

Assessing Informal Cancer Caregivers' Needs and Preferences for an Exercise Program
and Their Views Regarding Participating in a Dyadic Exercise Program with Their Care
Recipients

by

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Dalhousie University is located in Mi'kma'ki,
the ancestral and unceded territory of the Mi'kmaq.
We are all Treaty people.

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ABSTRACT

The number of informal cancer caregivers (ICC) is rising due to increased cancer prevalence and a shift towards home-based care. ICC have been shown to experience several physical, emotional, and social consequences leading to a reduced quality of life, an increased risk of all-cause mortality, and a reduced capacity to care for their loved ones. Exercise appears to be a potent intervention to improve the physical and psychosocial health of ICC but research in this area is lacking. This study used an Interpretive Description approach to explore the needs, preferences, and opinions of ICC regarding exercise programs. A throughline of missed opportunities to support ICC health with dyadic exercise programs underpinned three themes in the data: (1) No Time for Exercise, (2) Lack of Oncologist Support, and (3) Do It for Them. The findings highlight opportunities that can be capitalized on to improve ICC health.

LIST OF ABBREVIATIONS USED

HCP	Healthcare Provider
ICC	Informal Cancer Caregivers
QEP	Qualified Exercise Professional

CHAPTER 1 INTRODUCTION

1.1 BACKGROUND

Cancer is the leading cause of death in Canada. A growing and aging Canadian population has seen an increase in the number of new cancer cases each year (Canadian Cancer Statistics Advisory Committee, 2021). An estimated 233 900 new cases of cancer were expected to be diagnosed in Canada in 2022 (Brenner et al., 2022). With 5007.8 people living with or beyond cancer per 100, 000 people, Nova Scotia has one of the highest person-based cancer prevalence rates in Canada, trailing only New Brunswick (5078.4) and Newfoundland (5105.3)(Canadian Cancer Statistics Advisory in collaboration with et al., 2022).

Fortunately, mortality rates for many types of cancer are declining, largely due to progress in prevention, early detection, and treatment (Brenner et al., 2020). As many cancers can be managed for long periods of time, some cancers are now being considered chronic diseases or a disease with chronic characteristics requiring ongoing care and support (Pizzoli et al., 2019). For the remainder of this document, the term *cancer survivor*, or simply *survivor*, will be used to refer to a person at any stage on the cancer continuum from diagnosis onward (Definition of Survivor - NCI Dictionary of Cancer Terms - NCI, 2011).¹

¹ In using this definition, the author recognizes that the term survivor is controversial, with different opinions of when someone with a cancer diagnosis becomes a survivor and of whether “survivor” is the most correct or appropriate term (Committee on Cancer

Health expenditures in Canada are steadily rising, totaling \$264.4 billion in 2019. At 26.6% and growing, hospital spending accounts for the largest share of health expenditures (Canadian Institute for Health Information, 2019). Cancer care expenditures in Canada follow a similar pattern. The economic burden of cancer care rose from \$2.9 billion in 2005 to \$7.5 billion in 2012 with hospital care contributing to the largest and fastest growing proportion of expenses (de Oliveira et al., 2018). The rise in costs has prompted a shift from inpatient to outpatient and home-based care. As a result, family members are increasingly called upon to act as informal caregivers (Kent et al., 2016; Wittenberg & Prosser, 2016). The increasing number of cancer survivors combined with the shift to outpatient and home-based care means that the number of informal cancer caregivers (ICC) is increasing, as is the length and burden of care for ICC (Kent et al., 2016; Sun et al., 2019; Wittenberg & Prosser, 2016).

Informal caregiving refers to the uncompensated support, assistance, and care provided by family members and friends to their loved ones. Informal caregiving can negatively impact the caregiver's well-being and quality of life (Girgis et al., 2012). ICC are often ill-prepared for their caregiving role (Sun et al., 2019; T. Wang et al., 2018) and typically spend more hours per day and provide more intense care than caregivers of individuals with other chronic diseases (Kent et al., 2016). ICC have been shown to experience

Survivorship: Improving Care and Quality of Life & National Cancer Policy Board, 2006) and note that NIH National Cancer Institute includes family members, friends, and caregivers in their definition of cancer survivorship (Definition of Survivorship - NCI Dictionary of Cancer Terms - National Cancer Institute, 2011). While this report makes the case for including informal cancer caregivers as units of care in the cancer care model, the simple definition of survivor given here allows for a dichotomization of cancer survivors and their informal cancer caregivers that increases simplicity and comprehensibility in this report.

several physical (Beesley et al., 2011; Dionne-Odom et al., 2017; Northouse et al., 2010; Ross et al., 2020), emotional (Cotrim & Pereira, 2008; Dionne-Odom et al., 2017; Northouse et al., 2010; Teixeira et al., 2019), social (Kent et al., 2016; Northouse et al., 2012), and psychosocial consequences (Essue et al., 2020), leading to a reduced overall quality of life, an increased risk of all-cause mortality (Ferrell & Wittenberg, 2017; Kent et al., 2016; Perkins et al., 2013; Romito et al., 2013), and subsequently a reduced capacity to care for their loved ones (Northouse et al., 2012). ICC also experience a high degree of direct and indirect economic burden (Essue et al., 2020; Iragorri et al., 2021).

Of note, the health and well-being of cancer survivors and their ICC are known to be interrelated. Specifically, symptoms experienced by cancer survivors are positively correlated with caregiver burden, depression and anxiety, and quality of life (Tan et al., 2018). Declining physical function of cancer survivors has also been shown to lead to declining physical and mental health of caregivers (Kershaw et al., 2015; Litzelman et al., 2016; Sun et al., 2019). In turn, caregiver mental and physical health has been found to affect the health of the cancer survivor. Depressed caregiver mood can lead to worse physical and mental health for the care recipient (Litzelman et al., 2016; Litzelman & Yabroff, 2015; Northouse et al., 2012). In contrast, better caregiver physical and mental health can lead to better mental health of the care recipient (Kershaw et al., 2015; Litzelman et al., 2016; Litzelman & Yabroff, 2015; Northouse et al., 2012). Despite the known health detriments experienced by ICC and the relationship between caregiver and care recipient health, caregiver health is not integrated in the overall care plan for cancer survivors (Kim & Schulz, 2008; Stenberg et al., 2010).

Studies investigating the health of ICC have highlighted the need for interventions to improve the health of caregivers (Dionne-Odom et al., 2017; Rha et al., 2015; Ross et al., 2020; Teixeira et al., 2019) and in turn the health of their care recipient. Interestingly, while 32% of caregivers report being asked about what they need to better care for their care recipient, as few as 16% were asked about what they needed to better care for themselves (AARP Public Policy Institute & National Alliance for Caregiving, 2015).

While not widely studied in cancer survivors and ICC, dyadic exercise interventions have been shown to be beneficial for the psychosocial and physical health of caregivers and care recipients with other chronic diseases (Doyle et al., 2020; Lamotte et al., 2017).

Both ICC and survivors have consistently expressed an interest in exercise to support their health (Keir, 2007; Nightingale et al., 2016; Roddy et al., 2021). Cancer survivors' exercise intervention preferences have been assessed across a range of cancers (Jones & Courneya, 2002; Karvinen et al., 2006; McGowan et al., 2013; Philip et al., 2014; Vallance et al., 2006). However, little is known about ICC exercise intervention needs, preferences, and views.

Given an incomplete understanding of ICC interest in participating in dyadic exercise programs with their care recipients, the purpose of this study was to assess ICC needs and preferences for an exercise program and explore their opinions about exercise and participating in a dyadic exercise intervention with their care recipient. This information

can be used to design an exercise program that will hope to foster high uptake by ICC and/or ICC-survivor dyads.

CHAPTER 2 LITERATURE REVIEW

2.1 EXERCISE FOR ICC HEALTH

ICC require interventions to promote their health (Rha et al., 2015; T. Wang et al., 2018). ICC have been found to reduce their physical activity levels after becoming caregivers (Beesley et al., 2011; Queen et al., 2019; Rha et al., 2015; Ross et al., 2020), partly because ICC often set aside their own needs when they begin providing care (Longacre, 2013; Piolli et al., 2018; Sun et al., 2019) and report feeling a sense of guilt while engaging in personal activities (Lim et al., 2020). This reduction in ICC physical activity levels can lead to decreases in their physical (Northouse et al., 2010; Teixeira et al., 2019) and mental (Cotrim & Pereira, 2008; Dionne-Odom et al., 2017; L. L. Northouse et al., 2010; T. Wang et al., 2018; Willette-Murphy et al., 2009) health after they take on the caregiving role.

Psycho-education and self-management interventions for caregivers to individuals across a range of chronic diseases have been shown to be effective in reducing caregiver burden and improving caregiver quality of life, but not for improving their physical health (Lambert et al., 2016). The combined psychological and physical benefits of physical activity likely make exercise an important self-management strategy for caregivers in addition to mitigating the detrimental effects of caregiving on their health (Lambert et al., 2016).

It has been demonstrated that virtually everyone can benefit from exercise (Warburton & Bredin, 2016, 2017). A systemic review of exercise interventions for caregivers found exercise interventions were most efficacious at improving psychosocial health and physical activity levels among less active caregivers but may also be important for maintaining the health of active caregivers (Lambert et al., 2016). The review concluded that since most of these interventions were for caregivers to people living with dementia, future studies should be conducted for other caregiver groups (Lambert et al., 2016). More recently, Cuthbert and colleagues (2018) found that a group-based exercise program for ICC may improve caregiver health and well-being and should be considered as an important additional support offered to ICC.

2.2 BENEFITS OF DYADIC EXERCISE

Several studies have demonstrated the benefits of an exercise program for cancer survivors and exercise is increasingly being recognized as an important component of cancer care (Aaronson et al., 2014; Cormie et al., 2018; Schmitz et al., 2019; Thomas et al., 2021). Exercise has been demonstrated to be effective for managing cancer symptoms and treatment side-effects and exercise guidelines have been established for eight common cancer health-related outcomes (primary or secondary prevention, fatigue, pain, quality of life, physical function, depression, anxiety, sleep, bone health, breast cancer-related lymphedema) (Schmitz et al., 2021). Exercise has also been shown to reduce care costs through fewer hospital encounters, emergency room visits, readmissions, shorter length of hospital stay, and total charges (Wonders et al., 2019) and exercise programs for cancer survivors have been shown to be cost-effective (Y. Wang et al., 2023).

Unfortunately, only a minority of cancer survivors meet current physical activity guidelines (Knowlton et al., 2020; Mikkelsen et al., 2019; Roddy et al., 2021; D. D. Yang et al., 2017) and only a minority of oncology healthcare professionals refer patients to exercise programs (Schmitz et al., 2021). Moreover, exercise has not been widely adopted into standard practice in cancer care (Aaronson et al., 2014; Cormie et al., 2018).

Not providing exercise opportunities to cancer survivors is a missed opportunity as survivors express a general positive perception of physical activity and are interested in exercise (Knowlton et al., 2020; Mikkelsen et al., 2019). However, survivor concerns about their ability to exercise due to comorbidities or treatment side-effects (Frikkel et al., 2020; Knowlton et al., 2020; Mikkelsen et al., 2019; Sun et al., 2020; D. D. Yang et al., 2017), fatigue (Frikkel et al., 2020; Mikkelsen et al., 2019), and time (Knowlton et al., 2020; Sun et al., 2020; D. D. Yang et al., 2017) limit their exercise participation. Oncologist and nurse endorsement of, and referral to, exercise programs may help to overcome these barriers (Frikkel et al., 2020; Knowlton et al., 2020; Mikkelsen et al., 2019; D. D. Yang et al., 2017).

Dyadic exercise interventions where cancer survivors and their ICC exercise together may be an effective and efficient way of delivering exercise programming to both cancer survivors and their ICC. Despite acknowledging the benefits of physical activity, ICC often feel a sense of guilt when engaging in personal activities (Lim et al., 2020). Dyadic exercise interventions where the caregiver and care recipient exercise together may alleviate the guilt experienced by caregivers because they do not need to choose between caring for their loved ones or themselves. Indeed, numerous studies have suggested that

caregivers be included in exercise interventions (Kent et al., 2016; Langford et al., 2012; Northouse et al., 2012; Sun et al., 2019). Dyadic exercise interventions may also improve the strength of the relationship between the caregiver and care recipient (Ross et al., 2020), and provide the social support necessary for survivors to exercise. Social support has also been identified as a key factor in short and long-term motivation to exercise for cancer survivors (Barber, 2013; Mikkelsen et al., 2019; Stacey et al., 2016; Sun et al., 2020). While not widely studied in cancer survivors and ICC, dyadic exercise interventions have been shown to be beneficial for the psychosocial and physical health of caregivers and care recipients with other chronic diseases (Doyle et al., 2020; Lamotte et al., 2017).

Non-exercise dyadic interventions for caregivers and care recipients in the oncological context have been found to be feasible, acceptable, and beneficial. Dyadic psychosocial interventions for couples affected by cancer have been found to be at least as efficacious as survivor-only or caregiver-only interventions (Regan et al., 2012). In a web-based psychosocial and physical activity self-management program to encourage exercise, dyads learned to use behaviour change techniques to recognize the benefits of social support for exercise participation. Participants were particularly satisfied with the dyadic nature of the intervention (Hallward et al., 2020; Lambert et al., 2020). An 8-week theory-based nutrition and physical activity intervention increased step counts and decreased body weight for both ICC and cancer survivors. However, no health outcomes were measured, and researchers did not aim to recruit dyads. The data analysis compared the intervention and control groups and did not distinguish between ICC and survivors (James et al., 2015).

2.3 DYADIC EXERCISE INTERVENTIONS FOR CANCER SURVIVORS AND THEIR ICC

Dyadic exercise intervention studies in the oncological context are limited. Two studies have examined the effect of dyadic exercise interventions on the health and well-being of the cancer survivor and reported beneficial outcomes. Kamen et al. (2016) conducted a dyadic 6-week home-based aerobic and resistance training intervention that compared the effects of survivors exercising either with or without their partners. Survivors exercising with their partners experienced significantly greater decreases in depressive symptoms compared to those exercising alone (large effect size: $d = 1.26$). Regrettably, caregiver outcomes were not investigated. Lafaro et al. (2020) conducted a perioperative telehealth walking and lower body exercise intervention pilot study for older cancer survivors and their ICC. A total of five sessions took place: one before surgery to develop and teach a personalized walking program and lower body exercises, one after surgery before discharge to refine the program based on the survivor's functional status, and three in the four weeks following discharge to provide ongoing support. Survivors experienced predictable declines in function after surgery followed by clinically important improvements in function. Caregivers were only assessed for psychological distress. Notably, they had higher levels of distress than survivors, underscoring the need to consider ICC health in cancer treatment programs.

To the best of our knowledge, only four studies have examined the effects of dyadic exercise on ICC as a primary focus of their analyses; all reported beneficial outcomes. Anton et al. (2013) interviewed informal caregivers who had participated in a 12-week dyadic exercise program with their care recipients. Three themes emerged from the

interviews: (1) the importance of mutual (dyadic) participation, (2) perceived physical and psychological health benefits of participation, and (3) dyadic exercise as both a form of social support for ICC and a means of improving their abilities as caregivers. Winters-Stone et al. (2016) conducted a 6-month couples-based resistance exercise training intervention for prostate cancer survivors and their informal caregivers. ICC and survivors both experienced improved strength levels and caregivers experienced improved physical function compared to those undergoing usual care. ICC in the exercise group showed trends towards improved mental health whereas ICC in the usual care group showed declines in mental health. The applicability of this study is perhaps limited as prostate cancer is categorized as a survivable cancer and all participants were post treatment. As such, initial levels of ICC burden and distress may have been lower, and ICC mental well-being may have been higher than they would for other types of cancer. Nonetheless, ICC who exercised with their care recipients had better outcomes than ICC who did not. Dyadic exercise studies that include survivors of other cancer types are warranted. Milbury et al. (2018) conducted a five to six-week dyadic yoga intervention for cancer survivors with high grade glioma and their ICC. The participants rated the intervention as useful, beneficial, and efficacious in improving their mental health, although results showed a marginally statistically significant increase in objective measures of caregiver depression. This discrepancy between subjective participant perception and objective assessment scores highlights the need for more qualitative analysis of the caregiver experience in exercise interventions. Halkett et al. (2021) interviewed caregivers and survivors who participated in a seven-week dyadic exercise program for patients undergoing chemoradiotherapy and their ICC. Two main themes

emerged from the interviews: (1) both ICC and survivors experienced benefits from participating in the program and (2) there were some challenges with managing symptoms, fitting three exercise classes per week into the treatment and appointment schedule, and initially engaging with the program.

While limited, these studies indicate that dyadic exercise interventions for cancer survivors and their ICC are both feasible and beneficial for both partners. Studies investigating the effects of dyadic exercise on the physical and mental health of both ICC and survivors of more types of cancer are warranted. Halkett et al.'s (2021) work suggests that including a diverse range of cancer types in group exercise programs may help with program engagement and that two sessions per week may be more feasible than three sessions per week. However, questions surrounding the diversity of cancer types and number of exercise sessions per week should be further explored to better inform program design.

2.4 ICC AND SURVIVOR NEEDS, PREFERENCES, AND VIEWS REGARDING EXERCISE PROGRAMS

Numerous studies have sought to determine ICC and cancer survivors' needs and preferences for health-promoting interventions. Both groups have consistently expressed an interest in exercise (Keir, 2007; Nightingale et al., 2016; Roddy et al., 2021). Cancer survivors' exercise intervention preferences have been assessed across a range of cancers (Jones & Courneya, 2002; Karvinen et al., 2006; McGowan et al., 2013; Philip et al.,

2014; Vallance et al., 2006). However, little is known about ICC exercise intervention needs, preferences, and views.

Swartz and Keir (2007), Nightingale et al. (2016, 2019), and Roddy et al. (2021) have conducted studies to assess ICC interest in and preference for health promotion interventions. Swartz and Keir (2007) found exercise to be the top choice among all stress reduction interventions for ICC to survivors of brain tumors. Nightingale et al. (2016) found diet/exercise programs to be the top choice among wellness programs for ICC to survivors of head and neck cancers. Nightingale et al. (2019) and Roddy et al. (2021) found that lung cancer survivors and their ICC were both interested in exercise interventions.

Only Roddy et al. (2021) assessed interest in dyadic interventions. Sixty-four percent of ICC in their study reported that they would participate in an exercise program with their care recipient. Thirty-eight percent of the survivors reported they would participate with their ICC, another thirty-eight percent of survivors reported they would like to participate alone, and nineteen percent said they would like to participate with other lung cancer survivors.

While these studies demonstrate that ICC are interested in exercise programs, whether they would participate in dyadic exercise programs with their care recipients has yet to be fully explored. Roddy et al.'s (2021) findings suggest that at least some ICC are interested in dyadic exercise programs. Nightingale et al.'s (2016) findings that ICC were likely to participate in programs offered during the patient's medical treatment and

Longacre's (2013) findings that ICC forego leisure activities due to the time requirements of their caregiving duties indicate that dyadic exercise interventions may be a convenient method of providing health-promoting exercise for both ICC and cancer survivors.

2.5 EXERCISE INTERVENTIONS FOR ICC

Exercise has been shown to be beneficial for virtually everyone (Warburton & Bredin, 2016, 2017) and a number of studies have reported a need for exercise interventions to improve or maintain the health of ICC (Dionne-Odom et al., 2017; Rha et al., 2015; Ross et al., 2020; Teixeira et al., 2019). However, few studies have been conducted to date that examine the effects of an exercise intervention for ICC on their health.

Martin and Keats (2014) and Cuthbert et al. (2018) both conducted exercise interventions for ICC specifically. Martin and Keats (2014) conducted a six-week yoga intervention. Cuthbert et al. (2018) conducted a 12-week progressive group resistance and independent aerobic training intervention that also included bi-weekly group educational sessions. Both reported significant reductions in psychological distress and increases in the mental component of quality of life. Martin and Keats (2014) found a large effect size for changes in total mood disturbance ($n^2 = .61$) and the mental component of quality of life ($n^2 = .41$) scores. Cuthbert et al. (2018) also reported a large effect size for changes in the mental component of quality of life scores ($d = .74$). Cuthbert et al. (2018) noted that the group component was important for the ICC as it provided much valued social support. They also noted time-only effects on ICC depression and anxiety (these measures improved in the waitlisted control group as well) which suggests that simple recognition

of and attention to ICC is beneficial to their health. Interestingly, in a qualitative analysis of the same exercise intervention, Cuthbert et al. (2017) found that the ICC in the study perceived participating in the exercise program was beneficial for their physical and mental health and led to decreased levels of burden and distress. The ICC described a downward spiral of physical and emotional changes after taking on the caregiver role and an upward spiral of positive changes after starting the exercise program.

Anton et al. (2013) also conducted a qualitative analysis of ICC perceptions of participating in an exercise intervention and reported similar results. Following a 12-week dyadic exercise and nutrition education program, ICC perceived participating in the exercise program was beneficial for their physical and mental health and led to decreased levels of burden and distress. They particularly enjoyed the opportunity to spend quality time with their care recipient engaging in a healthy activity, to support their care recipient in healthy lifestyle changes, and the positive impact of the act of becoming educated regarding proper exercise training techniques and nutritional practices geared specifically toward the unique challenge of cancer survivorship.

Milbury et al. (2018) conducted a five to six-week dyadic yoga intervention for cancer survivors with high grade glioma and their ICC. All participants subjectively rated the intervention as useful, beneficial, and efficacious in improving their overall well-being. For survivors, clinically significant effects with large effect sizes were reported for cancer-related symptoms ($d = 1.03$), symptom severity ($d = .81$), and sleep quality ($d = 1.17$). Medium effect sizes were reported for depression ($d = .59$), symptom interference ($d = .79$), and mental component of quality of life ($d = .60$). For ICC, significant

improvements in mental component of quality of life were reported with a medium effect size ($d = .64$) but depression scores worsened ($d = 1.04$). The discrepancy between subjective participant perception and objective assessment scores reported by Cuthbert et al. (2017, 2018), Anton et al. (2013), and Milbury et al. (2018) highlights the need for more qualitative analysis of the ICC experience in exercise interventions.

Other studies (James et al., 2015; Kamen et al., 2016; Winters-Stone et al., 2016) investigating the effects of a dyadic exercise intervention for cancer survivors and their ICC have focussed on the physical and mental health of survivors and the degree to which the physical and mental health of ICC was studied has been limited.

Two systematic reviews investigating dyadic interventions have been conducted to determine whether interventions targeted at survivor-ICC dyads were superior to interventions targeting individuals. Lambert et al. (2016) conducted a systematic review of exercise interventions delivered to both survivor-ICC dyads and ICC alone. They found both types to be effective at reducing caregiver distress and increasing well-being and overall quality of life but were unable to report on the effectiveness of dyadic compared to ICC-only interventions as not enough dyadic interventions had been conducted. Regan et al. (2012) conducted a systematic review of dyadic, survivor-only, and caregiver-only psychosocial interventions for couples affected by cancer. The authors found that most dyadic interventions demonstrated significant improvements for intervention couples compared to controls on a range of psychosocial outcomes, though with small to medium effect sizes ($d = .35-.45$). Dyadic interventions tended to have the largest impact on improving outcomes such as couple communication, psychological

distress, and relationship functioning, and they sometimes maintained intervention effects longer than survivor-only interventions. While dyadic designs appear to be superior in psychosocial interventions, more dyadic exercise intervention designs are needed to determine their effectiveness compared to survivor-only and ICC-only exercise interventions.

2.6 ICC PREFERENCES FOR EXERCISE INTERVENTIONS

Swartz and Keir (2007), Nightingale et al. (2016, 2019), and Roddy et al. (2021) have conducted studies to assess ICC interest in and preference for health promotion interventions. Swartz and Keir (2007) found exercise to be the top choice among all stress reduction interventions for ICC to survivors of brain tumors. Nightingale et al. (2016) found most ICC to head and neck cancer survivors were interested in exercise programs and were likely to participate during the survivor's medical treatment. Nightingale et al. (2019) and Roddy et al. (2021) found exercise was regarded positively by lung cancer survivors and their ICC and examined their preferences for exercise interventions.

Swartz and Keir (2007), Nightingale et al. (2016), and Nightingale et al. (2019) only broadly assessed interest in stress reducing and health promotion interventions and did not assess any specific preferences for exercise interventions. Roddy et al. (2021) explored barriers to exercise participation and exercise intervention preferences more deeply. Participants were asked about their interest in learning about ten different topics related to living with cancer and health, their interest in different potential modalities of

receiving this information, and exercise intervention specific questions: frequency, type, duration, timing in the cancer continuum, solo/group/dyadic participation, time of day, intensity, location, and facilitator (e.g., physiotherapist, fitness instructor, healthcare professional/specialist nurse).

Roddy et al. (2021) found that sixty-four percent of ICC reported that they would participate in a physical activity intervention with the survivor while only thirty-eight percent of survivors reported they would participate with their ICC. Another thirty-eight percent of the survivors reported they would like to participate alone, while nineteen percent said they would like to participate with other lung cancer survivors. Although lung cancer survivors and their ICC are both interested in health-promoting exercise interventions, it is unclear whether these interventions should be for ICC alone or for ICC-survivor dyads and whether the type or stage of cancer plays a role in this preference. Lung cancer survivors have been found to feel shame and perceive that their ICC blame them for their disease (Nightingale et al., 2019). This phenomenon seems to be particular to lung cancer. Therefore, the preferences of lung cancer survivors and their ICC may not apply to survivors and ICC of other cancer types. An analysis of preferences of survivors and ICC of other cancer types would be beneficial to inform future interventions.

2.7 LIMITATIONS IN THE RESEARCH TO DATE AND HOW THIS STUDY ADDRESSES THEM

The studies conducted to date have shown that ICC need and are interested in exercise interventions. However, specific preferences for these interventions and the barriers to

participation have only been assessed in a small sample of lung cancer caregivers. It is unknown whether ICC to survivors of other types of cancer share the same preferences for exercise interventions or the same barriers to participation.

Studies have also shown that ICC and survivor exercise programs are beneficial for their health and that dyadic exercise programs for ICC and survivors may address many barriers to exercise participation identified by ICC and survivors. However, little is known about ICC interest in dyadic exercise programs.

Qualitative studies are warranted when the next logical question in advancing disciplinary knowledge is one for which relevant themes and patterns have not been well documented (Thorne, 2016). The preference studies conducted thus far have been quantitative. Thus, the purpose of this study was to explore ICC needs, preferences, and opinions regarding dyadic exercise programs.

CHAPTER 3 METHODOLOGY

3.1 QUALITATIVE METHODOLOGY

Given the pragmatic aim of this research, the study was conducted using Interpretive Description, a qualitative research approach used in applied health fields where the intention is to gain knowledge that can be directly applied to improving patient outcomes (Thorne, 2016). This chapter explains how the research was conducted following the principles of interpretive description. Procedures used to recruit participants, collect, and analyze data, and considerations for enhancing credibility of the research findings are discussed.

3.1.1 INTERPRETIVE DESCRIPTION

Interpretive description was developed by Sally Thorne and her research team to meet the needs of qualitative research in applied healthcare fields. They found that while traditional qualitative approaches such as phenomenology, ethnography, and grounded theory were useful for generating broad social theories about the nonclinical world in which health and wellness play out, researchers in applied health fields require a methodology that allows for a direct, pragmatic application of research findings into clinical practice (Thorne, 2016).

Like other qualitative descriptive approaches, interpretive description is a systematic analysis of a phenomenon based in inductive reasoning (Thorne, 2016). Researchers build from specific observations toward broader generalizations about pattern in order to

describe something whose description would benefit an applied practice field. The *interpretative* component aims to place this description into the context of this practice field. Thorne describes the interpretative component as answering the “so what does this mean?” question (Thorne, 2016). The aims of interpretive description then, are to describe a new understanding of a phenomenon and to interpret the findings for people working in the field so that they can use this new understanding to inform their practice. In essence, interpretive description is a qualitative approach whereby applied healthcare researchers working on the pressing problems of their disciplinary field can generate credible, defensible knowledge that is meaningful and relevant in the applied practice context (Thorne, 2016).

Thorne (2016) outlines the foundational underpinnings of interpretive description that distinguish interpretive description studies from other qualitative descriptions.

Interpretive description studies:

- are conducted in as naturalistic a context as possible in a manner that respects the comfort and ethical rights of participants,
- explicitly attend to the value of subjective and experiential knowledge as one of the fundamental sources of insight for applied practice,
- capitalize on human commonalities as well as individual expressions of variance within a shared focus of interest,
- reflect issues that are not bounded by time and context, but attend carefully to the time and context within which human expressions are enacted,

- acknowledge a socially “constructed” element to human experience that cannot be meaningfully separated from its essential nature,
- recognize that in a world of human experience, “reality” involves multiple constructed realities that may well at times be contradictory, and
- acknowledge an inseparable interaction between the knower and the known, such that the inquirer and the “object” of that inquiry influence one another in the production of the research outcomes (p. 82).

As a credible, transparent process for developing understanding and generating knowledge that can advance clinical practice, interpretative description is being used with increasing frequency in health care research in studies aiming to capture the subjective experience of a population and use this knowledge to inform practice (Thompson Burdine et al., 2021).

3.1.2 ORIENTING THE RESEARCH(ER)

A researcher following an interpretive description approach must be aware of the disciplinary context in which they work and of their position within it (Thorne, 2016). It is important to surface, acknowledge, and reflect upon how a researcher’s position, experiences, characteristics, and values may influence the design and implementation of a research project. At the time this study was designed, the author was a clinical exercise physiologist delivering exercise programs to survivors in an exercise oncology research program and was aware of a future planned exercise intervention for ICC-survivor dyads. ICC regularly accompanied survivors to their exercise sessions. Some would shadow

their survivor, some would exercise themselves, and others simply sat and waited. The researcher had many discussions with ICC and survivors about exercise and their health and was interested in learning more about the ICC experience and ICC opinions regarding exercise programs.

The original motivation for this research was to gain an understanding of ICC needs, preferences, and opinions regarding exercise programs in order to design appealing exercise programs for ICC that would foster high uptake. An interpretative description approach was chosen for its ability to engage with important clinical questions in a pragmatic way and for its purposeful intent to generate clinically meaningful and applicable knowledge. Paraphrasing Thorne (2016), interpretive description research is rooted in an important “why” and culminates in a relevant “how to”. This research started with a topic worth investigating: supporting ICC health through exercise, and evolved, as is interpretive description’s wont, beyond the researcher’s original intent, ending with a new understanding and pragmatic recommendations for improving cancer care.

3.2 PARTICIPANTS

ICC from across Canada were invited to participate in semi-structured interview. ICC were eligible to participate if they were 18+ years of age, were able to provide written consent in English, were providing physical or psychological support to an adult (18+ years) cancer survivor at the time of participation, and resided in Canada.

Participants were recruited using a number of strategies. ICC to survivors participating in in-person and virtual exercise interventions conducted by the PAC Lab in Halifax, Nova Scotia were asked if they would like to participate. Recruitment posters were placed in cancer treatment areas in the Victoria General Hospital in Halifax, Nova Scotia, and in libraries and community boards in Halifax and other communities in Nova Scotia. Recruitment information was shared online on social media (Facebook, Twitter, Instagram) and in cancer care and ICC forums and support groups. The total number of participants was not set a priori. Recruitment continued for a period of 14 months (January 2022-March 2023).

Individuals interested in participating were invited to contact the author by email. The author then explained the study and screened them for eligibility. Eligible individuals who were still interested in participating were sent an email with a secure link to the study Informed Consent Form. Individuals who completed the Informed Consent Form were invited to participate in a semi-structured interview either in person at the Dickson building in Halifax, Nova Scotia, over the phone, or over a secure Nova Scotia Health Zoom call.

3.3 ETHICAL APPROVAL

This study was approved by the Nova Scotia Health Research Ethics Board (File #1027500). All participants consented to participate in this study using a Nova Scotia Health Informed Consent Form administered online using REDCap, a secure web-based survey tool and database. Steps to protect participant identity in this report include the

use of pseudonyms and the editing of participant quotes to omit unique identifying information (e.g., names, neighbourhoods, places of work).

3.4 DATA COLLECTION

Data was collected using semi-structured interviews in the period from April 2022 to February 2023. Interviews were conducted over Zoom, over the phone, and in-person. All interviews were conducted by the primary investigator and all participants were aware that the study was a part of the interviewer's M.Sc. research. Each participant was interviewed once. The interviews lasted between 30 and 75 minutes. The interviews were recorded and transcribed into written text in Microsoft Word by the primary researcher.

A semi-structured interview guide was developed prior to commencement of the interviews. Development of the guide was centered around gaining an understanding of ICC need for exercise programs; ICC understanding of and opinions about exercise; facilitators, barriers, and preferences for exercise participation; and opinions about exercising with their care recipient. The author created the guide with input from a supervisory team with experience conducting quantitative and qualitative, interview-based research. The interview guide contained three sections. Section one explored the participant's physical activity behaviour and whether/how it changed after becoming an ICC. Section two explored participants' thoughts about the benefits and risks of exercise for ICC and survivors and about their experience receiving exercise counselling. Section three explored their feelings about exercising with their care recipient and in different exercise environments (individual, with other ICC, with other ICC-survivor dyads) (see Appendix A). The semi-structured interview permitted some flexibility to allow for

exploring the full range of participant views. Questions on the list were occasionally skipped or modified and new questions were posed in response to the dynamics of the interviews to better understand the views of ICC.

3.5 DATA ANALYSIS

Analysis of the interview data was guided by Thorne's (Thorne, 2016) interpretive description approach. A central element of this approach is that the researcher should remain open to the many possible ways that the data can be organized while staying true to their disciplinary orientation (Thorne, 2016). All decisions in analysis should be made in consideration of why the phenomenon under investigation is worth exploring, how it's analysis can benefit clinical practice, and with an eye to enhancing credibility. As recommended by Thorne (Thorne, 2016), the researcher used the analytical techniques that best allowed them to become intimately acquainted with the data and to consider similarities and differences with respect to a wide range of dimensions among the various cases in the sample, so that they could follow a logical line of inquiry and eventually forward the aspects that might legitimately be considered meaningful patterns and themes.

The researcher made notes during the initial interviews, during transcription, and with each re-reading/listening of the interviews about questions, potential connections, potentially meaningful elements, and other impressions about the data. After transcription, the researcher analyzed each interview individually to develop a sense of each participant's specific context and what they were trying to convey in light of that

context. Then, the transcribed interviews were added to the NVivo software version 1.7.1 for coding and further analysis. Initial coding was kept broad to avoid premature categorization that might prevent the researcher from seeing the bigger picture or from discovering important connections later in the analytical process. Following the initial coding, the data was grouped together in different ways based on commonalities. Key points that served as model and contrary cases with respect to these commonalities were highlighted. The analysis continued as an ongoing process of re-reading the transcripts and flagging, grouping, regrouping, and connecting the data. Emerging relationships between the data were tested against the rest of the data as they were discovered. This process of revisiting the data, attempting to view and organize it in different ways, and testing emerging relationships continued until the researcher arrived at themes that represented the meaning of the individual and collective data and were relevant within the clinical context.

3.6 CONSIDERATIONS TO ENHANCE CREDIBILITY

Qualitative research has the potential to tug at heart strings and feed biases and there is a considerable risk that study findings will be uncritically accepted by a hungry audience (Thorne, 2016). Therefore, qualitative researchers must take steps to ensure that all claims they make are credible. Quantitative researchers follow criteria throughout the research process to make claims of validity, reliability, and generalizability. Similar criteria also exist for qualitative researchers to follow to lend credibility to their findings. Thorne advises against using these criteria as a checklist, trusting that the research findings will be credible if each criterion has been checked. Rather, the research should

consider credibility in every decision made throughout the research process from deciding that the topic is worth investigating (i.e., that doing so is necessary and would be beneficial to the field), through all the decisions in the planning and conducting of the study, to analysing and interpreting the data, and finally in presenting the findings (Thorne, 2016).

According to Thorne (2016), whether a checklist is followed or not, credible interpretative description studies demonstrate a high degree of moral defensibility (the knowledge being extracted from study participants is necessary and this knowledge will be used to provide benefit and not harm), disciplinary relevance (the knowledge is appropriate to the development of the disciplinary science), pragmatic obligation (researchers should treat their findings as if they will indeed be applied in practice), and contextual awareness (researchers should recognize that their perspective exists within their own historical context and by their disciplinary perspective, and that the perspective of the participants exists within their own social and historical context). Credible interpretive description research reflects the deep questioning that the researcher has engaged in when selecting the questions to ask, in making claims about how the knowledge furthers meaning and practice in the field, and in considering the implications of what they have come to believe through the research process.

Moral defensibility: Chapters 1 and 2 described how the number of ICC is steadily increasing, how ICC would benefit from exercise programs, and how little is known about ICC preferences for and opinions about exercise programs. This study seeks to gain knowledge about the ICC experience that can be used to design exercise interventions that meet the needs and preferences of ICC and foster high participant uptake.

Disciplinary Relevance: ICC are not well supported in the current cancer care model. This is especially unfortunate given what is known about the negative impacts of caregiving on ICC health and the interrelated nature of ICC and survivor health (Kershaw et al., 2015; Litzelman et al., 2016; Litzelman & Yabroff, 2015; L. Northouse et al., 2012; Sun et al., 2019; Tan et al., 2018). Introducing knowledge of the ICC experience and preferences for exercise into the cancer care field can lead to direct and indirect health benefits for both ICC and survivors.

Pragmatic Obligation: Extreme care was taken throughout the study to ensure that all claims made are made responsibly, under the assumption that they may be acted on by actors in the field of cancer care. The researcher kept the original intent of the study in mind throughout the process, remained faithful to an inductive reasoning process, tested connections between the data against the whole, and remained open to different interpretations of the data until only the most probably true and relevant themes remained.

Contextual Awareness: The researcher remained cognizant of their experience as an exercise physiologist who has worked with ICC and survivors and took care to identify and challenge a priori assumptions about the possible findings throughout the data collection and analysis phases of the research. In data collection, the researcher took care to minimize the effect of their clinical and research experience on the interviews. This involved not leading the participants in the interviews, not presenting themselves as or assuming the role of an expert, and allowing the interviews to progress naturally according to the flow dictated by the participants. In data analysis, the researcher remained aware of their experiences and a priori assumptions to ensure they didn't

influence the data and studied each participant interview thoroughly to maximize understanding of their particular context.

Thorne (2016) recommends that all qualitative researchers create an “audit trail”, a reasoning pathway that other researchers could presumably follow. An audit trail was established in this study by keeping all transcripts, NVivo data files and coding, and notes.

CHAPTER 4 RESULTS

The aim of this inquiry was to understand any apparent themes and patterns in ICC opinions regarding dyadic exercise interventions in order to design exercise interventions that will foster the best uptake among ICC. The data contained a throughline of missed opportunity to care for ICC and survivors in the standard cancer care model. Three main themes described the ways in which ICC were primed to participate in dyadic exercise programs to improve their health but were left wanting due to a lack of institutional support in cancer care. Each theme was characterized by opposing opportunities and barriers to participating in dyadic exercise programs. This chapter describes the participants in the study and the study findings.

4.1 PARTICIPANTS

Twenty-two people expressed interest in participating. Twenty met the eligibility criteria. Of these, fourteen completed the consent form and consented to participate in the semi-structured interview. Six of these did not respond to follow-up communication regarding scheduling the interview and eight were interviewed.

Age (range)	38-76
Gender	
Women (<i>n</i>)	6
Men (<i>n</i>)	2
Employment Status	
Working full-time (<i>n</i>)	3
Retired (<i>n</i>)	3
Retired and working part-time (<i>n</i>)	1
Education	
Post-secondary degree (<i>n</i>)	3
Graduate degree (<i>n</i>)	4
Months in caregiver role (range)	1-53
Care recipient's cancer illness	
Breast (<i>n</i>)	2
Brain (<i>n</i>)	2
Bile duct (<i>n</i>)	1
Melanoma (<i>n</i>)	1
Ovarian (<i>n</i>)	1
Prostate (<i>n</i>)	1
Relationship to care recipient	
Spouse (<i>n</i>)	6
Child (of recipient) (<i>n</i>)	2
Province of Residence	
British Columbia	1
Manitoba	2
Nova Scotia	5

Table 1. Participant Characteristics (N = 8)

4.2 MISSED OPPORTUNITIES

A throughline of missed opportunities to improve ICC health through dyadic exercise programs underpinned the experience of participants in cancer care. Three main themes described the ways in which ICC were knocking on the doors of dyadic exercise

programs to improve their health but left outside due to a lack of institutional support in the healthcare system: (1) No Time for Exercise, (2) Lack of Oncologist Support, (3) Do It for Them. Each theme was characterized by opposing opportunities and barriers to participating in dyadic exercise programs. These three themes are summarized in Table 2.

Theme	Opportunity	Barrier
No Time for Exercise	ICC View Exercise as Valuable for Both Physical and Mental Health	Exercise Becomes Difficult After Caregiving Begins
Lack of Oncologist Support	ICC Want Their Care Recipients to Exercise to Gain Fitness	Exercise is Rarely Discussed by Oncologists
Do It for Them	ICC Are Willing to Participate in Dyadic Exercise Programs for Their Care Recipient's Benefit	Do Not Believe Dyadic Exercise Programs Are Sufficiently Challenging

Table 2. Themes

4.3 THEME 1: NO TIME FOR EXERCISE

4.3.1 Opportunity: ICC View Exercise as Valuable for Both Physical and Mental Health

ICC often remarked on how beneficial exercise was for their physical and mental health. Most of the ICC in this sample were regular exercisers or had been regular exercisers in the past. Many of them commented on the physical benefits of exercise:

“I honestly believe there have been significant benefits to me because of being so active all these years”-Participant 8

“It’s good for the body just physically” -Participant 1

While not every ICC said they exercised to benefit their physical health, every one of them commented on the mental health benefits of exercise:

“Fit body, fit mind – you can handle things more when your body’s well”

“It’s a good way to relieve stress. It’s a good way to keep your own personal health up, to take care of yourself”-Participant 4

“I need to do it just to maintain muscle and core strength and my mental health is just so much better when I exercise”-Participant 8

*“I think it’s mental well-being. Exercising helps my mental well-being”
-Participant 5*

Many of the ICC noted the importance of exercise for maintaining their own health specifically in the context of caregiving:

“and I think for caregivers it’s very easy to be totally consumed with the act of caregiving and always being focussed on the person you’re looking after. It’s really important to have something that you do just for yourself. Not to be selfish about it, but essentially if the caregiver isn’t healthy, caregiving isn’t going to be healthy”-Participant 1

“You’re probably mentally more fit to help out someone because you’ve got a bit of a break; you’ve given yourself some time to relax. To me, exercise is important in that sense”- Participant 8

“[You] can’t pour from an empty cup”- Participant 2

“You can’t help other people if you don’t take care of yourself”- Participant 5

4.3.2 Barrier: Exercise Becomes Difficult After Caregiving Begins

Despite all recognizing the value of exercise and the importance of being healthy in order to provide better care, many of the ICC struggled with getting regular exercise. Many of the ICC noted that increased demands associated with caregiving made finding time to exercise more difficult:

“one of the things when you have someone that needs a little bit more care that can affect the time that you have or that you choose to make or take to get the proper physical activity”-Participant 4

“It just seemed like always very busy and that made me even more busy. So, part of it is time and also part of it is just my own decision of like, I’m not going to make time because I’m doing this other stuff instead”-Participant 7

“I sometimes feel like I’m just waiting for the next bomb to drop. And instead of going to exercise while I wait, I am waiting for the bomb to drop”-Participant 3

Others commented that they might be able to find the time, but were concerned about leaving their care recipient alone while they exercised:

“It’s weird-in my head I keep thinking ‘I need to know he’s okay’ I don’t know why. It shouldn’t matter. It shouldn’t stop me from doing these things and I know I need to take care of myself. But it’s a mental block for me sometimes to just say ‘I’m going to take an hour and go do this.’ There’s no reason why I can’t.”

-Participant 6

“I have to be more selective with when I do exercise. Sometimes, you know if my wife wants to have a bath in the evening, I won’t let her get out of the bath without me being nearby because sometimes not good things, not always good results. [...] There’s been a few evenings or a few days where I haven’t done something because she’s been feeling particularly poorly, and I didn’t want to be out of contact”-Participant 8

Some ICC experienced feelings of guilt associated with taking time for themselves:

“you’re not getting your homework done, you’re not getting the house clean, you’re not making [your partner] feel better, you’re not accomplishing anything tangible”-Participant 5

“Sometimes a big thing is I think you feel guilty if you’re taking care of yourself. That’s a common thread for me over the last year and a half: is taking time for myself. I feel bad about it because hey shouldn’t I be going and doing something more important over here?”-Participant 7

4.4 THEME 2: LACK OF ONCOLOGIST SUPPORT

4.4.1 Opportunity: ICC Want Their Care Recipients to Exercise to Gain Fitness

ICC expressed difficulty in watching their care recipients lose fitness secondary to their illness and treatments.

“I was really concerned about how wiped out she was. Like in the beginning she’d climb the stairs to go upstairs and that was it. I could see that that took everything out of her, just to climb the stairs and for her that was very emotionally difficult. She really felt...I know that hit her hard mentally. I remember her saying something along the lines of “I can’t even climb stairs. I’m never going to survive this; I can’t even climb stairs.” -Participant 7

Most ICC wanted their care recipients to exercise for the purpose of gaining fitness or regaining lost function.

“He needs to be more active.” -Participant 6

“Even when he was healthy I couldn’t convince him to workout with me. So now when he’s feeling down mentally and physically -he’s going through some chemo treatments- the last thing he wants to do is exercise. It’s not that it’s not good for him. Any amount of movement is good. Even if I can get him out to walk with me. I do, but it doesn’t happen as easily as I would like” -Participant 6

“I do notice him getting older, like his arms and stuff. So to me I want him to exercise more but I’m also told I shouldn’t push him because all those symptoms are caused by his medicine and stuff so...” -Participant 5

“Right now, for example, my wife is very, very weak. She’s lost a huge amount of weight. Lost a lot of muscle mass [...] As I said earlier, I don’t want her getting out of the bathtub on her own because I’m afraid she’s going to go down. So, I think there often is a loss of muscle mass which makes the exercise even more important” -Participant 8

4.4.2 Barrier: Exercise is Rarely Discussed by Oncologists

Exercise was rarely discussed in appointments with the survivors' oncologists. In these appointments, survivors were given general recommendations to not become sedentary or to engage in moderate exercise, but specific exercise recommendations, prescriptions, or resources were not provided.

"As I recall, they mentioned it. I don't know what degree of encouragement. They mentioned it was a good idea. So I would say yes." -Participant 1

"I cannot personally remember a time that it's been mentioned. I hate to say it hasn't been. I don't recall any specific mention. You know 'Do what you feel you're able to' but not 'We would encourage you to do this three times a week.' There's never been that type of discussion. I don't believe there's been any specific mention of you should be trying to do this or do that. And that's from anybody on the health care team. They've all been absolutely wonderful people to deal with. We really feel lucky to have had such a great group of people, but exercise has not been a topic that's been discussed." -Participant 8

Some ICC expressed frustration about not receiving information about exercise from the oncologist:

"With me not at all. With her, I don't think very much. Nobody's asked about it and they've kind of just blown it off. Like it's not something that they want to talk about." -Participant 2

"Zero.

Interviewer: Aside from Dr. [X] I guess?

Not even. Nope. Nothing. [...] I find it shocking how little consultation from the medical team has been shared with us about fitness and nutrition or exercise and nutrition. And if it wasn't for me being an advocate for us on all of that, if we listened to the things that they were saying are okay to do, it's shocking. It's horrible." -Participant 6

"Except for Dr. [X] mentioning it the very first day, not at all. That's including if you bring it up." -Participant 6

One long-term ICC was also a survivor and related her experience with the oncologist:

"I remember being in the office with the oncologist going 'What can I do? What can I do diet-wise to make this process go smoother? What can I do exercise-wise to make this process go better?' Because I knew that I had spent a year and a half with this other person doing nothing. Not nothing, but physically I wasn't doing a lot. So for me that was important. And they just gave me the general eat well, exercise" -Participant 4

Only one ICC reflected positively about how the healthcare team discussed exercise with them and their care recipient:

"I remember being in a couple of appointments with her main surgeon or main doctor saying that she wanted her to...20 minutes per day walking around, go for a short walk, that kind of thing. I don't think it was something they emphasized every single meeting, but it was definitely something that was brought up in the

beginning and definitely something that I heard here and there throughout the whole program.” -Participant 7

4.5 THEME 3: DO IT FOR THEM

4.5.1 Opportunity: ICC are Willing to Participate in Dyadic Exercise Programs for Their Care Recipients’ Benefit

Every ICC said they would be very willing to participate in an exercise program with their care recipient. Some were very enthusiastic about exercising with their care recipients:

“I love it. I do” -Participant 6

“Oh, I’d love it, yeah.” -Participant 3

Other ICC were less excited about exercising with their care recipients but would do so for their care recipient’s benefit:

“If it would get her involved and doing things and encourage her or keep her involved, I would be glad to do it.” -Participant 8

*“If I was told it would help him, I would just do whatever I was told to do”
-Participant 5*

Most of the ICC perceived a social benefit from participating in group exercise programs with their care recipients. For some this was a sense of shared experience:

“Especially if you’re just getting started it’s a big cheering squad because everybody is coming in with, if you say ‘I’m tired’ they go like, ‘yeah, you’re tired’ and you know they get it. So having that type of program with people that are having these similar experiences, there’s a lot of value there.” -Participant 4

“It’s realizing you’re not alone. It’s listening and picking up things you might not have known before. It’s a support network. It’s... just... living beyond the cancer.” -Participant 5

“I really don’t have a network of caregivers here. Like I’d say that’s a bit of a missing link to some of the things I’ve experienced-not having someone to talk about things with.” -Participant 8

Many ICC welcomed the opportunity to learn from other participants:

*“It would be helpful to be able to debrief and just find out other people’s experiences. And that’s where a group would be good [...] the benefits are just the sharing of experience and sometimes just the networking that can happen for different treatments or just hearing peoples’ stories would be helpful because you’re kind of isolated in all this. When you first set out it’s very isolating.”
-Participant 3*

“For me I think having the chance to maybe talk to others who are in a similar position, maybe exchange some ideas. How are you dealing with this? How are you doing this?” -Participant 8

Others perceived a benefit in being able to share their experience with others and help others through their cancer experience:

“I think everybody also has something to offer and I think that the idea of giving is always a powerful healer in itself. So, when you’re there you’re not only there to take from the class but you’re also there to give to the class as well.”

-Participant 4

“I feel a benefit of going through all this when you can share your experiences or encourage other people or yeah, just encourage other people. So that’s a benefit.” -Participant 1

4.5.2 Barrier: ICC Do Not Believe Dyadic Exercise Programs Are Sufficiently Challenging

Although all the ICC were willing to participate in exercise programs with their care recipients and perceived some kind of social benefit, some expressed reservations. These reservations fell into three categories. Most notably, many of the ICC expressed concerns about their ability to get a quality workout because they were fitter than their care recipients:

“She walks too slow. [laughs] I’d enjoy the conversation I just don’t know how much exercise exercise we’d be getting, but we would be moving.” -Participant 3

“She has gone to-she calls it an exercise class-it’s not what I would consider to be strenuous exercise but we all have our own points of view on... [...] Her

definition of exercise and mine are significantly different and they always have been.” -Participant 8

“I would have to have my own routine that benefits me.” -Participant 5

Other ICC would prefer exercising alone:

“My wife likes the community aspect of these things a lot more than I do. For me it’s not a personal benefit but I know that it would be good for her. So for that reason I would say “let’s do it”. But it’s not for me. I’m just kind of a loner.”

-Participant 7

“I typically like to listen to some music, and I don’t view exercise so much as a social thing.” -Participant 8

“I’ve always exercised alone and it’s like my quiet time, so that would be the biggest thing. Giving up my quiet time.” -Participant 2

Lastly, some ICC didn’t like the idea of being in another environment where cancer was the focus:

“Part of me feels like the exercise part of our day should be for us to get stronger and feel better and maybe being around other people who are also going through something like through cancer might just be a constant reminder, whereas going to the gym for me is my clear my head space. I don’t know. I’m trying to minimize the inputs where my day is all about cancer all the time, so I don’t know.”

-Participant 8

“After a while I need to be away from those conversations. Right, like after healing is done and you start to feel better, then it was more: okay I really would rather get out and just be social and not social with this group reminding me all the time.” -Participant 4

“I’m in a caregiver support group. I haven’t been in a while. [...] initially it was good. But the problem was is that I would get to know these people and then bad things would happen to the people they were with and in the end, I think that was probably what made me stop going. I just couldn’t take it anymore. I kept.... I’d get to know these people and then the next week it would just be a mess because a new test result came back that was bad or this was bad or chemo was horrible that week, all these things. And it was just ...it just became...I grew to not like it because of that [...] Initially it was really good. It was good to see that I wasn’t the only one that was feeling all this stuff. I wasn’t the only one that was a total mess [...] And that would be the only thing I could think of that would be a negative thing for me for a group for a caregiver and caregivee-I don’t know what the word is-I could see that over a particular period of time there’s going to be more of that kind of bad news stuff. ‘Oh look, these two aren’t here anymore. What happened?’ [...] And I see even like, my wife has made some friends through Cancer Care, other patients. When one of them gets bad news, I can see how hard it hits her. From my perspective, that’s the only thing I can really imagine that’s a downside. And whether that outweighs the other benefits I can’t say, I don’t think it does, but it’s hard, I think. I think it’s hard for everybody involved.” -Participant 7

CHAPTER 5 DISCUSSION

Chapter four presented the three themes that characterized ICC needs, preferences, and opinions about participating in exercise programs. These themes were presented in the form of opposing opportunities and barriers to supporting ICC health with dyadic exercise programs. This chapter discusses these themes and proposes solutions to overcome the barriers. It also discusses the limitations of this study and proposes future research to address these limitations and build on the findings to support the health of ICCs.

5.1 NO TIME FOR EXERCISE

5.1.1 Opportunity

The first missed opportunity presented was that all the ICC in this study explicitly talked about the value of exercise for their personal health. The benefits of exercise for their mental health were brought up frequently in the interviews. That ICC recognize the mental health benefits of exercise is an important finding for two reasons. As discussed in chapter one, ICC have been shown to experience negative physical (Beesley et al., 2011; Dionne-Odom et al., 2017; L. L. Northouse et al., 2010; Ross et al., 2020), emotional (Cotrim & Pereira, 2008; Dionne-Odom et al., 2017; L. L. Northouse et al., 2010; Teixeira et al., 2019), social (Kent et al., 2016; L. Northouse et al., 2012), and psychosocial (Essue et al., 2020) consequences secondary to caregiving, and ICC and survivor health are linked (Kershaw et al., 2015; Litzelman et al., 2016; Litzelman & Yabroff, 2015; L. Northouse et al., 2012; Sun et al., 2019; Tan et al., 2018). ICC that

already recognize the benefits of exercise for their health are likely a receptive audience to information about exercise that is presented in the context of cancer care.

5.1.2 Barriers

ICC enthusiasm for exercise is a missed opportunity because participants struggled to make to time to exercise as much as they would like. A perceived lack of time is also the most commonly cited barrier to exercise in the general population (Hoare et al., 2017). ICC consistently reported that since taking on the caregiving role, they had increased amounts of tasks to accomplish in their day. These tasks included specific caregiving duties and non-specific but related duties, such as taking on an increased share of household chores that the survivor was not able to perform. ICC often prioritized these tasks over exercise. These experiences are consistent with research showing ICC forego leisure activities due to the time requirements of their caregiving duties (Longacre, 2013; Roddy et al., 2021).

ICC also related experiencing feelings of guilt associated with taking the time for self-care. ICC were reluctant to dedicate time to their own health because they felt they *should* be using their time on specific caregiving duties or on non-specific but related duties which, for some ICC, seemed omnipresent and never-ending. These feelings of guilt have been seen in the cancer caregiver literature (Lim et al., 2020).

Other key reasons for not achieving their desired amounts of exercise included mental struggles with leaving their survivor alone long enough to achieve a meaningful workout and feeling so overwhelmed by the ICC experience to find the motivation to exercise.

Some ICC spoke specifically about how overwhelming the beginning of the caregiving experience was. In the period immediately after diagnosis, they described being unable to motivate themselves to exercise while “waiting for the next bomb to drop” and being overwhelmed with information in their initial meetings with the oncologist about things they should be careful of, refrain from doing, and watch out for. Some ICC related a sense of wanting some sort of positive action that they *could* do in the face of so much information about what they could *not*.

5.1.3 Solutions

Given the negative mental and physical health consequences associated with becoming an ICC, the health of ICC must be considered in the cancer care model. ICC must be educated about the benefits and importance of exercise in supporting both their own health and that of their care recipients when they become caregivers. In some cases, ICC may need to be explicitly instructed to exercise. This is important both for ICC who already recognize the benefits of exercise but are likely to down-prioritize exercise in their new caregiving role, and for ICC who do not already recognize the benefits of exercise and stand to gain much by beginning an exercise program when they become caregivers.

This discussion should occur in the initial meetings ICC and survivors have with the cancer care team. ICC should be educated about the negative effects of caregiving on ICC physical and mental health and about how exercise has been shown to be protective or beneficial in these regards. ICC should also be educated about the interrelated nature of ICC and survivor health so that ICC understand that taking care of their own health

benefits their survivor, or that neglecting their own health can have harmful effects on their survivor. ICC should also have their physical activity levels assessed in these initial meetings and be given exercise prescriptions if they do not meet physical activity guidelines. Finally, ICC should be presented with ways to achieve their exercise prescription.

ICC should leave these initial meetings with some appreciation of the physical and mental health challenges they are about to encounter and a feeling of empowerment that they have the knowledge and tools and to face these challenges. Follow-up meetings should include re-assessments of ICC physical activity levels and adherence to exercise prescriptions and any necessary coaching to help ICC maintain or meet their exercise prescriptions.

A similar model of exercise and lifestyle support has existed in Canada for over sixty years in the form of cardiac rehabilitation programs (Tran et al., 2018). Cardiac rehabilitation programs have been shown to reduce morbidity, mortality, rehospitalization, and to be cost-effective (Grace et al., 2016; Tran et al., 2018). Given the known benefits of exercise for cancer survivors (Campbell et al., 2019; Cormie et al., 2017; Friedenreich et al., 2016; Kimmel et al., 2014; McTiernan et al., 2019; Newton & Galvão, 2008; Patel et al., 2019; Schmitz et al., 2021) and ICC (Cuthbert et al., 2018; Lambert et al., 2016), the reductions in cancer care costs associated with exercise programs (Wonders et al., 2019), and the demonstrated cost-effectiveness of exercise programs for survivors (Y. Wang et al., 2023), including dyadic exercise programs in the cancer care model appears to be a logical course of action, both for the health of ICC and survivors, and for the financial health of the healthcare system.

Recent work has investigated the implementation of exercise programs in cancer care and the development of pathways for connecting survivors with appropriate exercise programs and/or resources. Recommendations from this work include integrating qualified exercise professionals (QEPs) (e.g., exercise physiologists, kinesiologists) into the oncological healthcare team, initiating conversations about exercise at the earliest opportunity, screening or assessing survivors to provide them with appropriate exercise programs and resources, and including cancer exercise education in professional healthcare degrees and continuing education programs for QEPs (Adams et al., 2021; Coletta et al., 2022; Kennedy et al., 2022; Mina et al., 2018; Newton, 2018; Stout et al., 2020).

In the pathway model described by Mina et al. (2018), when a person receives a cancer diagnosis, their healthcare provider (HCP) discusses exercise with them. If the survivor is already meeting exercise guidelines, the HCP gives them support resources to maintain their exercise and checks in with them about their exercise levels in their next meeting. If a survivor is not meeting exercise guidelines or would like additional support, the HCP refers them to a QEP who screens them, assesses their risk, and sends them to an exercise program appropriate to their individual needs. Survivors are reassessed on a regular basis as their fitness, symptoms, circumstances, and functional ability change to ensure they are always in the appropriate exercise program or have the level of support they require.

Including ICC in the pathway and allowing dyadic participation in the exercise programs could address the many barriers to exercise identified by the participants in this study.

The ICC would already be committed to assisting the survivor in getting to and from the exercise program, so participating in the program at the same time would be the time-

efficient option rather than a competing time demand. Dyadic exercise programs would also help alleviate the feelings of guilt associated with self care, as the ICC would be instructed to exercise and is doing so at a convenient time when they couldn't be performing caregiving or other related tasks anyway. Having QEP-led dyadic exercise programs would also free the ICC from worrying about their survivor while they do their own exercise. Finally, a dyadic exercise program may help alleviate the feelings of overwhelm experienced by ICC. Soon after diagnosis, when ICC-survivor dyads receive a lot of cautions and prohibitions intended to mitigate risk for the survivor, participating in an exercise program that benefits both the ICC and survivor could give them a limited but important sense of agency in their situation.

Adams and colleagues (2021) conducted an international stakeholder survey to develop a list of high-priority research and knowledge translation themes to support the implementation of exercise as a standard of cancer care. The highest ranked themes were integrating QEPs into primary care teams, evidence-based exercise oncology models for HCPs working with survivors, and accessibility of medically supervised and community-based cancer exercise programs and support services to meet the needs of diverse groups of cancer survivors. Notably, policy makers and the other stakeholder groups (healthcare providers, QEPs, researchers, and survivors and support persons) inversely ranked two themes. 'Integrating QEPs into primary cancer care teams' was ranked among the highest by all stakeholder groups except for policy makers, who ranked it the lowest. Similarly, 'Understanding the high-priority 'patient-level' and 'economic' outcomes for healthcare funders and decision-makers' was ranked the highest by policy makers and among the lowest by all other stakeholder groups. This difference in perspective may account for

some of the difficulty in implementing exercise programs for survivors and ICC and highlights the importance of focussing on policy makers' priorities when lobbying for the inclusion of ICC, QEPs, and dyadic exercise programs in cancer care.

5.2 LACK OF ONCOLOGIST SUPPORT

5.2.1 Opportunity

The second missed opportunity presented was that all the ICC in this study wanted their survivor to engage in exercise. This came from a concern for their survivors' health and their functional fitness. ICC related that it was difficult to watch their survivors' fitness decline while they were on treatment. Many related that it was difficult to motivate their survivors to exercise when they felt poorly and struggled with finding a balance between being encouraging and nagging.

All participants believed that exercise was beneficial for survivors. Indeed, exercise has been shown to be beneficial in all stages of cancer from diagnosis, through treatment, and into survivorship (Campbell et al., 2019; Cormie et al., 2017; Friedenreich et al., 2016; Kimmel et al., 2014; McTiernan et al., 2019; Newton & Galvão, 2008; Patel et al., 2019; Schmitz et al., 2010). That ICC want their survivors to exercise represents an important opportunity for cancer care because ICC are supportive of exercise interventions for survivors.

5.2.2 Barriers

All but one ICC in the study reported that healthcare teams are not discussing exercise with them or their survivors. This is a significant missed opportunity to support the health

of both ICC and survivors during their cancer journey, especially given that ICC want to exercise themselves and want their survivors to exercise.

These findings align what has been shown in the literature over the last 20 years. Studies have consistently shown that less than a third of oncologists initiate conversations about exercise with their patients (Jones & Courneya, 2002; Nadler et al., 2017; Peeters et al., 2009). The most commonly cited reason for not discussing exercise is lack of time (Nadler et al., 2017; Peeters et al., 2009), although lack of knowledge about exercise and cancer exercise guidelines may also be an important factor (Nadler et al., 2017).

One ICC, who was also a survivor, related their frustration with the lack of discussion about exercise, nutrition, and other lifestyle-related factors that they could use to find some feelings of control over their situation. Not being able to discuss these things with their oncologist led them to a naturopathic doctor who gave them things they could do to help manage their symptoms, such as remove sugar from their diet to manage their nausea. The ICC acknowledged that this was not evidenced-based care but spoke about the power of feeling listened to and the placebo effect that came from having something to do to feel better. Indeed, not feeling listened to and a desire for a positive action to manage their health have been cited as motivators for seeking alternative medicine (McCaffrey et al., 2007).

5.2.3 Solutions

It may be important that oncologists initiate discussions about exercise with ICC and survivors. Jones and Courneya (2002) found that survivors who reported oncologist-initiated discussion of exercise during their treatment consultation reported performing

more exercise during subsequent treatment than survivors who reported survivor-initiated or no discussion of exercise during their treatment consultation. Similarly, breast cancer patients who recalled receiving an exercise recommendation from their oncologist reported more physical activity than those who did not (Jones et al., 2004). Conversely, not receiving an exercise recommendation has been cited as an important factor for lack of exercise among survivors (Schmitz et al., 2019).

While oncologists should initiate discussions about exercise, oncologists should not be expected to shoulder the burden of making exercise prescriptions or of supporting ICC and survivors in adhering to exercise guidelines. Rather, oncologists should be supported by a multidisciplinary team including QEPs who are trained in assessing, prescribing, and facilitating exercise. Guidelines for providing nutritional therapy for cancer patients stress the importance of spreading responsibility for patient care across a closely collaborating multidisciplinary team (Muscaritoli et al., 2019). Indeed, Yang et al. (2019) found that offering individualized dietitian counselling to patients improved patient outcomes, with more frequent counselling being associated with better outcomes.

A similar model, such as the pathway described in section 5.1.3. should be employed for exercise counselling whereby oncologists initiate discussions about the importance of exercise and then refer ICC and survivors to QEPs who assess current exercise behaviour, make exercise prescriptions, and support ICC and survivors in achieving these prescriptions. The implementation of such a model could prevent the feelings of alienation and desire to seek alternative medical care experienced by the ICC in this study.

5.3 DO IT FOR THEM

5.3.1 Opportunity

The third missed opportunity presented was that every ICC in the study expressed a high amount of willingness to participate in dyadic or group exercise programs with their survivors. The ICC all said that if participating in an exercise program with their survivor would benefit their survivor, then they would absolutely do so, regardless of their own experience in the program. This willingness is a significant endorsement for including dyadic exercise programming in the cancer care model.

Many of the ICC imagined they would derive social benefits from participating in group exercise programs with other caregivers. For some this was a sense of community, others welcomed the opportunity to learn from or share information with other dyads, and others saw the group exercise environment as motivational. Indeed, participants in group exercise programs often cite benefits such as a sense of camaraderie, shared experience, being with people in a similar situation, and increased motivation and accountability (Emslie et al., 2007; Malcolm et al., 2016; E. Martin et al., 2015).

5.3.2 Barriers

Most of the ICC in the study felt that they would not derive any physical benefits from participating in an exercise program with their survivor. The ICC in this study all reported having much higher fitness than their care recipients. Therefore, most felt, the type of exercise that was suitable for their care recipients would not be sufficient to provide any benefit to themselves. One ICC however, had been in a group exercise program for survivors and related her experience of being in an exercise class with

knowledgeable instructors who could tailor exercises and intensities to members of the class with different abilities and fitness levels.

Some of the ICC remarked that they preferred to exercise by themselves. For them, exercise was described as a valued time for them to be alone and do their own thing.

Two of the ICC said that they would not like to be in a group environment where cancer was the unifying element. One related the difficulties they had being in an ICC support group and having to share in the struggles and loss experienced by other ICC in the group. They imagined that a similar phenomenon might occur in a group exercise program with other dyads. The other felt like cancer already occupied enough space in their life and would prefer not to add any more elements where cancer was the focus.

5.3.3 Solutions

QEPs should educate ICC and survivors about how QEP-led exercise programs are run to allay ICC concerns about exercise not being adequately challenging for them to derive physical benefits. Conversely, survivors are often concerned about their ability to exercise due to comorbidities or treatment side-effects (Frikkel et al., 2020; Knowlton et al., 2020; Mikkelsen et al., 2019; Sun et al., 2020; D. D. Yang et al., 2017). Therefore, QEP-led discussions may similarly allay potential survivor concerns that exercise may be too challenging for them at their current fitness level.

QEPs should be prepared to support ICC who prefer exercising alone with exercise prescriptions that can be followed alone, either in the context of a group-based exercise

program or at the same time but independently such that the ICC and survivor could still arrive and depart together.

ICC should also be assured that while the exercise program is part of cancer care, the focus of the exercise program would be on helping ICC and survivors maintain, improve, and enjoy their health and fitness, not on the cancer. Emslie (2007) has reported that survivors in an exercise group were almost surprised with how little space cancer took in their exercise group and the empowerment they experienced in being able to exercise beyond their cancer. Accounts like this may help alleviate ICC concerns about being in “another” cancer environment.

5.4 LIMITATIONS

5.4.1 Transferability

As a qualitative study using an interpretive description methodology, the findings of this study may not necessarily apply to all ICC. Most of the ICC that participated in this study identified as regular exercisers or as having a history of being an exerciser. ICC who already value exercise are more likely to want to participate in research about exercise. This potential selection bias means that the study was not able to capture the opinions of ICC who do not exercise regularly, and attempts should be made to understand the opinions and experiences of ICC who do not exercise regularly. Notwithstanding, these ICC stand to benefit as much or more from dyadic exercise programs as ICC who identify as exercisers.

5.4.2 Recruitment

Recruiting ICC to participate in this study proved difficult. Multiple recruitment methods were employed. ICC to survivors participating in research studies were approached about participating in this study. Many of these ICC expressed willingness to participate when initially approached but few followed through with completing or even opening the online informed consent form. Social media posts (Instagram, Facebook, Twitter) on the PAC Lab, Halifax Research Studies, and personal accounts yielded similar results; several ICC responded to posts, but few followed through with completing or opening the online consent form. Study information and posters were shared with 13 online and in-person cancer and caregiver support groups. Two of these agreed to post study information on their channels. Many Facebook support groups were discovered, those most explicitly prohibited caregiver solicitation for research participation. Printed study posters were posted in cancer treatment areas in the Victoria General Hospital in Halifax, Nova Scotia, and in libraries and community boards in Halifax and other communities in Nova Scotia. Journalists with CBC and the Herald who had previously written about cancer and cancer research were contacted but did not respond.

Difficulty recruiting ICC may be explained by their perceived lack of time. Participating in a research study might represent “another” task on an already long list of tasks.

Recruitment efforts may have benefitted from an incentive associated with participation such as a gift card, monetary, or other compensation. Regrettably, this study had no budget for incentives.

5.4.3 Cross-Sectional Nature

This study captured the experiences of ICC in a moment in time. Although ICC in the study had been providing care in a range of one to 53 months, there may not have been enough caregivers at each point in the range to get a full understanding of how opinions and experiences differ for ICC who have provided care for short, medium, or longer periods of time. This could be mitigated in the future by asking retro- and prospective questions about the ICC experience. For example, “How/Has this changed since you started caregiving?” or “How/Do you envision this changing in the next three/six/12/etc. months?”

5.4.4 Sample Size and Caregiver Comparison

The original study design included a survey that gathered ICC demographic information including socioeconomic information; relationship to care recipient; care recipient’s cancer type, treatment status, and time since diagnosis; weekly time spent providing care in hours; duration of caregiving in months; caregiving tasks provided; self-reported physical; quality of life; and exercise program participation preferences. Regrettably, the number of participants who completed the survey was not sufficient for this data to be used in a meaningful way. Therefore, this study can not provide insight into how opinions about participating in dyadic exercise programs differ among ICC who vary across these characteristics.

5.5 IMPLICATIONS FOR CANCER CARE

ICC should be included in the care cancer model. ICC have been shown to experience negative physical (Beesley et al., 2011; Dionne-Odom et al., 2017; L. L. Northouse et al., 2010; Ross et al., 2020), emotional (Cotrim & Pereira, 2008; Dionne-Odom et al., 2017; L. L. Northouse et al., 2010; Teixeira et al., 2019), social (Kent et al., 2016; L. Northouse et al., 2012), and psychosocial (Essue et al., 2020) consequences, their health is interrelated with that of the survivors they support (Kershaw et al., 2015; Litzelman et al., 2016; Litzelman & Yabroff, 2015; L. Northouse et al., 2012; Sun et al., 2019; Tan et al., 2018), and they have been included in the National Institutes of Health definition of survivorship (*Definition of Survivorship - NCI Dictionary of Cancer Terms - National Cancer Institute*, 2011).

This study highlights the missed opportunities in supporting the health of ICC. ICC are ready and willing to participate in dyadic exercise programs with their care recipients but lack the resources and institutional support to do so. The health of both ICC and survivors would be better served if QEP-led dyadic exercise programs became standard treatment in the cancer care model, if oncologist-initiated conversations about exercise occurred in initial meetings with ICC and survivors, and if QEPs consulted with ICC and survivors to assess, prescribe, support, and facilitate exercise as part of the interdisciplinary cancer care team.

Exercise programs for survivors have been shown to be cost-effective (Y. Wang et al., 2023) and may reduce health care system utilisation costs (Wonders et al., 2019).

Introducing dyadic exercise programs into standard care might be beneficial to the greater

healthcare system in addition to ICC and survivors. Further, introducing QEPs and exercise programs into the healthcare system as a whole would be similarly beneficial for the healthcare system and people living with other illnesses.

5.6 DIRECTIONS FOR FUTURE RESEARCH

ICC in this study overwhelmingly said that they would participate in dyadic exercise programs. Despite this apparent willingness to participate, dyadic exercise programs for ICC and survivors are rare. Studies investigating the effects of dyadic exercise programs on the psychosocial and physical health of ICC and survivors are warranted. The feasibility, cost-effectiveness, and effects on ICC and survivor health of including QEPs in the multidisciplinary cancer care team should also be studied. The ICC who had been caregiving the longest seemed to be better at making time for exercise, though they still did not achieve as much exercise as they would like. Future research might investigate how being counselled about the benefits of exercise and supported in achieving it early in the cancer trajectory affects short and long-term exercise behaviour of ICC. Finally, the benefits of exercise for survivors have been well established and more research demonstrating the benefits of exercise for ICC is emerging. Future work should focus on overcoming the political and structural barriers to implementing exercise programs in cancer care and in the healthcare system more broadly.

CHAPTER 6 CONCLUSION

The purpose of this research was to understand ICC needs for, preferences for, and opinions about participating in dyadic exercise programs with their care recipients. It was driven by a recognition that ICC often experience negative psychosocial and physical health consequences after taking on the caregiving role and that although exercise could be a potent intervention to support ICC, ICC often struggle to make time for exercise. After analyzing interviews with ICC, three themes relating to participating in dyadic exercise programs became clear. The themes were united by a throughline of missed opportunity to improve ICC health. Each theme was characterized by opposing opportunities and barriers to ICC participation in dyadic exercise programs.

These themes were: (1) No Time to Exercise, (2) Lack of Oncologist Support and (3) Do It for Them.

Recommendations were made to capitalize on the opportunities of and overcome the barriers to dyadic exercise program participation in order to improve the health of ICC and survivors after a cancer diagnosis. In essence, ICC should be included in the cancer care model from the time of diagnosis; dyadic exercise programs for ICC and survivors should be standard care; and after initiating discussions about exercise in early meetings, oncologists should refer ICC and survivors to QEPs who would assess, prescribe, support, and facilitate exercise.

APPENDIX A SEMI-STRUCTURED INTERVIEW GUIDE

Introduction: Hello [participant name]. My name is Tom Christensen. Thank you for taking the time to meet with me today. As a reminder, I am interested in learning more about your views relating to participating in an exercise program with your care recipient.

As a Clinical Exercise Physiologist, I am very interested in exploring informal cancer caregivers' views and beliefs regarding participating in an exercise program with their care recipients. For the purposes of this interview, the term informal cancer caregiver refers to anybody who provides uncompensated, or unpaid, care for a cancer survivor. The term cancer survivor refers to anyone who has received a cancer diagnosis regardless of whether they are pre-treatment, on treatment, or post-treatment.

Some of my questions are about physical activity and exercise. Physical activity is any kind of movement you engage in that requires energy. This includes many sorts of activities such as going for a walk, doing chores or yardwork, dancing, or playing with kids or grandkids. Exercise is a specific type of physical activity that is done with the purpose of increasing fitness.

I would like to remind you that your participation in this interview is voluntary, and you may withdraw your consent to participate now or at any time during the interview. You may also decline to answer any of the questions if you choose. Would you like to continue?

Section I: Exercise/Physical Activity Behaviour

- 1) How do you view your current fitness level?
- 2) Do you currently engage in any forms of exercise?
 - Probes: If yes:
 - (a) what type of exercise do you do?
 - (b) tell me more
 - (c) How often?
 - If no:
 - (a) have you exercised regularly in the past?
 - (b) if yes, why did you stop?
 - (c) what are some reasons why you don't engage in exercise?
 - (d) can you explain further?
- 3) Do you engage in any physical activity that you would not classify as exercise?

- a) If yes:
 - i) What type of physical activity do you do?
 - ii) How often?
- b) If no:
 - i) Have you been regularly active in the past?
 - (1) If yes, why did you stop?
 - ii) What are some reasons why you don't engage in physical activity?
 - Probe: can you explain further?/Tell me more/What does ___ mean?
- 4) How has being a caregiver impacted your ability to exercise or be physically active?
- 5) Some people prefer unstructured regular physical activity over structured exercise classes and programs. Do you prefer one or the other and why?
- 6) Do you think you would experience any physical or emotional benefits from participating in an exercise program?
 - a) If Yes: What benefits do you think you might experience?
 - b) If No: Why not?

Section II: Exploring Knowledge of Exercise for Caregivers and Cancer Survivors

- 1) Can you tell me what you know about the benefits or risks of exercise for caregivers?
- 2) Have you ever been counselled about exercise? i.e. by a doctor, personal trainer, friend
 - a. If yes, can you tell me a little about your experience?
 - b. Did you or did a healthcare provider initiate this interaction?
 - Probe: tell me more/can you explain further/what does not really mean?
- 3) Can you tell me about any concerns you might have about exercise or about becoming more active?
- 4) Can you tell me what you know about the benefits or risks of exercise for cancer survivors?
- 5) Has your care recipient's health care team discussed exercise with you and/or your care recipient?
- 6) Do you have any concerns about exercise for your care recipient or about them becoming more active?

Section III: Exploring Opinions About Dyadic Exercise

Now I would like to ask you some questions about exercising with your care recipient.

- 1) How do you feel about exercising with your care recipient?
 - a. What reservations do you have about exercising with your care recipient?
 - b. What aspects of exercising with your care recipient would you look forward to?
- 2) Would you prefer to prefer to participate in an exercise program with your care recipient or on your own?
- 3) How do you think your experience might be different if you exercised by yourself compared to with a group of other caregivers or with a group that included your care recipient?
- 4) Do you think you would experience any social or emotional benefits from participating in an exercise program with your care recipient and other caregiver-care recipient dyads?
 - a. If Yes: What benefits do you think you might experience?
 - b. If No: Why not?

Do you feel like there is anything else related to participating in an exercise program with your care recipient you would like to add? Or anything you would like to touch on?

Closing: Thank you for your time today. This finishes up the questions for the study today.

If asked how they will learn about the results of the study: I can send you a copy of the abstract of the final study. It will contain the highlights of the findings.

APPENDIX B SOCIAL MEDIA RECRUITMENT POSTER

CANCER CAREGIVER STUDY

Do you provide any kind of uncompensated care to an adult living with cancer (*personal care, physical care, nursing care, emotional support, care management*)? e.g., dressing, bathing, cleaning, laundry, dog walking, gardening, driving, making appointments, managing finances, etc.

We want to hear from you!

This research explores the needs, preferences, and views of informal cancer caregivers regarding exercise programs and physical activity



You may be eligible if you:

- Provide physical or psychological support to an adult living with cancer
- Reside in Canada
- Are 18 years of age or older
- *You don't need to be currently active to participate

You will be asked to:

- Complete a one-time online survey (30-45 minutes) or/and (your choice)
- Participate in a one-time interview (30-60 minutes)

If you are interested, please contact thomas.christensen@nshealth.ca



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Canadian Institutes of Health Research
Instituts de recherche en santé du Canada



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APPENDIX C PIN UP RECRUITMENT POSTER

Informal Cancer Caregivers needed for a study about **Providing Care to People Living with a Cancer Diagnosis**

Do you provide any kind of unpaid care for a person living with cancer?

This could include, but is not limited to:

- Personal Care (*dressing, bathing, lifting, feeding, grooming, ...*)
- Physical Care (*house cleaning, laundry, shopping, transportation, cooking, dog walking, gardening, snow clearance, ...*)
- Nursing Care (*medication administration, changing dressings, ...*)
- Emotional Support (*maintaining social interactions, emotional support, reassuring and validating experiences, managing depression/anxiety, ...*)
- Care Management (*identifying and locating needed services, making appointments, attending appointment and information sessions, managing financial matters, ...*)

We want to hear from you!

This research explores the needs, preferences, and views of informal cancer caregivers regarding exercise programs and physical activity



You may be eligible if you:

- Provide physical or psychological support to an adult living with cancer
- Are 18 years of age or older
- Reside in Canada
- *Being currently active is not required

You will be asked to::

- Complete a one-time online survey (30-45 minutes)
or/and (your choice)
- Participate in a one-time interview (30-60 minutes)

**For more information or to participate, please contact
thomas.christensen@nshealth.ca**



APPENDIX D INFORMED CONSENT FORM



Informed Consent Form Non-Interventional Study

STUDY TITLE: Assessing Informal Cancer Caregivers' Needs and Preferences for an Exercise Program and their Views Regarding Participating in a Dyadic Exercise Program with their Care Recipients

PRINCIPAL INVESTIGATOR: Tom Christensen
School of Health and Human Performance,
Dalhousie University
(782) 414-6186

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 to participate. Feel free to discuss it with your friends and family, family doctor, or health care provider.

Please ask the research team 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 caregiver to a cancer patient/survivor.

If you decide not to take part or if you leave the study early, the health care of your care recipient will not be affected.

2. Why is there a need for this study?

It is well known that performing regular exercise can maintain and improve physical and mental health. Caregivers often experience declining health after taking on the caregiving role. However, many caregivers do not know how beneficial exercise can be. Furthermore, the health of caregivers is rarely included in the care plan for cancer survivors/patients. As a result, most



cancer caregivers are not active enough to realize the many benefits associated with exercise. Thus, there is a need to offer and deliver exercise programs across clinical and community-based settings that are tailored to the unique needs of cancer caregivers. This study will provide useful information for designing exercise programs for cancer caregivers.

3. What is Being Tested?

This study is exploring the needs and preferences of cancer caregivers for an exercise program and their views regarding participating in an exercise program. The information collected will be used to inform the design of an exercise program for cancer caregivers and cancer survivors/patients. Some participants may be asked to participate in a follow-up interview that will allow a deeper understanding of their needs, preferences, and views.

4. How Long Will I Be In The Study?

The survey will require approximately 30 minutes and the interview will require approximately 30-60 minutes. If you are asked to participate in the follow-up interview your total time commitment will be approximately one to one and a half hours.

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

It is anticipated that a maximum of 690 people throughout Canada will participate in this study. A small number of participants who complete the survey will also participate in the follow-up interview (estimated 15-30).

6. How Is The Study Being Done?

Adult (18 years of age or older) caregivers to cancer patients or survivors residing in Canada may be referred to the study by an oncology care professional or they may self-refer. Following referral to the program, with your consent, a member of the research team will contact you by phone to answer any additional questions that you might have about the study. Pending your continued interest in participating, a member of the research team will provide you with instructions on how to enter a secure web-based platform known as REDCap where you will be asked to acknowledge your consent to participate and complete a survey assessing your needs and preferences for an exercise program, a short interview (30-60 minutes) to explore your thoughts about exercise and participating in an exercise program with other cancer caregivers and cancer survivors/patients, or both. Should you agree to participate in the interview, your comments will be recorded and transcribed (removing all personally identifiable information) so that we can refer back to them at a later time.

Your total time commitment for the study will be about one to one and half hours.

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

You will be asked to complete an online survey and/or participate in an interview.

The following procedures will be done as part of this study:

PROGRAM REFERRAL

You may refer yourself to the study or with your consent you may be referred to the study by a member of your care recipient's cancer care team.



SURVEY

You will be asked to complete a one-time online survey using the secure REDCap web-based application. Completing the survey may take approximately 30 minutes.

INTERVIEW

You will be asked to participate in an interview that will be conducted over the telephone, a secure Zoom meeting, or in person, depending on your preference. The interview may take approximately 30 to 60 minutes. The interview will be audio recorded and transcribed (removing all personally identifiable information) so that we can refer back to it at a later time.

NOTE: *You may decide to take part in only the survey, only the interview, or both. Participating in one does not obligate you to participate in the other.*

8. Are There Risks To The Study?

There are risks with this, or any study.

The survey will contain questions about your lifestyle behaviors and preferences for an exercise program. The interview will ask you about your exercise history, your knowledge of exercise and its benefits, your experience with exercise counselling, and about your preferences for participating in an exercise program. You may not like all of the questions that you will be asked. If you are uncomfortable in responding to any of these questions you may leave them blank, refuse to answer, or withdraw from the study at any time without penalty.

As with all research, there is a chance that confidentiality could be compromised; however, we are taking precautions to minimize this risk.

9. Are There Benefits Of Participating In This Study?

You may or may not benefit directly from participating in this study. However, possible benefits include informing the design of an exercise program that will improve the fitness, quality of life, and overall well-being of caregivers to people with cancer. Your participation may or may not help other caregivers to people with cancer in the future.

10. What Happens at the End 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. 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.

11. What Are My Responsibilities?

As a participant in the study, you will be expected to read and sign the consent form and complete the online survey, participate in a one-time interview, or both.

12. 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. The principal



investigator may decide to remove you from this study without your consent if you do not follow the directions of the research team or there is new information that shows that being in this study is not in your best interests.

You can also choose to end your participation at any time. 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.

13. Will It Cost Me Anything?

As all study procedures will be conducted online and/or over the phone, we do not anticipate that you will experience any added costs by participating in this study. If you choose to participate in the interview and choose to undergo the interview in person rather than online or over the telephone, you may be responsible for paying for parking while at the QEII Health Sciences Center.

Your signature on this form only indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate in the study. In no way does this waive your legal rights nor release the principal investigator, the research team, or involved institutions from their legal and professional responsibilities.

14. 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. However, complete privacy cannot be guaranteed. For example, the principal investigator may be required by law to allow access to research records.

If the results of this study are published or presented to the public in any way, nobody will be able to tell that you were in the study. This section describes the measures used by the research team to maintain confidentiality.

Use of Your Study Information

Any study data about you that is sent outside of Nova Scotia Health will have a code and will not contain your name or address, or any information that directly identifies you.

No personally identifiable information will be captured in the survey. For those who consent to participate in the interview, names or identifying places, etc. will be removed and replaced with pseudonyms.

All personally identifiable information will be collected on study questionnaires that identify the participant with a unique study code.

Consenting participants will complete an online survey with a randomly generated ID.

All study materials, including survey responses and interview recordings, will be stored in a secured lab in locked filing cabinets or on a password protected computer.

De-identified study data may be transferred to:

- Research team at Dalhousie University, Halifax, Nova Scotia.



Study data that is sent outside of Nova Scotia Health will be used for the research purposes explained in this consent form.

The research team and the other people listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The research team will keep any personal health information about you in a secure and confidential location for 7 years and then destroy it according to Nova Scotia Health policy. Your personal health information will not be shared with others without your permission.

After your part in the study ends, we may continue to review your health records for safety and data accuracy until the study is finished or you withdraw your consent.

The REB and people working for or with the REB may also contact you personally for quality assurance purposes.

Your Access to Records

You have the right to access, review, and request changes to your study data at any time. A description of this study will be available on www.thepaclab.com. This web site will not include information that can identify you. You can search this web site at any time.

15. Declaration of Financial Interest

This study is unfunded. The principal investigator has no vested financial interest in conducting this study.

16. What About Questions or Problems?

For further information about the study, you may contact the principal investigator who is the person in charge of this study and/or any other research team member listed below.

Tom Christensen, Principal Investigator Email: Thomas.Christensen@nshealth.ca

17. What Are My Rights?

You have the right to all information to help you decide whether or not to participate in this study. You also have the right to ask questions about this study 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

1. The Nova Scotia Health Research Ethics Board Office
 - email: ResearchEthics@nshealth.ca
 - Phone: 902-222-9263
2. Patient Relations
 - Email: healthcareexperience@nshealth.ca
 - Phone: 1-844-884-4177



18. Consent Form Signature Page

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

Assessing Informal Cancer Caregivers' Needs and Preferences for an Exercise Program and their Views Regarding Participating in a Dyadic Exercise Program with their Care Recipients

I was given the opportunity to discuss this study. All my questions have been answered to my satisfaction.

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

This signature on this 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 care.

I agree to audio recordings as described in this consent form.

E-messaging (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 done with you will be done through an NS Health email account 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 email account by research staff to communicate during this study. _____ (initials and date).

I do not wish to be contacted by email, unless I otherwise give permission at another time during this study _____ (initial and date).

I agree to permit the researchers to re-contact me to consider participation in future related research studies (e.g., follow-up interview, exercise intervention, etc.). (If yes, please provide contact information: _____)

Signature of Participant Name (Printed) Year / Month / Day*

Signature of Person Conducting Consent Discussion Name (Printed) Year / Month / Day*

Signature of Principal Investigator Name (Printed) Year / Month / Day*

***Note: Please fill in the dates personally**



I will be given a signed copy of this consent form.

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