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# Informal cancer caregivers' perceptions on dyadic exercise with their care recipients

by Thomas Christensen, Colleen Cuthbert, and Melanie R. Keats

## ABSTRACT

**Purpose:** To explore the needs, preferences, and opinions of informal cancer caregivers regarding exercise programs.

**Methods:** Guided by an interpretative description approach, semi-structured interviews with eight informal cancer caregivers were conducted. Interviews were transcribed verbatim and analyzed using an iterative approach.

**Results:** A throughline of missed opportunities to support informal cancer caregiver health with dyadic exercise programs underpinned three themes in the data: (1) No Time for Exercise, (2) Lack of Oncology Care Team Support, and (3) Do It for Them. Each theme was characterized by opposing barriers and opportunities to participating in dyadic exercise programs.

**Conclusions:** Informal cancer caregivers appear ready and willing to participate in dyadic exercise programs with their care recipient, yet opportunities and supports to do so are limited. Oncology nurses may play an important role in supporting their patients to be physically active through referrals to exercise programs led by qualified exercise professionals.

**Keywords:** informal caregiver, cancer, survivorship, exercise, dyadic intervention, qualitative

## INTRODUCTION

A cancer diagnosis is a stressful event placing new demands on both those living with and beyond cancer (LWBC) and their families, including coping with, and recovering from the

physical and psychosocial effects of the disease and its treatment. A shift from inpatient to outpatient and home-based care, driven by rising healthcare costs has resulted in family members taking on a greater proportion of disease management (Kent et al., 2016; Wittenberg & Prosser, 2016). With increasing responsibility for care, informal cancer caregivers (ICCs) often carry the responsibility of managing several caregiving tasks that include but are not limited to, meal preparation, personal care, transportation, medical care, communicating with healthcare providers, and emotional support. These responsibilities are often competing and are performed over an extended period time (Kent et al., 2016). While some ICCs share positive experiences associated with caregiving, such as personal growth and strengthened personal relationships (Song et al., 2024), caregiving is a mentally (Essue et al., 2020), physically (Northouse et al., 2012; Ross et al., 2020), emotionally (Northouse et al., 2012; Teixeira et al., 2019), and socially (Kent et al., 2016; Northouse et al., 2012) demanding role often negatively impacting ICC well-being and quality of life.

Importantly, the unmet emotional, cognitive, and/or physical needs of the ICC can negatively impact their ability to manage their care recipients' physical, emotional, and medical needs (Litzelman & Yabroff, 2015; Northouse et al., 2012). For example, high emotional stress in a spousal caregiver, if not treated, has been found to negatively affect the ability of the individual LWBC to adjust to their diagnosis (Northouse et al., 2012). Despite being a key partner in care, ICCs are often inadequately prepared or supported to take on this critical role, subsequently putting their own health and well-being at risk, and, by extension, that of their care recipient (Wittenberg & Prosser, 2016).

Studies investigating the health of ICCs have highlighted the need for interventions to improve the health of caregivers (Ross et al., 2020; Teixeira et al., 2019) and in turn, the health of their care recipient. Interestingly, while 32% of ICCs 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 (NAC and the AARP Public Policy Institute, 2015). With a growing understanding of the significance of informal cancer caregiving, there has been an increase in research involving interventions designed to mitigate ICC burden and the subsequent negative outcomes (Ferrell & Wittenberg, 2017). To date, these interventions have been largely psycho-educational, focusing on increasing caregiver knowledge and skills pertaining to caregiving tasks, coping skills, and self-care (Ferrell & Wittenberg, 2017; Lambert et al., 2016; Northouse et al., 2012).

The value of exercise has been well-demonstrated, showing that virtually everyone can benefit from moving more (Warburton & Bredin, 2017). Preliminary data suggests that

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exercise interventions show promise in mitigating ICC burden and improving health outcomes for both the ICC and care recipient (Cormie et al., 2017; Lambert et al., 2016) and both ICCs and those LWBC have consistently expressed an interest in exercise to support their health (Keir, 2007; Nightingale et al., 2016; Roddy et al., 2021). Regrettably, few interventions have specifically targeted exercise as a self-management strategy as a means of improving ICC health and well-being within cancer care (Anton et al., 2013; Cuthbert et al., 2018; Martin & Keats, 2014). While the exercise preferences of those LWBC have been widely studied across a range of cancers (Jones & Courneya, 2002; Karvinen et al., 2006; McGowan et al., 2013; Philip et al., 2014; Vallance et al., 2006), to the best of our knowledge no study has explored ICC needs or preferences with respect to engaging in dyadic exercise programs with one's care recipient.

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.

## METHODS

### Design

We conducted the study using interpretive description, a qualitative research approach that is increasingly being used in applied health fields to capture the subjective experience of a population where the goal is to gain knowledge, inform clinical practice, and improve clinical outcomes (Thorne, 2016; Thompson Burdine et al., 2021). Interpretive description, like other qualitative descriptive approaches, is a systematic analysis of a phenomenon based in inductive reasoning. Thorne (2016) describes how researchers should conduct interpretive description to create credible, defensible knowledge that is meaningful and relevant in the applied context. The Nova Scotia Health Research Ethics Board approved the study (File #1027500) before it commenced. All participants provided informed consent before each interview. The authors followed the 32-item checklist of the consolidated criteria for reporting qualitative studies (COREQ) in preparing this manuscript (Tong et al., 2007).

### Participants

ICCs who were 18+ years of age, were able to provide written consent in English, resided in Canada and were providing care to an adult LWBC at the time of participation were eligible to participate. We recruited participants through word-of-mouth, posters placed in local cancer clinics and community boards, shared on social media (Facebook, Twitter, Instagram) and in cancer care and online ICC forums and support groups. We invited potential participants to contact the lead researcher for additional information about the study. Participants were not provided any additional information about the researcher other than contact information and qualifications. Participants who consented were invited to participate in a semi-structured interview either in person, by phone, or over a secure Zoom call.

### Data Collection

We designed a semi-structured interview guide to gain an understanding of ICC's need for exercise programs, knowledge of and opinions about exercise, facilitators, barriers, and preferences for exercise participation, and their opinions about exercising with their care recipient. We developed the interview guide in consultation with experts in exercise oncology, exercise prescription, cancer caregiving, and qualitative 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 ICCs and those LWBC 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 ICCs, with other ICCs-care recipient dyads). T.C., a cisgender male master's candidate and clinical exercise physiologist in an exercise oncology research lab conducted all interviews between April 2022 and February 2023. No other individuals were present during the interviews. The researcher did not have a previous relationship with any of the participants. Interviews lasted between 30 and 75 minutes and were audio recorded and transcribed verbatim. T.C. took notes during the interviews, transcription, and with each re-reading/listening of the interviews about questions, potential connections, meaningful elements, and other impressions about the data. We did not conduct repeat interviews and we did not return transcripts for additional comment.

### Analysis

T.C. conducted the analysis of the interviews guided by interpretive description (Thorne, 2016). T.C. kept initial coding broad to avoid premature categorization that might prevent the researchers from seeing the bigger picture or from discovering important connections later in the analytical process. Following 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 assessed 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 themes that represented the meaning of the individual and collective data were relevant within the clinical context. All authors discussed and agreed upon the resulting themes.

## RESULTS

### Participant Characteristics

Twenty-two people expressed interest in participating and 20 met the eligibility criteria. Of these, 14 consented to participate in the semi-structured interview. Six of these did not respond to follow-up communication regarding scheduling the interview and eight (six females) were interviewed.

Participants were aged between 38–76 years, 75% were spouses of the care recipient, 88% had post-secondary and higher education, and 50% reported working full- or part-time. Time spent in the caregiving role ranged from 1 to 53 months.

### Missed Opportunities

A throughline of missed opportunities to improve ICC and care recipient health through dyadic exercise programs underpinned the experience of participants. Three main themes described the ways in which ICCs 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 (“No Time for Exercise”, “Lack of Oncology Care Team Support”, and “Do it for Them”) was characterized by opposing opportunities and barriers to participating in dyadic exercise programs. The three themes and representative quotations are provided in Table 1.

#### Theme 1: No Time for Exercise

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

ICCs often remarked on how beneficial exercise was for both their physical and mental health. While not every ICC said they exercised to benefit their physical health, all commented on the mental health benefits of exercise. Many of the ICCs also highlighted the importance of exercise for maintaining their own health specifically in the context of caregiving. Most of the ICCs in this sample reported that they were regular exercisers or had been regular exercisers in the past.

*Barrier: Exercise Becomes Difficult After Caregiving Begins*

Despite all recognizing the value of exercise and the importance of being healthy to provide better care, many ICCs struggled with getting regular exercise. Many noted that the increased demands associated with caregiving made finding time to exercise more difficult. Others commented that they might be able to find the time but were concerned about leaving their care recipient alone while they exercised. Some also expressed feelings of guilt with taking time for themselves.

Other key reasons for not achieving their desired amounts of exercise included fear with leaving their care recipient alone long enough to achieve a meaningful workout and feeling too overwhelmed by the ICC experience to find the motivation to exercise. Some ICCs 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 oncology care team about things they should be careful of, refrain from doing, and watch out for.

#### Theme 2: Lack of Oncology Care Team Support

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

ICCs expressed difficulty in watching their care recipients lose fitness and function secondary to their illness and treatments. Most ICCs wanted their care recipients to exercise for the purpose of gaining fitness or regaining lost function.

*Barrier: Exercise is Rarely Discussed by Members of the Oncology Care Team*

While one ICC reflected positively about how the health-care team discussed exercise with them and their care recipient, generally exercise was rarely discussed in appointments with the oncology care team. ICCs noted that during these appointments, their care recipients were given general recommendations to avoid becoming sedentary or to engage in moderate exercise. However, specific exercise recommendations, prescriptions, or resources were not provided. Some ICCs expressed frustration about not receiving specific information and guidance about exercise from members of the oncology care team.

#### Theme 3: Do It For Them

*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, while others were less enthusiastic, noting that they would do so for their care recipient's benefit. Most of the ICCs perceived a social benefit from participating in group exercise programs with their care recipients. For some this was a sense of shared experience and an opportunity to learn from and/or help other participants through their cancer experience.

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

Although all the ICCs were willing to participate in exercise programs with their care recipients, some reservations were expressed. These reservations fell into three categories. Most notably, many of the ICCs expressed concerns about their ability to get a quality workout because they were fitter than their care recipients. Others noted that they preferred exercising alone. Some ICCs expressed concern about engaging in another environment where cancer was the focus.

## DISCUSSION

Cancer has been characterized as a family affair, as it is a disease in which both the patient and their family are confronted by considerable physical and psychological stressors (Kent et al., 2016). Cancer care is multifaceted and the inter-relationship between the health of the patient and that of the ICC has been well-established (Northouse et al., 2012). This study highlights several missed opportunities in supporting the health of ICC and in turn, that of the care recipient.

First, all the ICC in this study explicitly talked about the value of exercise for their personal health but were reluctant to dedicate time to their own health because they felt they should be using their time on specific caregiving or related duties which, for some, seemed omnipresent and never-ending. These experiences are consistent with research showing that ICCs often forego leisure activities due to the time requirements of their caregiving duties (Longacre, 2013; Roddy et al., 2021) and feelings of guilt with taking time for themselves (Lim et al., 2021).

Second, all the ICCs in this study also believed that exercise was important for their care recipient, spoke to their

**Table 1**

*Qualitative Interview Themes and Representative Quotes*

Theme	Quotes
<b>No time for exercise</b>	
Opportunity	ICC view exercise as valuable for both physical and mental health
Physical health	<i>"I honestly believe there have been significant benefits to me because of being so active all these years"</i> – Participant 8
Mental health	<i>"Fit body, fit mind – you can handle things more when your body's well... It's a good way to relieve stress."</i> – Participant 4 <i>"I think it's mental well-being. Exercising helps my mental well-being"</i> – Participant 5
Caregiving	<i>"...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"</i> – Participant 1 <i>"[You] can't pour from an empty cup"</i> – Participant 2
Barrier	Exercise becomes difficult after caregiving begins.
Time	<i>"...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"</i> – Participant 4 <i>"It just seemed like always very busy and that made me even more busy."</i> – Participant 7
Worry	<i>"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.'"</i> – Participant 6 <i>"I have to be more selective with when I do exercise. [...] 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"</i> – Participant 8
Guilt	<i>"...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"</i> – Participant 5 <i>"Sometimes a big thing is I think you feel guilty if you're taking care of yourself. [...] I feel bad about it because hey shouldn't I be going and doing something more important over here?"</i> – Participant 7
<b>Lack of Oncology Care Team Support</b>	
Opportunity	ICC want their care recipients to exercise to gain fitness.
Regain fitness	<i>"I was really concerned about how wiped out she was. [...] 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.'"</i> – Participant 7 <i>"So, I think there often is a loss of muscle mass which makes the exercise even more important"</i> – Participant 8
Barrier	Exercise is rarely discussed by members of the oncology care team. <i>"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."</i> – Participant 2 <i>"Zero. [...] I find it shocking how little consultation from the medical team has been shared with us about fitness and nutrition or exercise and nutrition."</i> – Participant 6 <i>"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> – Participant 7
<b>Do if for them</b>	
Opportunity	ICC are willing to participate in dyadic exercise programs for their care recipient's benefit. <i>"If it would get her involved and doing things and encourage her or keep her involved, I would be glad to do it."</i> – Participant 8 <i>"If I was told it would help him, I would just do whatever I was told to do"</i> – Participant 5
Shared experience and information sharing	<i>"It would be helpful to be able to debrief and just find out other people's experiences. [...] 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."</i> – Participant 3 <i>"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."</i> – Participant 5
Barrier	ICC do not believe dyadic exercise programs are sufficiently challenging.
Not challenging	<i>"She walks too slow. [laughs] I'd enjoy the conversation, I just don't know how much exercise we'd be getting, but we would be moving."</i> – Participant 3 <i>"She has gone to – she calls it an exercise class – it's not what I would consider to be strenuous exercise. [...] Her definition of exercise and mine are significantly different and they always have been."</i> – Participant 8
Break from cancer	<i>"...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."</i> – Participant 8 <i>"After a while I need to be away from those conversations."</i> – Participant 4

Note. ICC = Informal Cancer Caregiver.

concerns over the loss of fitness and functional decline that they observed in their care recipient while they were on treatment, and reported wanting their care recipient to engage in exercise. Indeed, exercise has been shown to be beneficial through all stages of the cancer journey (Campbell et al., 2019; Cormie et al., 2017; McTiernan et al., 2019).

Thirdly, all ICCs explained that if participating in an exercise program with their care recipient would benefit their loved one, then they would absolutely do so, despite reservations about the benefits of dyadic exercise programs for their own health and fitness. Given the negative mental and physical health consequences associated with becoming an ICC, and the inter-relationship between ICC and patient health, it seems appropriate to consider the health of the ICC in the cancer care model and to support both ICCs and those LWBC in achieving adequate levels of exercise to support their health.

ICCs that already recognize the benefits of exercise for their and their care recipients' health are likely a receptive audience to information about exercise that is presented in the context of cancer care. Notwithstanding, some ICCs may need to be explicitly instructed to exercise. This is important both for ICCs who already recognize the benefits of exercise but are likely to down-prioritize exercise in their new caregiving role such as the ICCs in this study, and for ICCs who do not already recognize the benefits of exercise and stand to gain much by beginning an exercise program when they become caregivers.

Oncology care provider (OCP)-initiated discussions are known to play an important role in supporting patient engagement in exercise. OCPs, including nurses are well placed to discuss the importance of exercise with both ICC and their care recipients and may be an important enabler for them to engage in the exercise they require to maintain and improve their health (Bauder & Cabrera Chien, 2024; Campbell et al., 2019; Caperchione et al., 2022; Ramsey et al., 2022; Schmitz et al., 2019; Shea et al., 2020). We posit that ICCs and their care recipients would be well served if exercise was discussed in the initial meetings ICC and their care recipients have with the cancer care team. ICCs 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. ICCs should also be educated about the interrelated nature of ICC and their care recipient's health so that ICCs understand that neglecting their own health can have harmful effects on their care recipients. Like their care recipients, ICCs should also have their physical activity levels assessed in these initial meetings and be provided exercise prescriptions and supports to meet physical activity guidelines if they do not already. ICCs should leave these initial meetings with an appreciation of the physical and mental health challenges they are about to encounter and feeling empowered with the knowledge and tools they need to better face these challenges. Follow-up meetings should include reassessments of ICC physical activity levels and adherence to exercise prescriptions and any necessary coaching to help ICC maintain or meet their exercise prescriptions.

Despite the powerful effect of OCP-initiated discussions of exercise, and consistent with the findings of this study,

most OCP are not routinely promoting exercise in their practice (Hardcastle et al., 2018). The most commonly cited reason for not discussing exercise is lack of time, although lack of knowledge about exercise and cancer exercise guidelines may also be an important factor (Ligibel et al., 2019; Nadler et al., 2017). Therefore, while it is important for OCPs to initiate discussions about exercise, and for the healthcare team to support ICCs and their care recipients in achieving adequate levels of exercise, OCPs should not be expected to shoulder the burden of making and monitoring adherence to exercise prescriptions. Rather, OCPs should be supported by a multidisciplinary team including qualified exercise professionals (QEPs; e.g., exercise physiologists, kinesiologists) who are trained in assessing, prescribing, and facilitating exercise (Bauder & Cabrera Chien, 2024).

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). Recent work has investigated the implementation of exercise programs in cancer care and the development of pathways for connecting those LWBC with appropriate exercise programs and/or resources. Recommendations from this work include integrating QEPs into the oncological healthcare team, initiating conversations about exercise at the earliest opportunity, screening or assessing those living with cancer 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; Santa Mina et al., 2018; Newton, 2018; Stout et al., 2020). Including ICCs in the cancer care pathway and allowing dyadic participation in exercise programs may address the many barriers to exercise identified by the participants in this study. Many ICCs in this study reported their commitment to assisting their care recipient in engaging in and benefiting from an 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 fear from leaving their care recipient alone while engaging in their own exercise routine, or the guilt associated with self-care, as the ICC and care recipient would be participating and benefiting from the exercise together. While some ICCs expressed that they are much fitter than their care recipient and would, thus, not be challenged or benefit from the same exercise routine required to meet the reduced abilities of their care recipient, QEPs are able to individualize exercise programs to meet the preferences, needs, and abilities of ICCs and those LWBC alike. ICCs should be assured that while the exercise program is part of cancer care, the focus of the exercise program is to help *both* ICC and their care recipient maintain, improve, and enjoy their health and fitness.

## LIMITATIONS

The findings of this study should not be generalized to all ICCs. Most of the ICCs that participated in this study identified as being highly educated and as regular exercisers or as having a history of being an exerciser. The potential selection bias means that the study was not able to capture the opinions of ICC who are less well educated with potentially reduced access to supportive care resources and those who do not or have not exercised on a regular basis. Future studies are needed to assess the impact of additional socio-medical and demographic characteristics (overall health status, income, race, ethnicity, rurality, etc.) on the needs and preferences of ICC. Notwithstanding, ICC with less education or who do not identify as regular exercisers may have as much or more to gain from exercise counselling and support as the ICC in this study.

Given the cross-sectional nature of the study, we were only able to capture a single 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 ICC 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. Moreover, despite using multiple recruitment methods, recruiting ICC to participate in this study proved challenging. Finally, many ICC who initially

expressed an interest in participating failed to follow through with consent. Difficulty recruiting ICC may be partially explained by their perceived lack of time and an additional task on an already long list of tasks.

## CONCLUSIONS

While ICCs appear ready and willing to participate in dyadic exercise programs with their care recipients, they report lacking the resources and support to do so. OCPs should educate both their patients and ICCs about the mutual benefits of exercise. Given the known benefits of exercise for those LWBC (Baumann et al., 2024) and ICC (Cuthbert et al., 2018; Lambert et al., 2016), and the reductions in cancer care costs associated with exercise programs (Wang et al., 2023; Wonders et al., 2022), including dyadic exercise programs in the cancer care model appears to be a logical course of action. The health of both ICCs and their care recipient may be better served if QEP-led dyadic exercise programs became standard treatment in the cancer care model – at a minimum ICCs should be offered the opportunity to actively participate in exercise sessions with their care recipient.

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