descent: A mixed-methods approach.

And I have been given the opportunity to discuss this study with a research team member. All of my questions have been answered to my satisfaction.

- Disagree
 Agree

I authorize access to my personal health information, and research study data as explained in this form

- Yes
 No

Email and texting can be used by a member or members of the research team to communicate with you while you are in this study. All communication you will receive will only be through an NS Health email account (nshealth.ca), or text by a phone issued to a research member through NS Health. All efforts are made to keep information sent or received private, but it is possible other people may be able to see, read, and change messages sent to or from NS Health.

- I give my permission to be contacted by a member or members of the research team from an NS Health Webmail account or an NS Health cell phone by research staff to communicate during this study.
 I do not wish to be contacted by email or text message, unless I otherwise give permission at another time during this study.
 Not applicable

Providing my name, date, electronic signature and submitting this e-consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time without affecting my future health care.

Initial:

Date:

Email:

Phone:

Participant signature:

Signature:

First name:

Last name:

Date:



Principal Investigator signature:

Signature:

First name:

Last name:

Date:

Appendix F: Recruitment Poster

Volunteers needed for a research project on cancer survivors of African, Black and/or Caribbean descent



-
-
-
-
-
-
-

