Promoting self-care behaviours among cancer caregivers

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Abstract

Caregivers play an integral role in the cancer care system in Canada as they provide unpaid care and support for millions of adults living with and beyond cancer. Although caregiving can be a positive experience for some, assuming a caregiving role can be detrimental to caregivers' own physical and mental health. Research over the past decade has highlighted the negative impacts of caregiving and called for more efforts focused on improving caregivers' wellbeing. Most interventions targeting caregivers are largely designed to support them in providing care, with little emphasis placed on specifically promoting self-care behaviours. To address this gap, we designed a brief 4-week self-determination theory-based intervention to improve two self-care behaviours (i.e., physical activity and fruit and vegetable consumption) among cancer caregivers. The primary objective of the mixed-methods research presented in this thesis was to assess the feasibility and acceptability of the intervention. Exploratory objectives included understanding participants' experiences within the intervention. The single-arm intervention was delivered via four weekly video calls to 13 caregivers (mean age=57.6±15.4 years) across Canada. The enrollment rate was 62% and the retention, adherence, and fidelity rates ranged from 90 to 99%. The intervention was generally deemed acceptable by participants; however, modifications such as adding psychological support were suggested. Participants' experiences participating in the intervention were captured within three themes: (1) *(Re)prioritizing self-care behaviours;* (2) *Finding support for self-care behaviours within the caregiving context;* and, (3) *Becoming a better caregiver through self-care behaviours.* Although promising, modifications to the intervention methods are needed to improve enrolment and better meet caregivers' needs. This study highlights the importance of self-care behaviours for

caregivers and provides valuable information on how to foster these behaviours among this population.

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Chapter One: Introduction

In Canada, there are approximately 8 million adults who provide unpaid care and support for another person (e.g., partner, family member, friend, neighbour) who is living with a chronic or disabling condition [1]. There is increasing reliance on these adults, generally referred to as *informal caregivers* or *family caregivers* (hereafter referred to as caregivers), because they can relieve the financial burden on the Canadian healthcare system by helping to postpone or eliminate the need for professional care [1, 2]. In the cancer context, medical advances, shorter hospital stays, and increasing lifespan have contributed to a rise in the number of adults who assume the role of caregiver for people living with cancer. The role of cancer caregiver is now the second most prevalent type of caregiver in Canada, representing approximately 11% of all caregivers [1].

Although caregiving can offer positive outcomes for some [e.g., fostering a positive relationship with the care recipient, improving one's view of themself; 3, 4-6], there are numerous responsibilities that are stressful for caregivers and can negatively impact their mental, emotional, and physical health [7-9]. Examples include offering psychological support, assisting with activities of daily living (e.g., getting dressed, bathing the person, preparing foods), and/or providing instrumental support (e.g., arranging transportation, managing finances). There is mounting evidence that caregivers are at a higher risk than non-caregivers for developing a range of chronic diseases [e.g., cardiovascular diseases, obesity, depression; see 10 for a review]. Some studies also show that assuming the role of a caregiver can negatively impact one's participation in self-care behaviours [i.e., physical activity [PA], fruit and vegetable [FV] consumption; 11, 12, 13], which may be one reason, among others, why caregivers experience considerable health

declines [14]. Efforts promoting self-care behaviours among caregivers may help to enhance their health and wellbeing, and thus allow them to better assume the role of a caregiver [11].

Current interventions targeting caregivers are largely designed to support them in providing care, with little emphasis placed on specifically promoting self-care behaviours [15-17]. Owing to the wide range of physical and psychological health benefits associated with PA [e.g., 14] and the low PA levels among caregivers [11-13], interventions should aim to help caregivers increase PA levels. Presumably, by experiencing improved physical and psychological health via increased PA, caregivers may find it easier to manage the physical (e.g., helping with transportation, heavy lifting, bathing) and psychological demands (e.g., perceived stress, burden, anxiety) of caregiving. Importantly, when developing and implementing interventions, commonly reported perceived barriers for caregivers such as the care recipients' health issues, caregivers' experiences of guilt or a perceived inability to leave the care recipient, heavy caregiving responsibilities, and other tangible obstacles (e.g., weather, expenses, transportation) that may limit their participation in the intervention should be considered [9]. Accordingly, interventions that use technology (i.e., eHealth and/or telehealth interventions) and offer individuals the ability to participate remotely may help to address caregivers' busy schedules, unique responsibilities, and the aforementioned barriers [18-21]. Beyond considering the modality, it is equally important to ensure strategies designed to support key theory-based factors that underpin PA behaviour (i.e., caregivers' perceived competence, autonomy, relatedness and motivation for PA) are integrated to increase the likely success of interventions [22, 23].

Another self-care behaviour that is important to promote among caregivers is FV consumption. Despite evidence suggesting that FV consumption can reduce the risk of a number

of chronic conditions [e.g., cardiovascular diseases, obesity, colon cancer; 24], caregivers have poorer eating habits, including lower FV consumption, than those who are not caregivers [e.g., 25, 26]. Consuming more FVs is also linked to overall healthier eating patterns [27] and can lead to sustained energy balance, which may in turn improve caregivers' ability to engage in physically demanding tasks (e.g., heavy lifting, bathing). However, interventions aimed at increasing FV intake in caregivers are scarce. When looking at the PA and FV bodies of literature collectively, it is apparent that the existing few interventions aimed at improving self-care behaviours among caregivers have focused on a single behaviour [e.g., PA; 17] and seldom targeted key theory-based factors that underpin both behaviours. Reasons for the former may be because of the notion that caregivers have limited time and may be overwhelmed by attempting to change more than one behaviour simultaneously. Yet, it may not be feasible or desirable for caregivers to engage in multiple interventions for each behaviour. Acknowledging that resources and caregivers' time are limited, it may be of value to target PA and FV consumption behaviour change simultaneously as engagement in these behaviours may be explained by similar mechanisms [e.g., intrinsic motivation, self-regulation; 28]. Moreover, promoting PA and FV consumption simultaneously may help caregivers lead a healthier lifestyle and have adequate energy and skills to manage caregiving responsibilities [28-30].

To address the aforementioned limitations, we developed a brief 4-week eHealth intervention grounded in self-determination theory [SDT; 31] aimed at improving caregivers' self-care behaviours. Throughout the 4 weeks, the goal was to provide caregivers with autonomy support and foster their perceptions of autonomy, competence, and relatedness in relation to PA and FV consumption in order to promote self-determined (or autonomous) motivation for these self-care behaviours and ultimately increase PA and FV consumption. The main objective of this

mixed-methods study is to assess the feasibility and acceptability the brief intervention. The exploratory objectives are to examine if participants' self-care behaviours are correlated with targeted SDT-based constructs (i.e., autonomy, competence, relatedness, self-determined motivation) and explore caregivers' experiences and perspectives within the intervention to understand the impact it may have on their self-care behaviours and their role as a caregiver. By gaining insight into caregivers' experiences and perspectives, future programs can be tailored to meet their specific needs to foster self-care behaviours.

Chapter Two: Review of the literature

Caregiver's health status

Caregivers are a critical part of the healthcare system [2]. They report numerous negative physical and psychological health problems that can affect their role and their own health [see 10 for a review]. For example, cancer caregivers report poorer quality of life, emotional distress, more financial hardship, and greater physical strain compared to those who are not caregivers and compared to adults caring for someone living with a different type of chronic or disabling condition [e.g., problems associated with aging; 9, 10]. Cancer caregivers may experience poorer health outcomes based on the unique circumstances of providing care to someone with cancer, such as the sudden onset of disease, the perceived unpredictability of the disease, and the notion that cancer is a life-threatening condition [9]. Further, cancer caregivers provide, on average, more hours of care (e.g., assisting with dressing, bathing, arranging transportation, managing finances, doing housework) per week than those caring for the elderly [9, 32]. Given the negative consequences of caregiving and the unique context of cancer caregivers, it is important to explore strategies that may help caregivers better manage the caregiving role and protect their own health and wellbeing.

Self-care behaviours

One strategy to help caregivers' mitigate negative health outcomes may be to promote self-care behaviours (i.e., PA and FV consumption) because rates are lower compared to those who are not caregivers and caregivers report declines in self-care behaviours after assuming the caregiver role [1, 10, 13, 33-36]. A recent study of over 9,000 caregivers in Canada found that 17.2% to 32.4% of caregivers reported a decrease in PA and 10.8% to 19.1% reported a decrease in healthy eating upon assuming the caregiving role, with variations based on caregivers' age

[33]. In Australia, Beesley et al. [11] found that half of caregivers did not meet PA guidelines, 80% ate less than five servings of FVs per day, and 56% reported decreased participation in self-care behaviours (e.g., PA) after assuming the caregiving role. Low engagement in self-care behaviours is problematic because PA and FV consumption specifically can effectively prevent or help manage several negative consequences reported by caregivers [e.g., cardiovascular diseases, stress, depression, fatigue; 14, 24, 37, 38]. As evidence of this, Stenberg et al. [39] found that the most common physical health problems reported by cancer caregivers are sleep disturbances, fatigue, loss of physical strength, and impaired appetite – which may be alleviated by increased engagement in self-care behaviours.

In regards to PA, increases in PA may equip caregivers with the skills necessary to complete physical (e.g., helping with dressing, bathing) and emotional (e.g., stress management, providing emotional support) caregiving responsibilities [40]. Importantly, it has shown to be effective for the prevention and treatment of many physical [e.g., diabetes, cardiovascular disease, obesity; 14, 41] and mental health conditions [e.g., depression; 37]. Further, a number of mechanisms by which PA can alleviate stress have been proposed [42]. PA may offer distraction from stressful situations [43], act through neurobiological mechanisms to influence serotonin and dopamine [44], and/or foster feelings of accomplishment and mastery [23, 31]. Initial evidence suggests that PA may help alleviate feelings of burden among caregivers [45] and enhance caregivers' sense of control over caregiving choices [46]. A review of four interventions that encouraged PA with the intention of reducing burden in caregivers of those with dementia found a significant reduction of subjective caregiver burden among caregivers who were physically active [45]. These findings highlight that improvements in PA may equip caregivers with the

skills necessary to complete physical (e.g., helping with dressing, bathing) and emotional (e.g., stress management, providing emotional support) caregiving responsibilities [40].

In regards to healthy eating, a diet high in FVs helps with weight management and lowers the risk of many physical health conditions [e.g., cardiovascular diseases, colon cancer; 24, 47]. Moreover, increasing FV consumption is associated with improvements in overall diet through increasing micronutrient, carbohydrate, and fiber intakes while potentially decreasing fat intake [27]. In light of these findings, researchers have attempted to increase FV consumption among various populations (e.g., obesity, cancer patients). So far, efforts have yielded positive results. In their systematic review of 44 trials, Pomerleau et al. [48] suggest that interventions have been successful at increasing FV consumption; yet, such interventions are scarce among cancer caregivers. Interventions targeting FV consumption may be particularly beneficial for caregivers as they are at risk for poor nutritional status, have poorer eating habits than those who are not caregivers [e.g., 25, 26, 49], and require energy to complete physically and mentally demanding caregiving responsibilities.

Given that PA and FV consumption are two self-care behaviours that are reinforced by interrelated psychological, social, and environmental factors, it is not surprising that low PA and FV consumption tend to co-occur [50, 51]. Despite this, researchers have historically targeted one behaviour primarily due to limited resources (e.g., financial constraints, lack of space, limited researcher and participant time). Nonetheless, given the similarity between mechanisms underlying PA and FV behaviours (e.g., self-determined motivation, self-regulation, competence), some contend that interventions targeting the mechanisms underlying multiple behaviours may be the best use of limited resources [28, 30]. In support of this contention, researchers who have targeted multiple behaviours simultaneously have found that increases in

one behaviour tends to facilitate change in other behaviours [e.g., 52, 53]. For example, James et al. [53] conducted a randomized controlled trial with caregivers employing behaviour change strategies that successfully improved both PA and nutrition (characterized as intake of fruits, vegetables, red meat, processed meat, dietary fiber, and alcohol intake) among cancer patients and their caregivers. Their findings offer initial support for the notion that a single intervention aiming to change multiple health behaviours among caregivers may be effective. Nevertheless, the feasibility and acceptability of such interventions for caregivers needs to be assessed to ensure that targeting both PA and FV consumption together is an appropriate method to improve caregivers' self-care, health, and wellbeing.

Self-care interventions for caregivers

A recent systematic review of PA interventions to improve caregivers' psychosocial outcomes, PA, and physical health identified 14 interventions of which only one was specific to cancer caregivers [17]. Overall, the most commonly examined outcomes of the interventions reviewed were increases in caregivers' PA, wellbeing, quality of life, sleep quality, self-efficacy for caregiving and/or PA, and decreases in caregivers' distress. However, the types of PA promoted (e.g., walking, aerobic exercise, tai chi, strength training, stretching), delivery modality (e.g., group-based, home-based exercises, telephone support), and characteristics of the sample (e.g., adults caring for older adults, those with dementia, Alzheimer's, stroke, mental illness, and/or cancer) varied greatly and the quality of included articles (as assessed by the Cochrane Collaboration's Risk of Bias Tool) was rated low-to-moderate, hindering the ability to draw clear conclusions on the effectiveness of existing interventions and whether they can and should be implemented.

Two further limitations of existing interventions are the scarce application of behaviour change theories as a framework for the development, implementation, and evaluation of the intervention, and the inconsistent use and reporting of established behaviour change techniques. These are noteworthy because there is strong evidence showing that interventions conceptualized, developed, and implemented using theory and integrating behaviour change techniques are more effective at changing behaviours that those that do not [22]. For example, Farran et al. [54] conducted a 6-month telephone-based intervention (totalling 5 hours of intervention time) with 15 caregivers of persons with Alzheimer's disease to support engagement in PA. The single-arm intervention was based on social learning theory [55] and targeted improving caregivers self-efficacy for PA by employing self-management techniques such as goal setting, self-monitoring, feedback from the interventionist, identifying barriers and solutions to overcome them, and relapse prevention (also commonly classified as behaviour change techniques; [56]). After completing the intervention, 50% of caregivers self-reported that they increased their total PA. In a follow-up randomized controlled trial, Farran et al. [57] found that caregivers participating in their individualized PA intervention increased PA from baseline to 12 months. The intervention was guided by social cognitive theory [58] and delivered tailored sessions employing self-management techniques (e.g., setting short and long-term goals, planning PA, building a support system). Another noteworthy intervention that was based on social cognitive theory [58] and motivational interviewing [59] and that offered dementia caregivers 14 telephone calls over a 6 month period focused on self-management (e.g., setting goals, monitoring behaviour, problem solving) was successful at increasing PA among caregivers in the intervention group with low baseline PA compared to those in the control group [60].

Although social cognitive theory [58] and social learning theory [61] may help understand behaviour change through examining personal (e.g., self-efficacy) and environmental factors (e.g., peer influence), there is a lack of focus on motivation for the behaviour, a factor that has been shown to be a strong predictor of engagement in health behaviours [e.g., 62]. As such, applying theory focused on motivation for behaviour change such as SDT, which also embeds similar constructs to those of social cognitive theory [58] and social learning theory [61], when designing and implementing interventions may provide valuable insight into why caregivers engage in self-care. Whereas the above interventions provide initial evidence suggesting that PA interventions may be effective at increasing PA in caregivers, careful consideration of the theoretical framework, delivery modality (e.g., face-to-face, home-based, eHealth), and research design (e.g., quantitative, qualitative, mixed-methods) is warranted.

Theoretical framework and behaviour change techniques

Based on robust evidence supporting the use of theory to develop and implement behaviour change interventions [22], we developed the present intervention using SDT as a guiding framework. SDT is a theory that has been widely used to examine motivation for health behaviours in various populations [e.g., 23, 63-69], and in turn design interventions to change behaviours by fostering self-determined (or autonomous) motivation. It is a global theory of motivation that suggests if individuals' psychological needs of autonomy (i.e., need to be causal agents of ones' own life), competence (i.e., need to control outcomes and experience mastery), and relatedness (i.e., need to be interconnected, interact with, care for others, and be cared for) are satisfied, they are more likely to experience self-determined motivation to engage in a behaviour [31]. Above and beyond levels of psychological needs satisfaction, avoidance of needs frustration is also key as needs frustration is not the equivalent of low needs satisfaction and may

elicit defensiveness, ill-being, and/or psychopathologies [70-73]. Thus, it is important to consider both psychological needs satisfaction and frustration when studying motivation and designing interventions to change behaviours via motivation as they are uniquely associated with self-determined motivation and wellbeing [70, 73].

By providing autonomy supportive environments, which can be achieved in interventions by having the leader acknowledge the participant's perspectives, support their initiatives, offer choice about behavioural options, and provide relevant information, while not acting controlling or pressuring the participant [31], the basic psychological needs are more likely to be fulfilled and less likely to be frustrated. The provision of autonomy support and in-turn fulfillment of the basic psychological needs and avoidance of needs frustration is linked to more self-determined forms of motivation [31]. When individuals experience self-determined motivation, they engage in an activity for the inherent feelings of pleasure and satisfaction experienced (e.g., the activity is fun or satisfying) whereas when individuals experience controlled (or less self-determined) motivation, they engage in an activity because of external pressures, demands, and/or incentives (e.g., to avoid feelings of guilt or obtain a reward). Individuals with a relative absence of self-determined and controlled motivation and who lack intention to engage in a behaviour are said to be amotivated [31].

A large body of literature suggests that fostering self-determined motivation for PA leads to greater initial and sustained engagement in PA [see 23 for a review, e.g., 74, 75]. SDT has also been used as a framework in many studies targeting changes in eating behaviours and evidence supports the notion that self-determined motivation leads to positive changes in eating behaviours [51, 76-79]. Despite strong evidence supporting the use of SDT as a framework to understand motivation for engagement in PA and healthy eating in some populations (e.g.,

students, healthy adults, cancer survivors, adolescents), it is seldom used to explain caregivers' self-care behaviours. To date, most researchers have focused on the main effects of the intervention at the expense of understanding the mechanisms underlying behaviour change, which is critical to explain why an intervention is (or is not) effective in changing PA and FV consumption.

When implementing interventions to promote self-care behaviours, motivational interviewing is an effective technique that has been used in combination with SDT to foster the basic psychological needs [59, 80-83]. Motivational interviewing is a "client-centered, directive method for enhancing autonomous motivation to change by exploring and resolving ambivalence" [84; page 25]. Specifically, presenting clear and concise information about the behaviour, helping participants set goals, providing positive feedback, and supporting self-efficacy can lead to feelings of competence. Avoiding coercion, helping participants explore options, encouraging change talk, and allowing participants to make decisions of how and what behaviours they desire to change can foster autonomy. Expressing empathy, exploring the participant's concerns and understanding their concerns, and avoiding judgement or blame can build relatedness. Accordingly, when preparing and delivering the present intervention, motivational interviewing strategies will be used when speaking to participants and applied to dissemination materials throughout the intervention.

In addition to using a theoretical framework to guide the development and implementation of inventions to change PA and FV consumption and using an evidence-based delivery strategy (i.e., motivational interviewing), a number of other noteworthy behaviour change techniques have been shown to be effective. Michie et al. [56] identified the following among many effective behaviour change techniques: (1) providing information on costs and

benefits of engaging in the behaviour; (2) using social support (e.g., eliciting social support from others to help support behaviour change); (3) using goal setting (e.g., setting behaviour based goals that are specific, measurable, action based, reasonable, and time based); (4) using action planning (e.g., creating a detailed plan of what, when, where, and with who an individual will do a behaviour); (5) using self-monitoring (e.g., keeping a detailed record of specified behaviours); (6) identifying barriers (e.g., identify real or potential barriers to changing behaviour and identify methods to overcome them); (7) restructuring the environment (e.g., altering the environment in a way that is more support of the desired behaviour), and; (8) preventing relapse (e.g., planning how to maintain a behaviour that has been changed and developing strategies to manage situations that may threaten the behaviour). Interventions employing a combination of these behaviour change techniques is more likely to result in positive effects compared to those that do not employ behaviour change techniques [56]. Accordingly, the eight behaviour change techniques specified above will be used in the present intervention.

eHealth interventions

Beyond the content, it is important to consider where (e.g., home-based, in the community), how (e.g., face-to-face, using technology, over the phone) and with whom (e.g., individual, dyadic, group-based) an intervention will be delivered. As attrition rates among caregivers are higher for group-based face-to-face interventions (0-31%) compared to home-based interventions (0-16%), the latter may be preferred to accommodate caregivers' responsibilities and time constrains [17]. Barriers to participating in interventions away from the home include concerns about the care recipients' health, caregivers' experiences of guilt or a perceived inability to leave the care recipient, heavy caregiving responsibilities, and tangible obstacles [e.g., weather, expenses, transportation; 9]. Thus, interventions that allow caregivers to

participate at the time and location of their choosing may be the most effective way to reach caregivers. One promising method to facilitate the delivery of home-based interventions without having to dispatch staff to each person's home is to use increasingly popular technologies (e.g., email, Internet, video-calling).

Indeed, eHealth (i.e., the use of information and communication technologies for health) interventions may be an effective way to reach caregivers and facilitate the delivery of interventions targeting self-care behaviours. Specifically with caregivers, a systematic review of 65 articles found that 95% of technology based interventions focused on education, consultation, psychosocial and behavioural therapy, social support, monitoring, and clinical care delivery enhanced psychological health, improved caregiving knowledge, and improved coping and was an effective way to reach caregivers at home [85]. However, none of the included eHealth interventions focused on changing PA and eating behaviours in caregivers. In a range of populations (e.g., general population, overweight/obese, metabolic syndrome, diabetes, cardiac rehab), several systematic reviews found that eHealth interventions are as effective as traditional techniques (e.g., face-to-face, print materials) at increasing PA [86, 87]. Further, another systematic review of 85 studies found that the Internet is an effective way to promote other health behaviours (e.g., dietary behaviour, alcohol consumption, smoking abstinence) and found larger effect sizes for those that used theory to develop and implement the intervention [88]. The use of technology is also supported in interventions that aim to concurrently promote PA and nutrition [18, 89]. As such, an eHealth design will be used in the present study in order to accommodate caregivers' unique barriers to participating in traditional face-to-face interventions.

Qualitative and mixed-methods caregiver research

Whilst emerging evidence that engagement in self-care behaviours may have positive physical and psychological outcomes, caregivers' unique perspectives on the value of the impact of interventions targeting self-care behaviours have seldom been solicited. For example, Anton et al. [90] conducted a qualitative study with caregivers who had participated in a PA and nutrition intervention with their care recipient and found that the program helped provide a sense of support in their caregiver role and that it was beneficial physically and psychologically. More recently, Cuthbert et al. [91] conducted a qualitative study with cancer caregivers who had participated in a 12-week group-based exercise program independently from their care recipient. They found that upon assuming the caregiving role, participants felt a "downward spiral" in themselves based on a lack of acknowledgement by others and themselves in their role as a caregiver, overwhelming new responsibilities, changes in life habits, and declines in their physical and emotional health. Nevertheless, after engaging in the exercise program, caregivers reported creating an "upward spiral" in their lives as they learned to focus more time on themselves, enjoyed interacting with other caregivers, experiences more energy and vitality, and felt a greater sense of control over their own lives. Although informative, the experiences and perspectives of cancer caregivers participating in a one-on-one eHealth intervention have yet to be explored and may differ from those of caregivers engaging in PA with their care recipient or in a group setting. Gaining an understanding of how such interventions may influence caregivers' health and impact their perceptions of caregiving may provide valuable insight to guide the direction of future interventions, resources, and programs for caregivers. As most research with caregivers has collected either quantitative or qualitative data, the opportunity to integrate findings has been lost. Accordingly, the present study will employ a sequential

explanatory mixed-methods design in order to use qualitative findings to explain variations in quantitative findings [92].

Purpose of the Study

To address the aforementioned gaps and limitations in the literature, the purpose of this single-arm feasibility trial was to determine if a brief 4-week SDT-based one-on-one eHealth intervention aimed at improving cancer caregivers' self-care behaviours is feasible and acceptable. The main objective of this study was to assess the feasibility and acceptability of the intervention by tracking: a) enrollment rate (i.e., number of participants who express interest, meet inclusion criteria, and agree to participate out of the total number of participants who express interest within a 6-month period of time); b) adherence rate (i.e., number of sessions attended out of four) and fidelity (i.e., minutes of contact with participants); c) retention and attrition rates (i.e., number of online assessments completed out of two, number of participants who participate in the interview, and number of participants who drop out including reasons for dropping out), and; d) percentage of missing data within each completed assessment. Drawing on PA interventions delivered by telephone with caregivers [e.g., 54, 57] and SDT-based self-care interventions [e.g., 93], it was hypothesized that: a) approximately 75% of people who express interest would meet eligibility criteria and agree to participate; b) at least 75% of the sessions (3 out of 4) would be attended by participants and participants will have contact with the health and wellness advisor for at least 75% of the planned duration (45 minutes of the planned 60 minutes each session); c) more than 70% of participants would complete all assessments and the intervention, and; d) less than 10% of data on quantitative assessments would be missing.

Exploratory objectives were to describe the correlations between SDT constructs (i.e., perceived autonomy support, basic psychological needs satisfaction and frustration [autonomy,

competence, and relatedness], and self-determined motivation), self-care behaviours (i.e., PA and FV consumption), and caregiver burden, and to explore caregivers' experiences and perspectives within the intervention to understand the impact it may have on their self-care behaviours and their role as a caregiver.

Based on past research showing that basic psychological needs satisfaction, avoidance of needs frustration, autonomy support, and self-determined motivation leads to improved and sustained engagement in health behaviours [e.g., PA, smoking, medication use; 23, 31, 62, 70, 71], we hypothesized that greater increases in positive SDT constructs (i.e., needs satisfaction, autonomy support, self-determined motivation) and greater decreases in negative SDT constructs (i.e., needs frustration) would be associated with increases in self-care behaviours. No further hypotheses were formulated due to the qualitative nature of the exploratory objectives.

Chapter Three: Methods

Intervention development

The development process of our intervention was a key part of the present thesis. We engaged in the following activities: (1) initial development; (2) expert consultation; (3) detailed intervention guide and material development; (4) caregiver engagement and testing, and; (5) intervention refinement. First, for (1) we drew on similar behaviour change interventions for caregivers [e.g., 57, 94] and other populations [e.g., women, overweight or obese individuals; 64, 65-69] to develop the intervention structure and included topics (see Appendix C). Next, for (2) several experts with extensive experience in PA and FV behaviour change and SDT were consulted and their feedback was integrated into the intervention overview. Then, for (3) detailed intervention materials (e.g., information sheets and worksheets) and an intervention delivery guide were developed, drawing on a previous behaviour change intervention targeting PA and healthy eating [63, 95, 96], behaviour change technique literature [e.g., 56], and recommendations for integrating motivational interviewing principles with SDT [59, 80, 81, 83]. In the testing phase (4), one bereaved cancer caregiver was engaged to review and offer feedback on the intervention delivery guide and all intervention materials. The caregiver also took part in the intervention as it would be delivered to participants. For this, one-on-one sessions were scheduled once weekly over 4 weeks and intervention materials were sent to initials one day prior to the session via email. EW delivered the intervention, noted the length of each session, and took field notes. Feedback from the caregiver regarding the delivery style, topics covered, and intervention materials were recorded. The caregiver also had the opportunity to provide written feedback on the intervention materials. Changes were made based on EW's notes and

feedback from the caregiver was incorporated in the final materials. Data collected during the testing phase were not included in the final results.

Inclusion criteria

To be eligible to participate in the study, cancer caregivers must have: (1) been currently providing unpaid physical, psychological, or instrumental care to an adult (≥18 years of age) who has been diagnosed with cancer; (2) been ≥18 years of age; (3) been able to read, understand, and speak English; (4) not been meeting the Canadian PA guidelines of 150 minutes of moderate-to-vigorous aerobic PA in bouts of 10 minutes or more per week and not engaging in muscle and bone strengthening activities at least 2 days per week; (5) not been consuming 5 or more servings of fruits and/or vegetables per day; (6) been living in Canada and had access to Internet, email, and audio and visual equipment; (7) been ambulatory without assistive devices, and; (8) had no self-reported medical condition that prevented participation in PA.

Procedures

Research design. An explanatory sequential mixed-methods research design was used in this single-arm feasibility trial. A flow-chart of study procedures can be found in Appendix B. Quantitative measures were used to collect data pre- (week 0) and post-intervention (week 5), and semi-structured interviews were conducted post-intervention (week 6) to understand and explain changes (or lack thereof) occurring during the intervention and to gain insight into participants' experiences within the intervention.

Recruitment. Following approval from the University of Ottawa Research Ethics Board (see Appendix A), recruitment for the study began in January 2019. Recruitment posters and online posts included information on the purpose of the study, procedures, eligibility criteria, and contact information for the health and wellness advisor (EW). As recommended by Joseph et al.

[97] to recruit participants for small-scale studies and hard-to-reach populations, a combination of recruitment methods were used: (1) developed a comprehensive list of potential recruitment platforms and venues; (2) identified and fostered relationships with community gatekeepers, and; (3) leveraged existing social networks and personal contacts. For (1), we developed and contacted a list of potential recruitment platforms across Canada by compiling contact information for organizations, websites, and social media pages providing support for caregivers and/or cancer survivors. For (2), we contacted national, provincial, and community organizations with a mandate to support caregivers (e.g., Caregivers Alberta, Family Caregivers of British Columbia, The Ontario Caregiver Organization, The Change Foundation, Powerhouse Project), cancer specific organizations (e.g., Canadian Cancer Survivor Network, Canadian Breast Cancer Network, The Ottawa Regional Cancer Foundation, The Ottawa Integrative Cancer Center, Wellspring locations across Canada, Cancer Care Manitoba, Nova Scotia Health Authority, HopeSpring Cancer Support Center, West Island Cancer Center, Imerman Angels), and organizations with an interest in patient support and health (e.g., Virtual Hospice Canada, Patient Voices Network, Living Healthy Champlain, Family Services Toronto). Organizations assisted with recruitment by displaying our recruitment poster in their organization, including our study on their webpages, sharing via social media, distributing in electronic newsletters, emailing information about our study to members of the organization and/or word of mouth. For (3), we shared our recruitment poster using social media (i.e., Facebook, Twitter, Huddol) and invited individuals to share our study with others who may be interested (i.e., snowball sampling). In addition to online recruitment, members of the study team shared information about our study via word of mouth with personal contacts. We also ensured a physical presence by attending several events providing services for caregivers and/or cancer survivors (e.g., Crush it for Cancer

hosted by the Ottawa Regional Cancer Foundation, The Toronto Caregiver Show) and by displaying posters in various publicly accessible areas (e.g., libraries, community centers, coffee shops) in Ontario (e.g., Ottawa, Guelph, Perth, Tweed), Nova Scotia (e.g., Annapolis Royal), and British Columbia (e.g., William's Lake).

Screening. Interested participants contacted EW via telephone, email, or social media messaging. To confirm interest, EW scheduled a screening phone call to provide detailed information on the present study including study objectives, an overview of the topics covered, time-frame and commitment, and compensation. If participants confirmed interest, EW assessed eligibility by applying the above inclusion criteria. Interested and eligible participants were asked to provide full contact information (e.g., phone number, email address, video-call platform preference [e.g., Skype name, FaceTime number]).

Intervention flow. Interested and eligible participants were sent a link via email to the online consent form and pre-intervention questionnaire (administered by Qualtrics) and asked to complete the questionnaire within a one week-period. Upon agreeing to the online consent form (i.e., by clicking "I agree"), participants were directed to the pre-intervention questionnaire (week 0). Following completion of the pre-intervention questionnaire, EW contacted participants to schedule the four intervention sessions that occurred via video-call (weeks 1-4). Participants were sent the required materials (e.g., information sheets, worksheets) via email 1 day prior to the scheduled video-call. An overview of the session content and materials provided to participants can be found in Appendix C. Topics covered included the benefits of self-care and social support (week 1), goal setting, action planning, and self-monitoring (week 2), barrier identification and environmental restructuring (week 3), and relapse prevention and goal re-evaluation (week 4).

Following completion of the last video-call (week 5), participants were sent a link via email to complete the online post-intervention questionnaire. Last, an interview done via video-call was scheduled to explore their experiences within the intervention and understand their views and perspectives on how it impacted their self-care behaviours and caregiving responsibilities (week 6). To encourage honest feedback regarding the intervention, the interview was conducted by a 3rd year undergraduate student (JLR) who was not involved in the development or delivery of the intervention.

Measures

Participants completed an online questionnaire package (see Appendix D) pre- (week 0) and post-intervention (week 5). Information on sociodemographics and caregiver role was collected only pre-intervention, with the exception of body mass that was collected pre- and post-intervention. Nonetheless, as change in sociodemographic information and caregiver role is possible, an open-ended question asking about potential changes over the course of the intervention was included in the post-intervention questionnaire. Information on PA, FV consumption, motivation, basic psychological needs satisfaction and frustration, and caregiver burden was collected at both pre- (week 0) and post-intervention (week 5). Information on autonomy support was only collected post-intervention (week 5). Qualitative data collection occurred via video-call post-intervention (week 6). All feasibility measures were recorded during the intervention by EW.

Feasibility measures. Enrollment rate was measured by recording the number of people who expressed interest in participating, were screened for eligibility, met eligibility criteria, and agreed to participant out of the total number of participants who expressed interest during a 6-month period (January 2019 – July 2019). Adherence rate was measured by recording how many

of the four assessments participants attended. Fidelity was recorded as the length of contact with participants compared to the intended dosage (i.e., 60 minutes of contact time planned for each session). Retention and attrition rates were measured by recording how many of the assessments participants completed (i.e., two quantitative questionnaires, one interview) and the number of participants who dropped out of the intervention including their reasons for doing so. The percentage of missing data was computed for each quantitative measure at pre- and post-intervention.

Sociodemographics and caregiver role. Participants completed a sociodemographic questionnaire pre-intervention on age, sex, marital status, ethnicity, education, income, employment, body mass, height, and health status (see Appendix D). Participants also provided information pre-intervention regarding the care recipient (e.g., age, sex, type and stage of cancer), average number of hours spent caregiving, time in the caregiving role, types of caregiving activities, and changes in self-care after becoming a caregiver. Participants completed information on body mass and an open-ended question on potential changes in sociodemographics and caregiver role post-intervention.

PA. The International Physical Activity Questionnaire [IPAQ; 98] was used pre- and post-intervention to assess the frequency and duration of walking, and moderate and vigorous PA in the past 7 days (see Appendix D). The IPAQ consists of 27 open ended questions that will be used to compute a continuous score in metabolic equivalences (METs) for walking, moderate PA, vigorous PA, and total PA per week. PA is assessed independently across the following domains: leisure time; domestic and gardening activities; work-related; and transport-related PA. Sub-scores for each domain was calculated in METs. Adequate validity and reliably of the IPAQ

has been demonstrated [99]. Additionally, questions developed to assess the type, duration, and context of muscle and bone strengthening activities were administered.

FV Consumption. FV consumption was assessed using questions adapted from the Canadian Community Health Survey [100, 101] pre- and post-intervention (see Appendix D). Participants completed 6 questions to assess the frequency in which they consumed pure fruit juice (i.e., no sugar added), frozen, fresh, dried, or canned fruit, dark green vegetables, orange coloured vegetables, potatoes that were not deep fried, and other vegetable sources (i.e., pure vegetable juice) over a one-week period. The total number of times FVs are consumed per week was computed by summing the frequencies recorded in all 6 questions. This method of assessing FV consumption has been used in several national level surveys assessing health behaviours (e.g., the Canadian Community Health Survey, the Behavioural Risk Factor Surveillance System) and overall FV consumption frequencies are comparable to those estimated by extensive food frequency questionnaires [100].

Motivation. The Treatment Self-Regulation Questionnaire (TSRQ) was used to assess participants' motivation for self-care behaviours [102] pre- and post-intervention. The TSRQ was developed to assess different forms of motivation within SDT, namely amotivation, self-determined, and controlled forms of motivation [31]. Two modified versions of the TSRQ – one for the degree of motivation to engage in PA and one for the degree of motivation to consume FVs (see Appendix D) – were used. Both versions of the TSRQ contain 15 items. Participants indicated the extent to which reasons to engage in the behaviour are true using a 7-point Likert scale (1 indicating *not true at all* and 7 indicating *very true*). The TSRQ for PA was modified to begin with the stem, "The reason I would engage in PA regularly is:" and is followed by items representing autonomous motivation (6 items; e.g., "because I feel that I want to take

responsibility for my own health"), controlled motivation (6 items; e.g., "Because I would feel guilty or ashamed of myself if I did not engage in PA regularly"), and amotivation (3 items; e.g., "I really don't think about it"). The TSRQ for FV consumption was modified to begin with the stem, "The reason I would eat FVs is:" and is followed by items representing autonomous motivation (6 items; e.g., "Because I personally believe it is the best thing for my health"), controlled motivation (6 items; e.g., "Because I want others to approve of me"), and amotivation (3 items; e.g., "I don't really know why"). A Relative Autonomy Index (RAI) score was calculated by subtracting the average of the controlled motivation items from the average of the self-determined motivation items for both the TSRQ for PA and FV consumption. A higher RAI score indicates higher levels of self-determined motivation. The reliability and validity of the TSRQ for PA and healthy eating have been previously demonstrated [103].

Basic psychological needs satisfaction and frustration. Two modified versions of the Basic Psychological Need Satisfaction and Frustration Scale [BPNSF; 70] were used to assess the degree to which participants perceive the needs of autonomy, competence, and relatedness as they engage in PA and consume FVs (see Appendix D). The BPNSF was created to assess both satisfaction and frustration with the basic psychological needs in the general context; however, the measure has been modified to fit specific contexts [e.g., exercise; 104]. As such, one version was modified to reflect the PA context and one version was modified to reflect the context in which FVs are consumed. For example, the stem was modified to "Below, we are going to ask about your actual experiences of certain feelings pertaining to your PA" and individual items were slightly modified (e.g., replacing "things" with "PA"). Each modified questionnaire consists of 24 items in which participants were asked to respond on a 5-point Likert scale ranging from 1 (indicating *not true at all*) to 5 (indicating *completely true*). Mean scores for

satisfaction and frustration pertaining to autonomy (4 items for both satisfaction and frustration), competence (4 items for both satisfaction and frustration), and relatedness (4 items for both satisfaction and frustration) within the PA and FV context were computed by averaging items for each subscale. Psychometric properties of the original BPNSF have been supported [70].

Autonomy support. Perceived autonomy support provided throughout the intervention by the health and wellness advisor (EW) was assessed post-intervention using a modified version of the short Health-Care Climate Questionnaire [HCCQ; 105; see Appendix D]. While the HCCQ was initially developed to assess the degree to which patients perceive autonomy support from physicians or healthcare providers, it has also been used to assess perceived autonomy support from those leading behaviour change interventions [e.g., 69]. As such, the term "physician" was replaced with "health and wellness advisor". The short HCCQ contains 6 items representing perceived autonomy support (e.g., "I feel that my health and wellness advisor has provided me choices and options") in which participants rated their agreement with items on a 7-point Likert scale (1 indicating *strongly disagree* and 7 indicating *strongly agree*). A summary score was computed by averaging all items, where a higher score indicates a higher level of perceived autonomy support.

Caregiver burden. Subjective burden experienced by caregivers was assessed using The Burden Scale for Family Caregivers – Short [BSFC-s; 106] pre- and post-intervention (see Appendix D). The BSFC-s consists of 10 negatively stated items (e.g., "the care takes a lot of my own strength") that are rated on a 4-point Likert Scale (0 indicating *strongly disagree* and 3 indicating *strongly agree*). Responses on all items were summed with higher scores indicating greater caregiver burden. Validity, reliability, and internal consistency of the scale has been

demonstrated with caregivers [106, 107] and has been used specifically with cancer caregivers [108].

Interviews. Participants participated in semi-structured interviews via video-call following completion of the intervention and post-intervention assessments (week 6). The interviews were conducted by a member of the study team (JLR) who was not involved in the development or delivery of the intervention. The purpose of the interview was threefold: (1) to explore participants' experiences within the intervention and the health and wellness advisor; (2) to understand their views and perspectives on how the intervention impacted their self-care behaviours; (3) to gain insight into their self-care behaviours in relation to their caregiving roles. The interviews were informed by a pre-established interview guide (see Appendix D) and were audio-recorded.

Data analysis

Feasibility analyses. The Statistical Package for the Social Sciences (SPSS; IBM Corp. 2013) was used to perform quantitative data analyses. Descriptive statistics (e.g., mean, frequency) for enrollment, adherence, adherence, fidelity, retention, and attrition rates and missing data were computed.

Exploratory analyses. Descriptive analyses were used as this study was not designed to be powered to detect statistically significant changes in the outcome measures. Descriptive statistics (e.g., mean, median, interquartile range) for participants' sociodemographic information and SDT constructs were computed. Individual level data for basic psychological needs satisfaction and frustration were visualized using R Studio [109], following guidelines for complete representation of small datasets [110].

Qualitative data were analyzed using thematic analysis [111, 112]. Braun and Clarke's [112] six flexible and recursive steps (i.e., familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report) were used to analyse data at the sematic level. The first step involved transcribing the data verbatim, checking the accuracy of the transcription, and reading each transcript several times. Next, initial codes were generated by taking note of parts of the raw data that may be relevant to the research questions. Similar codes were grouped into subthemes and then into main themes. Themes were reviewed to ensure that data within themes fit well together (i.e., internal homogeneity) and that there is a clear distinction between themes (i.e., external heterogeneity). Themes (and subthemes if applicable) were then named and refined. Pertinent data extracts that highlight each theme are presented in Chapter 4. Participants' names were changed to pseudonyms to protect anonymity. Whilst an inductive approach was used during initial data analyses to identify salient features of the raw data, a theoretical deductive approach was then applied to understand the role of SDT constructs during the intervention.

Data integration. Integration of quantitative and qualitative data occurred at the design and interpretation level [113]. At the design level, an explanatory sequential approach was chosen to explain and provide insight into quantitative findings from the intervention phase. Data were integrated when presenting results through narrative as the quantitative and qualitative data are reported together on a concept-by-concept basis.

Chapter Four: Study Manuscript

This chapter presents the manuscript capturing the results of this thesis. It has been formatted for submission to the Journal of Applied Gerontology. We believe this article fits well within the scope of this journal as it employs a mixed-methods approach to assessing the feasibly and accessibility of an intervention to improve the health of caregivers. The Journal of Applied Gerontology is a reputable peer-reviewed journal with a strong emphasis on caregiving issues.

Author's Contributions

Emily Wolfe Phillips conceptualized the design of the intervention, developed the materials, recruited participants, delivered the intervention, collected and analyzed data, interpreted results, and drafted and revised the manuscript. Jennifer Brunet supervised the first author and contributed to the conceptualization and design of the intervention, material development, and data analysis and interpretation, and reviewed drafts of the manuscript, provided critical feedback, and approved the final version.

Title Page

You're a better caregiver if you're feeling well: A mixed methods exploration of caregivers' experiences within a brief self-care intervention

Emily Wolfe Phillips & Jennifer Brunet

Formatted for submission to the Journal of Applied Gerontology

Abstract

The primary objective of this study was to assess the feasibility and acceptability of a brief self-determination theory-based intervention to improve self-care behaviours among cancer caregivers. Exploratory objectives included understanding participants' experiences within the intervention. The single-arm intervention was delivered via four weekly video calls to 13 caregivers (mean age=57.6±15.4 years) across Canada. The enrollment rate was 62% and the retention, adherence, and fidelity rates ranged from 90 to 99%. The intervention was generally deemed acceptable by participants; however modifications such as adding psychological support were suggested. Participants' experiences were captured within three themes: (1) *(Re)prioritizing self-care behaviours;* (2) *Finding support for self-care behaviors within the caregiving context;* and, (3) *Becoming a better caregiver through self-care behaviours.* Although promising, modifications to the intervention methods are needed to improve enrolment and better meet caregivers' needs. This study highlights the importance of self-care behaviours for caregivers and provides valuable information on how to foster these behaviours among this population.

Introduction

Caregivers' health status

Informal or family caregivers are an integral part of the Canadian healthcare system as they provide unpaid care and support for millions of adults living with chronic conditions [1]. In the context of cancer, medical advances, shorter hospital stays, and increasing lifespan have contributed to a rise in the number of adults who assume the role of caregiver for people living with cancer, making them the second most prevalent type of caregiver in Canada [1, 2]. Although caregiving can be a positive experience for some [e.g., fostering a positive relationship with the care recipient, improving one's view of themself; 3, 4-6], there are numerous responsibilities that are stressful for caregivers and can negatively impact their mental, emotional, and physical health [7-9]. Caregivers often report feelings of isolation, guilt taking time away from the care recipient, and high levels of stress which may explain, in part, why assuming the role of a caregiver can negatively impact one's participation in self-care behaviours [11-13, 33]. For instance, a recent study of over 9,000 caregivers in Canada found that 17.2% to 32.4% of caregivers reported a decrease in PA and 10.8% to 19.1% reported a decrease in healthy eating upon assuming the caregiving role, with variations based on caregivers' ages [33].

Support available for caregivers

Over the past decade, there has been an increase in research to better understand caregiving, including efforts to mitigate the negative impacts of caregiving [15]. Current interventions targeting caregivers are largely focused on education related to providing care or providing psychological support with little emphasis placed on specifically promoting self-care behaviours [15-17]; despite preliminary evidence that these behaviours can improve caregivers' physical and psychological health and ability to manage caregiving [28-30]. A recent systematic

review of PA interventions to improve caregivers' psychosocial outcomes, PA, and physical health identified 14 interventions of which only one was specific to cancer caregivers [17]. Although these interventions provide preliminary evidence of the importance of self-care behaviours as a component of support available for caregivers, most do not qualitatively explore caregivers' experiences within the intervention. One notable exception is the study by Cuthbert et al. [91] exploring cancer caregivers' experience of participating in a structured group exercise program. The authors found that caregivers' valued the exercise program and reported creating an "upward spiral" in their lives as they learned to focus more time on themselves, enjoyed interacting with other caregivers, experienced more energy and vitality, and felt a greater sense of control over their own lives [91]. Existing studies have yet to understand caregivers' perceptions of one-on-one online support for self-care behaviours for caregivers. Gaining an understanding of how such interventions may influence caregivers' health and impact their perceptions of caregiving may provide valuable insight to guide the direction of future interventions, resources, and programs for caregivers.

Theoretical framework

Based on robust evidence supporting the use of theory to develop and implement behaviour change interventions [22], we developed the present intervention using SDT as a guiding framework. SDT has been widely used to examine motivation for health behaviours in various populations [e.g., 23, 63-69], and in turn design interventions to change behaviours by fostering self-determined (or autonomous) motivation. Within an intervention context, SDT posits that providing an autonomy supportive environment leads to fulfillment of the basic psychological needs – autonomy, competence, and relatedness – thus increasing the likelihood of experience self-determined motivation and initiation and sustainment of a desired behaviour [31,

62, 72]. Accordingly, we developed the present intervention materials and delivery guide with the intention of providing an autonomy supportive environment. To this end, the advisor aimed to acknowledge the participant's perspectives, support their initiatives, offer choices about behavioural options, and provide relevant information, while not acting controlling or pressuring the participant [31].

Objectives

The main objective of this mixed-methods study was to assess the feasibility and acceptability a brief 4-week SDT-based intervention aimed at improving cancer caregivers' self-care behaviours (i.e., PA and FV consumption). The exploratory objectives were to describe participants' self-care behaviours and SDT-based constructs (i.e., autonomy, competence, relatedness, self-determined motivation) and explore caregivers' experiences and perspectives within the intervention to understand the impact it may have on their self-care behaviours and their role as a caregiver.

Methods

Participants and Procedures

We recruited caregivers across a 6-month period (January 2019 – June 2019) through online and community-based methods. We contacted community-based, provincial, and national organizations with a mandate to support caregivers and organizations with an interest in patient support and health for assistance with recruitment. Strategies included posts on social media, notices on websites and electronic newsletters, as well as posters in the community and in-person recruitment at select Ottawa and Toronto-based events. Participation was limited to individuals who were (1) currently providing unpaid physical, psychological, and/or instrumental care to an adult (≥18 years of age) who had been diagnosed with cancer; (2) ≥18 years of age; (3) able to

read, understand, and speak English; (4) not meeting the Canadian PA guidelines of 150 minutes of moderate-to-vigorous aerobic PA in bouts of 10 minutes or more per week and not engaging in muscle and bone strengthening activities at least 2 days per week; (5) not consuming 5 or more servings of fruits and/or vegetables per day; (6) living in Canada and had access to Internet, email, and audio and visual equipment; (7) ambulatory without assistive devices, and; (8) not self-reporting one or more medical conditions that prevented participation in PA.

Interested participants that contacted the first author were screened to assess eligibility. Interested and eligible participants were sent a link via email to an online consent form and pre-intervention questionnaire (week 0). Following completion of the pre-intervention questionnaire, the first author contacted participants to schedule the four intervention sessions (weeks 1-4). The intervention was delivered one-on-one by the first author via video-call (e.g., FaceTime, Zoom). An overview of the session content and materials provided to participants can be found in Supplementary Table 1. Briefly, topics covered during the session included the benefits of self-care and social support (week 1), goal setting, action planning, and self-monitoring (week 2), barrier identification and environmental restructuring (week 3), and relapse prevention and goal re-evaluation (week 4). Following completion of the last session, participants completed an online post-intervention questionnaire (week 5) and participated in a one-on-one interview (week 6). Interviews were conducted by a trained student who was not involved in the delivery of the intervention via video-call and sought to explore participants' experiences within the intervention and understand their views and perspectives on how it impacted their self-care behaviours and caregiving responsibilities.

Measures

Feasibility measures (weeks 0 – 6). Enrollment rate was measured by recording the number of individuals who expressed interest in participating, were screened for eligibility, met eligibility criteria, and agreed to participant out of the total number of participants who expressed interest during a 6-month period (January 2019 – July 2019). Adherence rate was measured by recording how many of the four assessments participants attended. Fidelity was recorded as the length of contact with participants compared to the intended dosage (i.e., 60 minutes of contact time planned for each session). Retention and attrition rates were measured by recording how many of the three assessments participants completed (i.e., questionnaires, interview) and the number of participants who dropped out of the intervention including their reasons for doing so.

Sociodemographics, caregiver role, and caregiver burden (week 0 and 5). Pre-intervention, participants self-reported sociodemographic information and provided caregiving specific information (e.g., average number of hours spent caregiving, changes in self-care after becoming a caregiver). Post-intervention, participants were asked to report any changes in sociodemographics and caregiver role. Pre- and post-intervention, they also completed the Burden Scale for Family Caregivers – Short [BSFC-s; 106] – a subjective measure of burden experienced by caregivers.

Self-care behaviours (week 0 and 5). The International Physical Activity Questionnaire [IPAQ; 98] was used pre- and post-intervention to assess the frequency and duration of walking, and moderate and vigorous PA in the past 7 days. FV consumption was assessed using questions adapted from the Canadian Community Health Survey [100, 101].

SDT constructs (week 0 and 5). The Treatment Self-Regulation Questionnaire (TSRQ) was used to assess participants' motivation for self-care behaviours [102]. The TSRQ was

developed to assess different forms of motivation within SDT, namely amotivation, self-determined, and controlled forms of motivation [31]. Two modified versions of the TSRQ – one for the degree of motivation to engage in PA and one for the degree of motivation to consume FVs – were used. A Relative Autonomy Index (RAI) score was calculated by subtracting the average of the controlled motivation items from the average of the self-determined motivation items for both the TSRQ for PA and FV consumption. A higher RAI score indicates higher levels of self-determined motivation. Two modified versions of the Basic Psychological Need Satisfaction and Frustration Scale [BPNSF; 70] were used to assess the degree to which participants perceive the needs of autonomy, competence, and relatedness as they engage in PA and consume FVs. Perceived autonomy support provided throughout the intervention by the person delivering the intervention (herein referred to as the advisor) was assessed post-intervention using a modified version of the short Health-Care Climate Questionnaire [HCCQ; 105; see Appendix D].

Qualitative interviews (week 6). Following completion of the intervention, semi-structured interviews were conducted to: (1) explore participants' experiences within the intervention and the advisor; (2) understand their views and perspectives on how the intervention impacted their self-care behaviours; (3) gain insight into their self-care behaviours in relation to their caregiving roles. The interviews were guided by a series of open-ended questions and probes to encourage participants to provide more detail or clarity. The interview guide in presented in Supplementary Table 2.

Data analysis

All descriptive statistics were estimated using The Statistical Package for the Social Sciences (SPSS; IBM Corp. 2013). These data were used to describe the sample and report on

feasibility outcomes, as the objective of this study was not to detect statistically significant changes in the outcome measures. Individual level data for basic psychological needs satisfaction and frustration were visualized using R Studio [109], following guidelines for complete representation of small datasets [110].

Qualitative data were analyzed using thematic analysis [111, 112]. Braun and Clarke's [112] six flexible and recursive steps (i.e., familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report) were used to analyse data at the sematic level. Initially, an inductive approach was used to identify salient features of the data. Next, a theoretical deductive approach was applied to understand the role of SDT constructs during the intervention. Data pertaining to SDT constructs were integrated when presenting results through narrative as the quantitative and qualitative data are reported together on a concept-by-concept basis, where appropriate.

Results

Participants

In total, 13 caregivers provided consent and participated in this study. Sociodemographic information and details on participants' role as a caregiver are presented in Table 1. Participants were caregivers aged 26 to 81 years (mean age=57.6±15.4) who were providing care to a spouse (*n*=7), adult child (*n*=2), parent (*n*=3), or grandparent (*n=1*) diagnosed with cancer. Participants reported spending an average of 41 hours per week providing care, with most reporting that their PA (*n*=9) and FV consumption (*n*=8) deceased and that their overall health suffered as a result of their caregiving responsibilities (*n*=10).

Descriptive statistics (i.e., median, interquartile range) for PA, FV consumption, caregiver burden, and SDT constructs pre- and post-intervention are presented in Table 2. Pre-

intervention, participants engaged in 60 minutes per week of light PA (IQR=262.5) and 0 minutes of MVPA (IQR=330), compared to 110 minutes per week of light PA (IQR=315) and 265 minutes per week of MVPA (IQR=590) post-intervention. Participants reported consuming 3.1 servings of FVs per day (IQR=3.2) pre-intervention and 3.7 servings per day (IQR=3.7) post-intervention. Relative to the scale ranges, participants reported moderate levels of self-determined motivation for PA pre-intervention (median RAI=3.3 [IQR=2.9]) and post-intervention (median RAI=3.5 [IQR=2.7]). Participants reported low levels of self-determined motivation for FV consumption pre-intervention (median RAI=1.3 [IQR=4.6]) and post-intervention (median RAI=1.2 [IQR=3.7]). Individual level data for basic psychological needs satisfaction and frustration for PA and FV consumption are presented in Figures 1 and 2, respectively.

Feasibility

Recruitment and enrollment. Of the 27 individuals who expressed interest in participating over a 6-month period, six could not be reached for the screening call. Of the 21 who were screened for eligibility, six were ineligible for the following reasons: meeting PA guidelines (*n*=2); living outside Canada (*n*=1); not currently a caregiver (*n*=1); not ambulatory without an assistive device (*n*=1); and pre-existing medical condition preventing participation in PA (*n*=1). This left 15 who met the inclusion criteria and agreed to participate (enrollment rate=61.9%); however contact was lost with two, yielding a sample size of 13.

Retention and attrition. Of the 13 participants who enrolled in this study, one withdrew after completing the pre-intervention assessment because of changes in the care recipients' health (prior to participating in any video-calls) and contact was lost with another after the third session

(attrition rate=15.4%). Eleven participants completed online questionnaires pre- and post-intervention, as well as the post-intervention interview (retention rate=89.7%).

Intervention adherence and fidelity. Of the 12 participants who started the intervention, the average attendance was 3.9 sessions out of 4, representing an adherence rate of 97.9%. Fidelity to the intervention, assessed by the average number of minutes of contact per session, was 99.1% (average of 59.4 minutes of the planned 60 minutes per session).

Missing data. Less than 10% of quantitative data were missing on the pre- and post-intervention questionnaires. Of the 12 participants who started the intervention, 11 completed the intervention took part in the post-intervention interview.

Participants' views of the intervention and the advisor

Participants expressed overall positive impressions of the intervention, using words such as "awesome", "highly satisfied", "great", and "well done". The opportunity to speak one-on-one with the advisor was an important piece of the intervention that allowed participants to feel a sense of connectedness and accountability to the program. Caregivers appreciated the opportunity to discuss their own health and behaviours without the care recipient present as this created a safe, non-judgemental space. This sentiment was expressed by Natalia, "*I think it's kind of special to keep it to the caregivers, because there's a lot of support given to the patient themselves but … I just feel privileged to have any time for myself."*

The personalized nature and ability to tailor the intervention were also identified as positive aspects, as Heather described, *"I found that as my needs shifted, her direction shifted. She adapted the program. I liked the personal touch that she provided throughout. It wasn't one of those textbook things where I want you to do A, B and C. I was like 'Well I really like A', and she*

goes, 'Okay let's elaborate on A, let's forget about B for right now,' so I liked that part." Participants felt supported by the advisor, felt comfortable speaking with her, and felt a sense of belonging within the program. The emphasis on small, maintainable changes reduced feelings of pressure and guilt, as Danielle highlighted, "*The advisor was really supportive and I think that that was very important, in being flexible too, that my needs are obviously different that other people's needs, so I think it was really important not to have judgment or feel guilty if you can't achieve those goals but to just keep going and not let that be a barrier."* This sentiment was supported by the quantitative results as participants reported high perceived autonomy support post-intervention, relative to the scale range (median score 6.5 [IQR=1]; see Table 2).

Participants were generally satisfied with the content and format of the intervention; nevertheless, they had divergent views on the duration of the intervention. Some found the 4-week intervention manageable and easier to commit to than a longer intervention, whereas others desired longer term support. In terms of the mode of delivery, although several participants experienced technical barriers (e.g., inconsistent internet access, learning unfamiliar technology), most felt that video-call was an acceptable method of delivery as it increased flexibility, allowed them to stay at home during the sessions, and fostered a more personal relationship with the advisor than if they had occurred without video.

Participants also offered recommendations to improve future programs. Some suggested providing opportunities to connect participants with other caregivers during or after the program, and would like more flexibility in the intervention length (i.e., needs-based) and delivery mode (i.e., to choose between video, phone, or messaging-based). They also felt that the intervention could offer more emotional or psychological support. Natalia underscored that, *"I would definitely add some kind of emotional support, because it's all connected. For me, its personal, if*

somebody's binging or if someone isn't eating right it's all, if you're not exercising and you're feeling exhausted and lethargic, it's all emotional. There's something emotional about it for everything, for me, that comes before the behaviour." In regards to online data collection, participants did not express concerns using an online survey platform (i.e., Qualtrics) or videoconferencing for the post-intervention interview; however, a few participants found the questionnaires "confusing" and "repetitive" and suggested that the assessments be simplified.

Participants' experiences throughout the intervention

In addition to exploring participants' views of the intervention and the advisor, we aimed to understand the impact of the intervention on their self-care behaviours and their roles as caregivers. Throughout the interview, participants described how their current roles and responsibilities as caregivers influenced their initial attitudes towards self-care behaviours, their ability to find support for and begin engaging in self-care behaviours, and how the eventual benefits fed back into their ability to provide care. Thus, we captured participants' experiences throughout the intervention within three main themes: (1) *(Re)prioritizing self-care behaviours;* (2) *Finding support for self-care behaviors within the caregiving context;* and, (3) *Becoming a better caregiver through self-care behaviours.*

(Re)prioritizing self-care behaviours

Caregivers described how caring for a significant other with cancer limited their own participation in self-care behaviours such as PA and FV consumption, because this role was "all consuming" and because they would feel "guilty taking care of themselves". Engaging in the intervention helped them shift their perspectives and create space in their lives for self-care

behaviours. Participants expressed how their activities and goals where "moving away from being guilt-based" and becoming "more empowerment and positive reinforcement", which allowed them to (re)prioritize their own health. Christina emphasized that "*I think what the program did is it allowed me to - it gave me permission to prioritize my own care*". Although self-care behaviours were generally identified as a priority, some participants expressed that their motivation to engage in these behaviours was not the limiting factor, as Natalia said, "*it's not a lack of organization or motivation, you know, it's more emotionally driven."* This sentiment was reflected in relatively stable pre- and post-intervention values for motivational regulations for PA (median RAI [IQR] change from 3.3 [2.9] to 3.5 [2.7]; see Table 2) and FV consumption (median RAI [IQR] change from 1.3 [4.6] to 1.2 [3.7]; see Table 2).

Several participants also reported minimal changes in competence satisfaction and frustration for PA (see Figure 1) and for FV consumption (see Figure 2). Natalia explained that, "*I don't think participating in the program affected my confidence … Unless I was running a marathon, and someone was coaching me to run a marathon … she wasn't my exercise coach or my trainer."* However, this was not the case for all participants, as visualized in Figures 1 and 2 and expressed by Elizabeth, "*Because it became a habit, the confidence increased with the habit forming. So it came together. As each week went on, then I found I was more confident."*

Finding support for self-care behaviors within the caregiving context

Participants articulated that the caregiving journey can be very isolating, thus making it challenging to elicit support from their social networks. Participants' divergent perspectives on support for self-care behaviours provide insight to our quantitative findings for relatedness satisfaction and frustration for PA and for FV consumption (see Table 2). Individual level data

are visualized in Figures 1 and 2, demonstrating that some participants reported increased relatedness satisfaction and decreased frustration whereas others reported relatively stable values from pre- to post-intervention. Several participants noted that the intervention encouraged them to seek out additional support, for example through group-based PA. While participating in the intervention, Maria joined an aqua-fitness group and emphasized that "*being outside of the house and being with this group of people and doing something that I enjoy … that was the part where I feel the social aspect plus the aspect of enjoyment has played a role."* Others noted that having support from their family enabled them to make time for themselves to engage in more self-care behaviours. For example, Elizabeth expressed that *"It's very hard to make time for yourself, but I have the support of my daughter and my husband to do that."*

In contrast, some participants had difficulty identifying positive sources of support that aligned with their shifting values, and in turn struggled to engage in self-care behaviours. David stated: "*We were talking about the gym buddies and activity buddies and stuff like that, and I've been unable to match up with somebody that fits my schedule, or my goals, or my activities, so that just makes it very difficult because you've got nobody*". For Amy, her existing support system was a challenge as "*going to restaurants, eating junk food, that's what people do, so if anything it probably makes social interactions worse if that's all people want to do together*." Of note, some participants mentioned that the intervention did not change social aspects of their lives and did not elaborate on the role of support in changing their self-care behaviours.

Becoming a better caregiver through self-care behaviours

Many caregivers expressed that engaging in more self-care behaviours as a result of participating in the intervention led to positives changes in their lives. Engaging in self-care

behaviours that were personally meaningful helped some participants regain a sense of control, which was especially important within the context of cancer caregiving, as articulated by Heather: "*Even though I'm not in control of cancer, or my husband's health, there's a lot of things that I'm not in control of, but you know, [self-care] is something that I am."* Maria further explained that "*Well when you are going on an experience like [cancer caregiving], you have control over nothing, you know, the circumstances that are happening. Every decision is being made for you, there are not many choices or options that are there. I think that to have a certain level of control, even if you consider them as more activities, I think they are important."* Participants' changes in autonomy are reflected in quantitative findings, as many individual level scores on autonomy satisfaction for PA (see Figure 1) and FV consumption (see Figure 2) trended upwards. Of note, autonomy frustration remained relatively stable (see Figures 1 and 2), which could, in part, reflect additional environment factors as Amy explained: "*I've always felt like I had a choice in my fruit and vegetable consumption, I think it's just more a matter of resources, finances, affordability factors."*

Participants also expressed that changes made throughout the program helped them feel better physically and emotionally thus enabling them to be better caregivers. Mateo explained that "*the program gave me tools, methodology, to follow in order to satisfy [my wife's] needs being a caregiver. I am the main caregiver; I am the only one that is offering the support that [my wife] needs and I have to be in the best situation and position to help her."* Further, Christina said that by caregiving "*we're depleting our own energy"* and later discussed how "*through the exercise program, when we talk about social interaction with those positive people in your life, good nutrition, deep, more spiritual growth, that would be purpose in life, making sense of what's going on in your life, those things replenish your energy ... so there in lies, I*

believe, the crux of this program, 'what are those things that give us energy and how do we replenish it so we can be better caregivers?'" Similar positive changes in ability to manage caregiving were discussed by several other participants; nonetheless, this sentiment was not reflected in participants' self-reported caregiver burden (median caregiver burden [IQR] change from 1.1 [1.0] to 1.6 [1.6]; see Table 2).

Above and beyond managing their roles as caregivers, some participants also discussed how they're regaining energy for enjoyable activities by "having a little bit of fun" and "reconnecting with friends and coworkers". Joanne expressed that "*I love dancing, but I had no energy this year and no feeling of talking and laughing around the table. It's too much. But now I have to start back some of the things."* Heather also discussed how "*It's easy when you're a caregiver to just sort of be secluded and be content to be the little hermit in the house. But no, I got back out doing things with my friends and I'm still doing that. That was probably the biggest change, was just to say, you know, nothing's going to happen, the earth's not going to shatter if I step away for an hour."*

Discussion

In the present study, the primary objective was to assess the feasibility and acceptability of a brief intervention aiming to improve caregivers' self-care behaviours. Exploratory objectives included describing participants' self-care behaviours and SDT-based constructs (i.e., autonomy, competence, relatedness, self-determined motivation) and exploring caregivers' experiences and perspectives within the intervention. Low recruitment and enrollment rates resulted in a small sample size; however, retention rates and intervention adherence and fidelity were high. Participants expressed positive views of the intervention and the advisor, indicating that the intervention was somewhat acceptable, with some suggestions for improvements. From a

theoretical perspective, using SDT to deliver an autonomy supportive intervention was perceived positively participants. Taken together, inconsistencies in quantitative data and insights from participants suggest that high autonomy support may not have translated to changes in motivation and self-care behaviours. Within the context of this small study, this suggests that SDT may be helpful to understand some aspects of caregiver's self-care behaviours but does fully not encompass the complex realities of caregiving.

Several changes are warranted before further assessing or scaling up the present intervention. First, low recruitment and enrollment rates need to be addressed to increase interest and engagement among caregivers. Our recruitment strategy primarily involved online, passive methods, which may not be the most effective way to engage caregivers. In the future, more collaborative and robust partnerships and engagement with caregivers and organizations providing services to caregivers is recommended. Within the cancer context, researchers may wish to consider recruiting in partnership with hospitals and oncologists; however this may present additional barriers for feasibility. Involving caregivers in the co-design, development, and implementation of future interventions may be one method to increase caregiver engagement and subsequent enrollment in future interventions. Although assessing sustainability was beyond the scope of the present study, delivering interventions in collaboration with organizations with existing relationships with the target population and establishing strong multi-sectoral partnerships is likely more feasible in the long-term. For example, the Powerful Tools for Caregivers program [114], is currently being delivered in partnership with provincial governments across Canada. Despite challenges recruiting caregivers, all other indices of feasibility were promising, indicating that the intervention components and delivery mode may

be feasible. Nonetheless, the small sample could represent a highly motivated subset of the population and may not accurately reflect feasibility of larger-scale trials.

Similarly, participants expressed very positive views of the intervention and the advisor, indicating that many interventions components were acceptable to this cohort of participants. Although similar interventions have traditionally been delivered to caregiver and care-recipient dyads [17], participants appreciated the opportunity to have individual support, focus on their own health, and express themselves without judgement. Concerns were also expressed around the care-recipients willingness and ability to participate, suggesting that future interventions should offer the option for caregivers to participate alone. The one-on-one interactions with the advisor and tailored nature of the intervention were also identified as strengths – therefore these components should be considered in future research. Participants' divergent views on the intervention length and occasional technical barrier suggest that more flexibility in the intervention delivery is warranted. Although participants expressed satisfaction with the personalized nature of the intervention, several identified that not all topics were equally relevant to them and desired more emotional or psychological support. A modular or need-based intervention could be further explored [e.g., 115] to allow participants to focus on topics most pertinent to their current needs and transition to less frequent interactions (e.g., transition from weekly to monthly calls when the caregiver feels ready).

Notably, throughout the interviews, most participants discussed how their caregiving experiences prior to starting the intervention made it more difficult to engage in self-care behaviours as they struggled with prioritizing their own health. Participants subsequently discussed the positive impact of the intervention on their own self-care behaviours, finding support for these behaviours within a caregiving context, and how engaging in self-care

behaviours made them better caregivers. This is consistent with emergent caregiving research by Cuthbert et al. [91], suggesting that participating in an exercise program created an "upward spiral" in their lives, improving their ability to provide care and as well as personal enjoyment above and beyond engaging in self-care behaviours. As most interventions aiming to help caregivers manage their roles do not include PA and FV consumption [15], future programs should consider promoting these behaviours alongside existing strategies (e.g., education, psychological support).

Last, inconsistencies in the qualitative and quantitative findings related to SDT constructs suggest that this theoretical framework may not be the most appropriate to fully understand the caregiving context within this sample. Although caregivers responded positively to an autonomy supportive style and reported high levels of autonomy support, this did not translate into improved autonomy, competence, relatedness and subsequently more self-determined motivation as posited by SDT [31]. Many participants suggested that SDT constructs were not the key factors influencing their self-care behaviours, but rather discussed additional individual level (e.g., emotional factors) or environmental level (e.g., access to facilities, resources) influences. Accordingly, we recommend exploring how SDT could be integrated with broader theoretical frameworks that better encompass multiple levels of influence, such as a socioecological framework [116].

Limitations

Several limitations of the present study should be noted. Consistent with many behaviour change interventions, it is likely that our sample represented highly motivated participants. Additionally, inclusion criteria allowed anyone who self-identified as a caregiver to an individual diagnosed with cancer to participant, regardless of the number of hours of care provided or total

length of time as a caregiver. It is plausible that participants' needs may vary depending on their current caregiving responsibilities and past experiences as a caregiver. Our sample was primarily female and self-reported high income and education level. Efforts are warranted to address the unique needs of more diverse sub-groups of caregivers, namely those with limited access to technology or with low digital literacy, low socioeconomic status, and those who speak a language other than English. Further, the results presented herein are only applicable to the present 4-week intervention and could vary with any modifications to the intervention content or delivery mode. Next, PA and FV consumption only represent two dimensions of self-care behaviours and do not fully encompass the concept of self-care used in other disciplines (e.g., any activity that is done deliberately in order to take care of mental, emotional, and physical health). Last, the intervention was primarily focused on individual level behaviour change and did not address a range of environmental or societal factors that contribute to the health and wellbeing of caregivers.

Conclusion

Although promising, several modifications to the methods and content of the present intervention are needed to improve the feasibility and acceptability. Results suggest that more efforts are needed to engage caregivers at all phases of the research by working collaboratively across sectors, co-designing intervention materials, and partnering with organizations already serving caregivers to improve enrollment rates as well as satisfaction with the intervention. Although PA and FV consumption represent two dimensions of self-care behaviours that were viewed positively by caregivers; these strategies should be integrated with more comprehensive interventions encompassing educational, psychosocial, and environmental aspects of caregiving.

Though exploratory, our findings provide an exciting step towards optimizing interventions with the ultimate goal of improving the health and wellness of caregivers.

Acknowledgements

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Table 1. Sociodemographics and caregiving information pre-intervention (*n*=13)

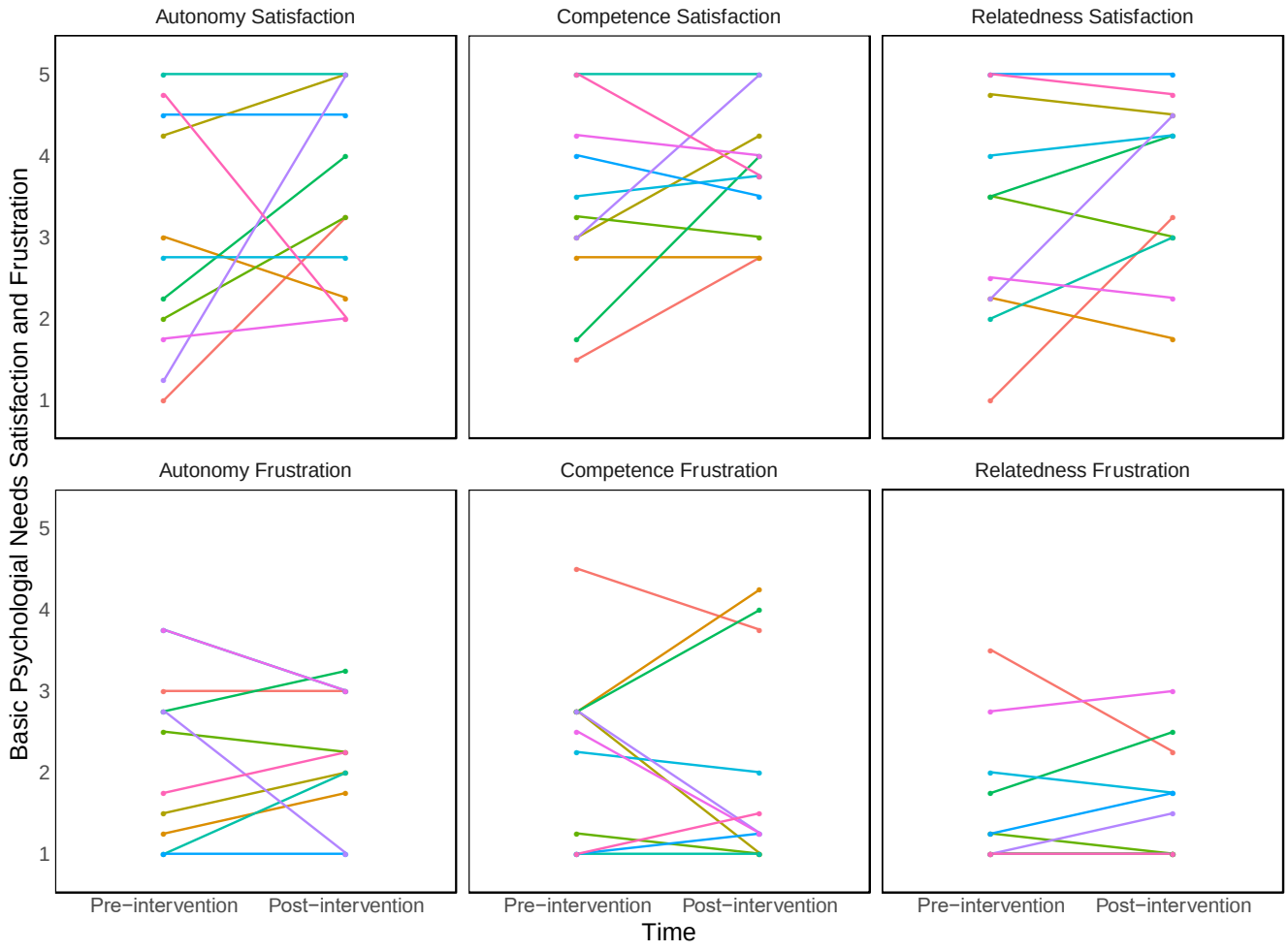
	Mean (SD)	***n* (%)**
Sociodemographics		
Age (years)	57.6 (15.4)	
Body mass index (kg/m^2)	29.9 (7.4)	
Sex		
Female		10 (76.9%)
Male		3 (23.1%)
Marital status		
Married		11 (84.6%)
Single		2 (15.4%)
Ethnicity		
White		10 (76.9%)
Latin American		2 (15.4%)
Other		1 (7.7%)
Highest level of education		
Highschool or some university/college		2 (15.4%)
Completed university/college		8 (61.5%)
Completed graduate degree		3 (23.1%)
Self-rated general health		
Excellent or very good		3 (23.1%)
Good		5 (38.5%)
Fair or poor		5 (38.5%)
Self-rated mental health		
Excellent or very good		1 (7.7%)
Good		7 (53.8%)
Fair or poor		5 (23.1%)
Caregiving		
Hours per week providing care	41.2 (41.7)	
Age of care recipient	65.6 (14.7)	
Relationship with care recipient		
Spouse		7 (53.8%)
Parent		3 (23.1%)
Daughter		2 (15.4%)
Grandfather		1 (7.7%)
Care recipients' cancer diagnosis		
Breast		2 (15.4%)
Colon		2 (15.4%)
Lung		2 (15.4%)
Multiple myeloma		2 (15.4%)
Leukemia		2 (15.4%)
Rectal		1 (7.7%)
Glioblastoma		1 (7.7%)
Liver		1 (7.7%)
Physical activity decreased as a result of caregiving responsibilities		9 (69.2%)
Fruit and vegetable consumption decreased as a result of caregiving responsibilities		8 (61.5%)
Overall health suffered as a result of caregiving responsibilities		10 (76.9%)

Table 2. Self-care behaviours, caregiver burden, and self-determination theory outcome scores for participants pre- and post-intervention.

	Scale range	Pre-intervention (*n*=13) (median [IQR])	Post-intervention (*n*=11) (median [IQR])
Self-care behaviours			
Light PA (*minutes/week*)	0-∞	60.0 (262.5)	110.0 (315.0)
MVPA (*minutes/week*)	0-∞	0.0 (330.0)	265.0 (590.0)
FV consumption (*servings/day*)	0-∞	3.1 (3.2)	3.7 (3.7)
Caregiver burden	0-3	1.1 (1.0)	1.6 (1.6)
Autonomy support	1-7	-	6.5 (1.0)
Motivation for PA	1-7		
RAI		3.3 (2.9)	3.5 (2.7)
Motivation for FV	1-7		
RAI		1.3 (4.6)	1.2 (3.7)
BPNS for PA	1-5		
Autonomy		2.8 (2.5)	3.3 (2.8)
Competence		3.0 (1.6)	3.8 (1.3)
Relatedness		3.5 (2.6)	4.3 (1.5)
BPNF for PA	1-5		
Autonomy		2.8 (1.9)	2.3 (1.3)
Competence		2.8 (1.6)	1.3 (2.8)
Relatedness		1.3 (0.9)	1.5 (1.3)
BPNS for FV	1-5		
Autonomy		3.5 (2.0)	4.0 (1.8)
Competence		3.8 (1.5)	3.8 (1.5)
Relatedness		3.5 (2.4)	4.3 (1.5)
BPNS for FV	1-5		
Autonomy		2.0 (0.6)	1.8 (1.0)
Competence		2.0 (1.3)	1.0 (1.6)
Relatedness		1.0 (0.3)	1.0 (1.0)

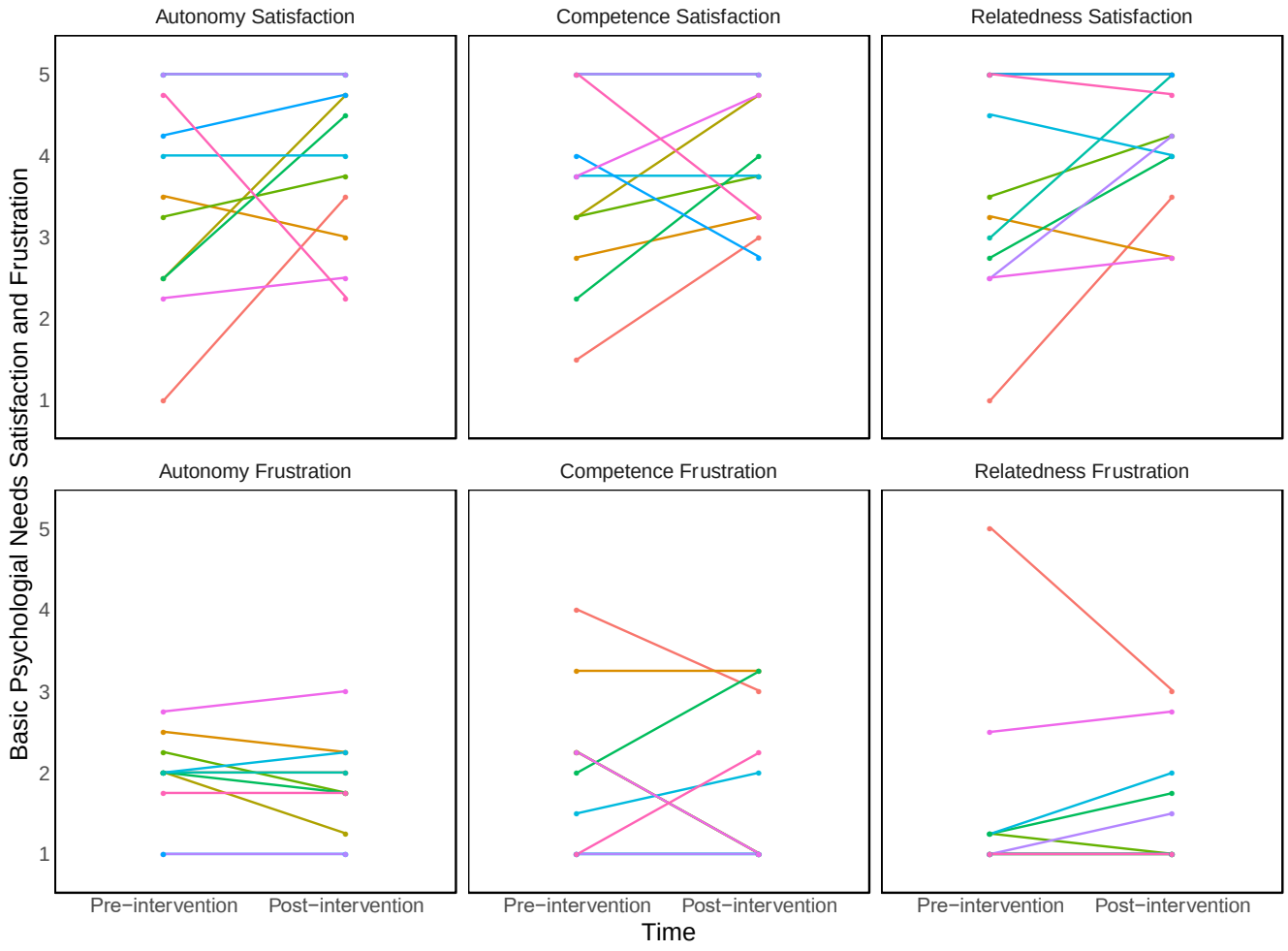
IQR= interquartile range; PA=physical activity; MVPA= moderate to vigorous physical activity; RAI=relative autonomy index; BPNS= basic psychological need satisfaction; BPNF=basic psychological need frustration.

Figure 1. Paired scatterplots representing individual level pre- and post-intervention scores for basic psychological needs satisfaction and frustration for physical activity for intervention completers (*n*=11).



Note: Each line represents a unique participant.

Figure 2. Paired scatterplots representing individual level pre- and post-intervention scores for basic psychological needs satisfaction and frustration for fruit and vegetable consumption for intervention completers (*n*=11).



Note: Each line represents a unique participant.

Supplementary Table 1. Intervention Overview

Week	Topic	Discussion points during video-call	Materials provided via email
1	Self-care and social support	- Benefits of PA and FV - Discuss personal costs and benefits of engaging in self-care - Discuss how being a caregiver influences self-care - Identify existing and potential sources of support - Plan to elicit social support from others	- 1.1 Self-Care information sheet - 1.2 Decisional Balance Worksheet - 1.3 Social Support - 1.4 Additional information
2	Goal setting, action planning, and self-monitoring	- Provide information on SMART goals - Help set personalized goals focused on PA and FV behaviour rather than outcomes (i.e., weight management) - Provide information on action planning - Create detailed action plans for PA and FV goals - Provide information on self-monitoring and benefits - Chose a feasible method to monitor behaviour (i.e., PA diary or log, using an app, marking a calendar)	- 2.1 Setting SMART goals - 2.2 Creating an Action Plan - 2.3 Self-monitoring
3	Barrier identification and environmental restructuring	- Check-in on goals and progress - Identify barriers to meeting goals and ways to overcome barriers - Prompt modifications to foster a more supportive environment - Revise action plans	- 3.1 Barrier identification - 3.2 Environmental restructuring worksheet
4	Relapse prevention and goal re-evaluation	- Check in on goals and progress - Identify potential future situations that may hinder progress in behaviour - Develop strategies to manage potential relapses - Re-evaluate goals and set longer term goals - Re-evaluate action plans	- 4.1 Maintaining motivation - 4.2 Rethinking your goals - 4.3 Rethinking your action plans

Supplementary Table 2. Interview Guide

Introduction

- The purpose of this interview is to discuss your thoughts and feelings about your experiences in this self-care program as well as your engagement in self-care and your role as a caregiver.
- If we start talking about something on this topic that is important to you, please feel free to talk openly and honestly about it. If you do not want to talk about a certain topic, that is okay as well. Remember, there are no right or wrong answers for this interview.
- This interview will also be audio-recorded so that I will be able to better listen to you now.
- Your name as well as other names used during this interview will be kept confidential and will be replaced with a pseudonym once the interview is over. This way, your confidentiality and anonymity will be assured.

Opening question

- What prompted you to sign up for this study?

Part 1: Experiences within the program and health and wellness advisor

- What are your overall impressions of the program that you participated in (delivery mode, content, frequency, length)?
    - What were the most helpful parts of the program?
    - What were the least helpful parts of the program?
    - What techniques learned (e.g., goal setting) did you find most/least useful? And which ones did you apply?
    - What would you change about the program in the future?
        - What would you change to be more applicable to caregivers?
- Did you experience any barriers to participating in the program?
    - Please explain.
        - Would participating in the program with your [care recipient] have been more or less beneficial for you?
    - Do you feel that you were able to prioritize your own self-care [and/or health] during the program? Why/Why not?
- Did participating in the program impact your physical, mental, and/or social health and wellbeing/functioning?
    - Please explain.
- What were your experiences with the health and wellness advisor who lead the program?
    - Do you feel that she supported your engagement in physical activity and fruit and vegetable consumption? Why/Why not?
    - What could she have done differently to make you feel more supported and improve your experience with the program?
    - What did you like/dislike about your interactions with her?

- Would you participate in a similar program again in the future?
    - Would you recommend the program to a friend?

Part 2: Self-care and self-determination theory constructs

[Discuss changes in self-care informed by quantitative results]

- Did your levels of physical activity change? Please explain.
- Did your fruit and vegetable consumption change? Please explain.
    - [If participants self-care increased] Do you plan on continuing to engage in regular self-care following the program?
- What motivated you to want to make changes in your physical activity behaviour?
- What motivated you to want to make changes in your fruits and vegetables consumption?
- Did your motivation for physical activity change since starting the program? How so?
- Did your motivation for fruit and vegetable consumption change since starting the program? How so?
- How did participating in the program affect…
    - your confidence to make changes to your physical activity behaviour;
    - your confidence to make changes to your fruit and vegetable consumption;
    - your sense of control (e.g., over your physical activity, fruit and vegetable consumption, health in general); and
    - social aspects of your life (e.g., sense of connectedness with others [e.g., health and wellness advisor, care recipient, others outside of the program].

Part 3: Self-care and caregiving

- How has participating in the program affected your relationship with your [care recipient]?
- Can you tell me what it has been like trying to engage in self-care while you are a caregiver to a cancer survivor?
- Did you apply any of the techniques learned (e.g., goal setting) to other areas of your life (i.e., areas other than physical activity and fruit and vegetable consumption)? Which ones and why these ones?
    - How did the program affect how you were able to manage your role as a caregiver?
        - Please explain.

Conclusion

- Is there anything else related to the program that you would like to discuss that we have not covered?
- Thank you for your participation!

Chapter Five: Global discussion

The research presented in this thesis represents important groundwork to improve the health and wellbeing of cancer caregivers – a group often underrepresented and poorly acknowledged within the cancer care system. Within Canada, medical advances, shorter hospital stays, and increasing lifespan have contributed to a rise in the number of adults who assume the role of caregiver for people living with cancer [1, 2]. Providing care is not without consequences as many caregivers report high levels of stress, declines in mental and physical health [7-9], and less engagement in self-care behaviours upon assuming a caregiving role [11-13, 33]. Efforts to mitigate the negative impacts of caregiving and to promote the wellbeing of caregivers have largely focused on educational and stress management interventions [15]; whilst efforts to encourage self-care behaviours among caregivers are scarce [17]. Considerable gaps remain as few researchers have explored caregivers' preferences for and experiences participating in self-care interventions. Accordingly, we designed a 4-week intervention promoting self-care behaviours using a SDT lens to better understand caregivers' preferences and to understand their motivations for engaging in self-care behaviours. The results of the present study (presented in Chapter 4), raise important theoretical, conceptual, and practical considerations.

Theoretical considerations

SDT has been used extensively to understand and promote self-care behaviours in many population sub-groups [e.g., 23, 69]. SDT has also been applied within the caregiving context to gain an understanding of caregivers' motivations to provide care [117]; however, SDT has not been previously applied in an intervention setting to promote self-care behaviours among caregivers. Within the present intervention, SDT was applied in two ways: (1) to design an autonomy supportive intervention; and (2) to describe participants' basic psychological needs

satisfaction and frustration in relation to self-care behaviours. The tenants of an autonomy supportive intervention, namely acknowledging participants' perspectives, supporting their initiatives, offering choices within the intervention, and providing relevant information, while not acting controlling or pressuring, were viewed positively by participants and reflected in qualitative and quantitative assessments. However, participants' high levels of perceived autonomy support did not consistently translate to satisfaction of the basic psychological needs, more self-determined forms of motivation, or improved self-care behaviours. Taken together, inconsistencies in quantitative measures and qualitative accounts of participants' experiences suggest that additional factors should be considered to better capture the participants' realities and understand the broad context in which they are assuming a caregiving role.

Indeed, Deci and Ryan [118] acknowledge that proximal social contexts are embedded within broader pervasive contexts including cultural, political, and economic levels of influence. The relationships between each level of influence are complex and play a role in shaping an individual's behaviour [118]. Specifically within the caregiving context, cultural variations in the approach to caregiving can influence whether assuming the role of a caregiving is perceived positively or negatively and impact caregivers' wellbeing [e.g., 119]. From a political perspective, policies and support available to caregivers (e.g., tax rebates, subsidized respite care) could play in role in the time and resources caregivers can dedicate to engaging in self-care behaviours. Similarly, economic systems play a role in caregivers' ability to manage their responsibilities and other competing demands (e.g., needing to work multiple jobs or manage inconsistent hours, inaccessibility of home care) as well as the accessibility of safe and accessible physical activity and affordable fruits and vegetables. Further, pervasive contexts contribute to basic psychological needs more generally [118] and could be considered before

narrowing down on needs satisfaction and frustration related to self-care behaviours. For example, Dombestein et al. [117] found that satisfaction of the basic psychological needs within the caregiving context led to more autonomous forms of motivation for caregiving that were in turn related to greater caregiving wellbeing. Applying SDT to understand individuals' motivations for becoming a caregiver has potential to screen and identify caregivers who require additional support [117], before promoting individual-level behaviours changes.

Although SDT can be used to understand the influences of both proximal and pervasive contexts [118], interventions grounded in SDT typically focus on proximal, individual level factors. This approach can inadvertently blame individuals, place the onus on them to change their own behaviours, and fail to acknowledge the broader community and societal context. For example, within the present intervention, we encouraged participants to identify sources of support within their existing networks and did not provide the resources or environment to foster new connections. When designing future interventions, researchers may wish to consider a complementary socioecological approach to better understand multiple layers of influence, align with public health policies, and avoid blaming individuals for their roles in unhealthy behaviours [120]. A socioecological framework is complementary to individual approaches as it places the individual within broader systems [120-122] and has been used in an integrative manner with SDT to explain physical activity behaviours [e.g., 123]. Although findings offer support for the acceptability of an autonomy supportive intervention, more work is needed to understand the role of basic psychological needs satisfaction and frustration within the broader caregiving context and in relation to self-care behaviours among caregivers.

Conceptual Considerations

Traditionally, interventions aimed at improving the health and wellbeing of caregivers have contained educational, stress management, and/or psychological support [15]. Over the past decade, there has been a limited number of interventions tailored to promote self-care behaviours among caregivers [17], including PA and FV consumption– though these behaviours were rarely targeted together [53]. Advancements in this area have largely focused on dyadic PA interventions that are not specific to the cancer context. Two notable exceptions are the Renewing Caregiver Health and Wellbeing through Exercise (RECHARGE) trial [94] and the Tailored, wEb-based, psychosocial and physical activity (PA) self-Management PrOgram (TEMPO) to support men with prostate cancer and their caregivers [124]. Caregivers who participated in the RECHARGE trial – a 12-week structured exercise program assessing physical functioning, PA levels, and psychological wellbeing among family caregivers for adult cancer patients – identified exercise as a positive experience that contributed to physical and emotional strength, sense of control, and an opportunity to "focus on me" [94]. Similarly, caregivers who engaged with TEMPO – a 10-week, interactive web-based self-management intervention – supported the use of PA as a self-management strategy [124]. The present study offers additional support for the notion of PA as an appropriate self-care strategy to help caregivers manage negative consequences of providing care. As noted by Lambert et al. [124], PA remains an under-studied and under-utilized strategy within this population. Similarly, FV consumption has rarely been promoted as a self-care strategy for caregivers and these behaviours are scarcely promoted together [53]. The focus on FV was also supported; however several participants recommended a broader approach to healthy eating (e.g., focus on other food groups and general nutrition guidance).

Within the present study, conceptualizing self-care behaviours as only PA and FV consumption presented several limitations and may not have been in line with more broad definitions of self-care (i.e., any action to preserve or improve one's own health). Although content specific to PA and FV was well-received, participants identified a desire for a wider range of support, including emotional or psychological support. As such, future work could consider how PA and FV can be better integrated as options for self-care behaviours in more comprehensive interventions covering educational, psychological, and social aspects of caregiving. For example, the Powerful Tools for Caregivers program covers a wide range of topics related to caregiving (e.g., communication strategies, emotional management) and conceptualizes each strategy as a "tool" that participants can use and adapt to their specific context [114]. As highlighted within the interviews and previously noted in the literature [125, 126], the needs of caregivers vary based on the cancer trajectory and current needs of their care recipient. Accordingly, different strategies to support caregivers' health (e.g., education, emotional support, behaviour change support, self-care behaviour maintenance or modifications) may be more appropriate than others at varying points along the cancer trajectory. As many interventions are delivered statically to caregivers at only one time point [e.g., onset of caregiving, palliative care; 127], better consideration of the cancer and caregiving trajectories is needed. The *Cancer Family Caregiving Experience* model [127] offers additional support for providing a range of support services to meet the specific needs of caregivers at varying time points. Moving forward, it is important to continue to incorporate qualitative methodologies to better understand and explore caregivers' preferences within such interventions.

Practical considerations

Findings from the present study raise important practical considerations to help inform future work. As discussed in more detail in Chapter 4, several modifications are warranted to enhance the feasibility and acceptability of the present intervention. Participants expressed a desire for more flexibility with the delivery method (e.g., the option to engage with the advisor outside of video-calls) and the ability to better personalize content (e.g., spend more time on a content of particular interest). As such, a modular approach in which participants can select the most meaningful modules to them may be more appropriate and a better use of caregivers limited time. Findings also showed that although some participants preferred a brief intervention, others desired longer-term or varying degrees of support. A more gradual, stepped down approach in which more support is given at the beginning of the intervention and tapers off to less frequent support could be tested as a way to increase flexibility and acceptability. Going forward, meaningful engagement with caregivers, including co-designing intervention priorities and materials should be explored. The co-design approach has been implemented successfully within the caregiving context [128, 129] and could be used to further refine the present intervention and ensure caregivers' needs are being met. The notion of co-design is also in line with the Knowledge to Action Framework [130], which calls for upfront needs assessments and stakeholder involvement prior to intervention design.

In regards to feasibility, a major challenge of our study was recruitment. As highlighted by Cuthbert et al. [16, 94], recruiting caregivers is further hindered by a healthcare system that is not inherently designed to identify and support caregivers, a reluctance for many to identify with the term "caregiver", and a lack of acceptance that caregivers themselves require support. To enhance recruitment and to begin to explore sustainability, it is essential to establish multi-

sectoral partnerships, work across sites, secure resources, and utilize varied means of recruitment. Within Canada, there is a growing number of provincial organizations offering support for caregivers (e.g., Ontario Caregiver Organization), representing the opportune time to foster academic and community partnerships.

Limitations

The present study is not without limitations. As previously discussed, the study is limited by its small sample size, which likely represents a highly motivated sub-group of caregivers. Perspectives of a larger, more diverse group may have altered results and should be considered for future work. Although participants were asked to discuss the acceptability of the intervention, a quantitative measure of acceptability was not included and thus hindered our ability to triangulate data. Both quantitative and more in-depth qualitative questions could have been asked regarding each specific component of the intervention. Additional study limitations are presented in Chapter 4.

Conclusion

The evolving Canadian health care system, a growing number of individuals living with and beyond cancer, and an increasing reliance of caregivers to be active partners in care delivery highlight the need for improved support for caregivers. The findings from this thesis contribute to the limited body of research exploring the role that self-care behaviours have in supporting caregivers. Important theoretical, conceptual, and practical insights are presented to help guide future work seeking to design and deliver self-care behaviour interventions for caregivers. Though preliminary, the work presented within this thesis represents an exciting step towards enhancing the health and wellbeing of caregivers.

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Appendices

Appendix A: Research Ethics Board Approval

24/12/2018

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

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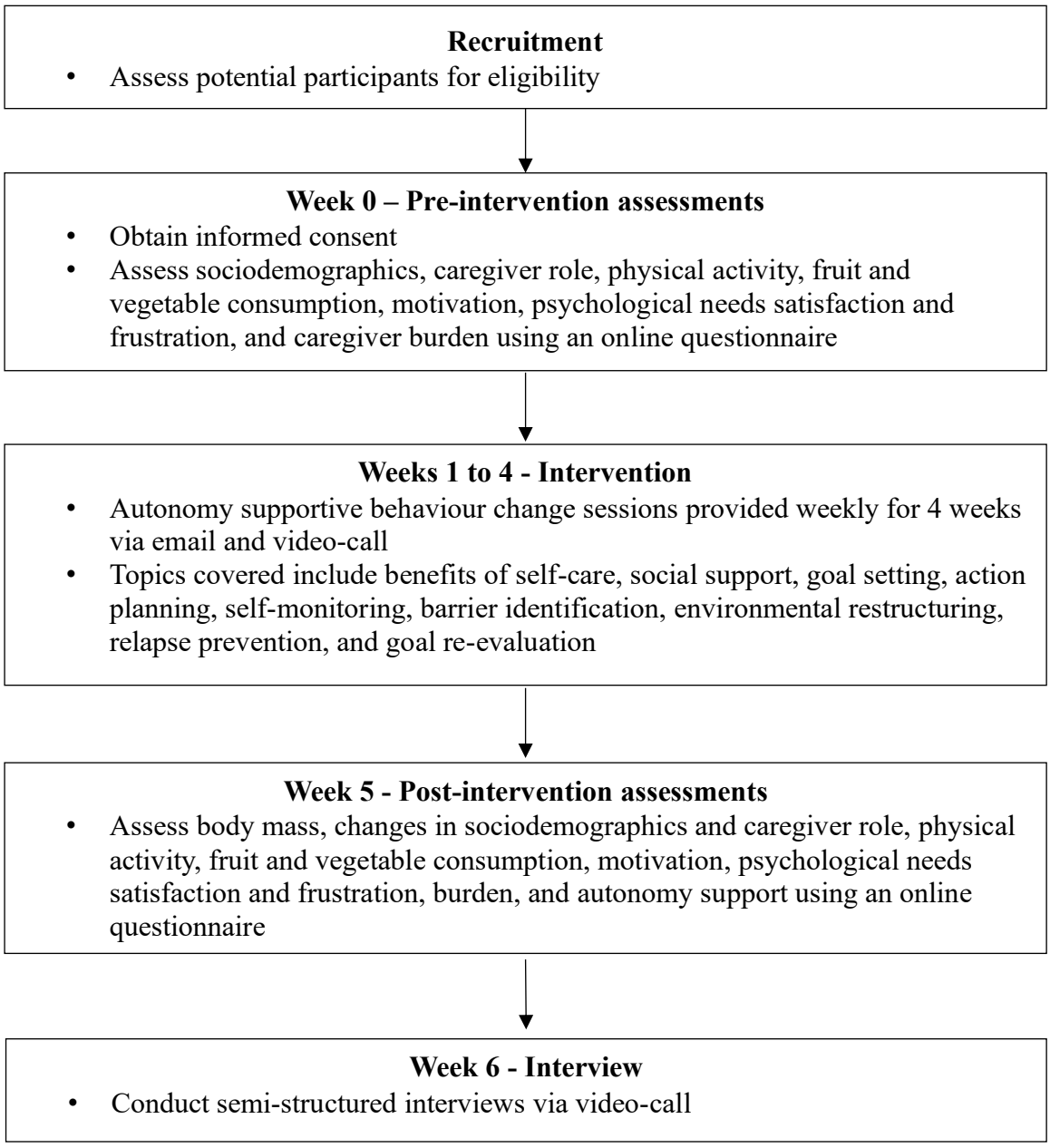
Appendix B: Study flow chart



Appendix C: Intervention overview

Week	Topic	Discussion points during video-call	Materials provided via email
1	Self-care and social support	- Benefits of PA and FV - Discuss personal costs and benefits of engaging in self-care - Discuss how being a caregiver influences self-care - Identify existing and potential sources of support - Plan to elicit social support from others	- 1.1 Self-Care information sheet - 1.2 Decisional Balance Worksheet - 1.3 Social Support - 1.4 Additional information
2	Goal setting, action planning, and self-monitoring	- Provide information on SMART goals - Help set personalized goals focused on PA and FV behaviour rather than outcomes (i.e., weight management) - Provide information on action planning - Create detailed action plans for PA and FV goals - Provide information on self-monitoring and benefits - Chose a feasible method to monitor behaviour (i.e., PA diary or log, using an app, marking a calendar)	- 2.1 Setting SMART goals - 2.2 Creating an Action Plan - 2.3 Self-monitoring
3	Barrier identification and environmental restructuring	- Check-in on goals and progress - Identify barriers to meeting goals and ways to overcome barriers - Prompt modifications to foster a more supportive environment - Revise action plans	- 3.1 Barrier identification - 3.2 Environmental restructuring worksheet
4	Relapse prevention and goal re-evaluation	- Check in on goals and progress - Identify potential future situations that may hinder progress in behaviour - Develop strategies to manage potential relapses - Re-evaluate goals and set longer term goals - Re-evaluate action plans	- 4.1 Maintaining motivation - 4.2 Rethinking your goals - 4.3 Rethinking your action plans

Appendix D: Questionnaires and Data Collection Tools

Sociodemographic and caregiver information

Pre-intervention questionnaire

Sociodemographic information. The following questions will gather information so that we can describe the group of people who are participating in this study. The information you provide below will be combined with the information provided by other participants and presented as averages or percentages. Your participation is voluntary and your answers will be kept strictly confidential. You are not required to answer any questions you do not feel comfortable answering.

1. What is your age? _____ years

2. What is your sex?
   - ☐ Male
   - ☐ Female
   - ☐ You do not have an option that applies to me. I identify as (please specify): _____

3. What is your civil (or marital) status?
   - ☐ Single
   - ☐ Married
   - ☐ Common law (i.e., two people who live together as a couple but who are not legally married to each other)
   - ☐ Widowed
   - ☐ Divorced
   - ☐ Separated
   - ☐ In a committed relationship, but not living together
   - ☐ Prefer not to answer

4. People living in Canada come from many different cultural and racial backgrounds. Which of the following best describes your background? (check all that apply)
   - ☐ Aboriginal (e.g., Inuit, Metis, North American Indian)
   - ☐ Arab (e.g., Egyptian, Kuwaiti, Libyan)
   - ☐ Black (e.g., African, Nigerian, Somali)
   - ☐ Chinese (e.g., Chinese, Taiwanese)
   - ☐ Filipino
   - ☐ Japanese
   - ☐ Korean
   - ☐ Latin American (e.g., Chilean, Costa Rican, Mexican)
   - ☐ South Asian (e.g., Bangladeshi, Punjabi, Sri Lankan)
   - ☐ South East Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian)
   - ☐ West African (e.g., Afghan, Assyrian, Iranian)
   - ☐ White (Caucasian)

- ☐ Other visible minority not included above, please specify: _____
- ☐ Prefer not to answer

5. What is the highest level of education you attained?
   - ☐ Elementary school
   - ☐ High School
   - ☐ Some university/college
   - ☐ Completed university/college
   - ☐ Some graduate school (e.g., Master's degree, PhD)
   - ☐ Completed graduate degree (e.g., Master's degree, PhD)
   - ☐ Prefer not to answer

6. What is your annual household income?
   - ☐ Less than $5,000
   - ☐ $5,000 - $9,999
   - ☐ $10,000 - $14,999
   - ☐ $15,000 - $19,999
   - ☐ $20,000 - $24,999
   - ☐ $25,000 - $29,999
   - ☐ $30,000 - $34,999
   - ☐ $35,000 - $49,999
   - ☐ $50,000 - $74,999
   - ☐ $75,000 - $99,999
   - ☐ $100,000 - $149,999
   - ☐ $150,000 - $199,999
   - ☐ $200,000 - $249,999
   - ☐ $250,000 or more
   - ☐ Do not know
   - ☐ Prefer not to answer

7. What is your current employment status? (check all that apply)
   - ☐ Full-time student
   - ☐ Part-time student
   - ☐ Full-time worker
   - ☐ Part-time worker
   - ☐ Homemaker
   - ☐ Unemployed
   - ☐ Retired
   - ☐ On disability
   - ☐ Other, please specify: _____
   - ☐ Prefer not to answer

8. How many people do you live with? _____
   If you answered 0, skip to question 10.

9. Who do you live with? (check all that apply)
   - ☐ Spouse/partner
   - ☐ Child/children
   - ☐ Sibling(s)
   - ☐ Parent(s)
   - ☐ Roommate
   - ☐ Other, please specify: _____

10. Do you have any children?
    - ☐ Yes
    - ☐ No

    a) If yes, please indicate their ages and if they are currently living with you.

    Child 1: _____years ☐ Currently lives with me
    Child 2: _____years ☐ Currently lives with me
    Child 3: _____years ☐ Currently lives with me
    Child 4: _____years ☐ Currently lives with me
    Child 5: _____years ☐ Currently lives with me
    Child 6: _____years ☐ Currently lives with me

11. In general, would you say your health is:
    1) Excellent
    2) Very good
    3) Good
    4) Fair
    5) Poor

12. In general, would you say your *mental* health is:
    1) Excellent
    2) Very good
    3) Good
    4) Fair
    5) Poor

13. Has a doctor or nurse ever told you that you have the following? (check all that apply)
    - ☐ Angina
    - ☐ Heart attack
    - ☐ Stroke
    - ☐ Diabetes
    - ☐ High blood pressure
    - ☐ High cholesterol
    - ☐ Arthritis
    - ☐ Asthma/lung disease
    - ☐ Osteoporosis/osteopenia
    - ☐ Hip/joint replacement
    - ☐ Cancer
    - ☐ Other (please specify): _____

14. Are you currently taking any medications?
    - ☐ Yes (please specify): _____
    - ☐ No

15. At the present time, how often do you smoke cigarettes?
    - ☐ Every day
    - ☐ Occasionally
    - ☐ Not at all

    a) If "every day" or "occasionally", how many cigarettes do you smoke per day on the days that you do smoke? _____

    b) If "not at all", have you ever smoked cigarettes daily?
    - ☐ Yes
    - ☐ No

    c) If yes, when did you stop smoking? _____/_____ (month/year)

16. What is your current height? _____feet _____inches OR _____centimeters

17. What is your current weight? _____pounds OR _____kilograms

18. Are you concerned about your weight?
    - ☐ No
    - ☐ Yes, I am trying to *lose* weight
    - ☐ Yes, I am trying *gain* weight
    - ☐ Yes, I am trying to *maintain* weight

19. Have you gained or lost more than 5 kilograms (11 pounds) over the past year?
    - ☐ Yes
    - ☐ No

    a) If yes, was this intentional or unintentional. Please explain.

    _____

20. Do you have any current or future weight-related goals?
    - ☐ Yes
    - ☐ No

    a) If yes, please describe your current or future weight-related goals.

    _____

    _____

    _____

Caregiver information. The next questions ask about help or care you may have given to someone (e.g., family member, friend, neighbour) who has been diagnosed with cancer. This person will be referred to as the care recipient. This help may include driving them, shopping with or for them, helping with housework, personal care or anything else. This excludes paid help to clients or patients, or help provided on behalf of an organization.

1. What is your relationship with the care recipient?
   - ☐ Spouse
   - ☐ Partner
   - ☐ Friend
   - ☐ Sibling
   - ☐ Daughter/son
   - ☐ Parent
   - ☐ Co-worker
   - ☐ Neighbour
   - ☐ Other (please specify): _____

2. What is the age of the care recipient? _____ years

3. What is the sex of the care recipient?
   - ☐ Male
   - ☐ Female
   - ☐ You do not have an option that applies. The care recipient identifies as (please specify): _____

4. When was the care recipient diagnosed with cancer? Please include the month and year.
   _____

5. Has the care recipient had a recurrence of cancer?
   - ☐ Yes
   - ☐ No

6. What type of cancer was the care recipient diagnosed with? (check all that apply)
   - ☐ Breast
   - ☐ Colon
   - ☐ Rectal
   - ☐ Lung
   - ☐ Cervical
   - ☐ Prostate
   - ☐ Bladder
   - ☐ Melanoma
   - ☐ Thyroid
   - ☐ Kidney
   - ☐ Pancreas
   - ☐ Oral
   - ☐ Lymphoma
   - ☐ Other (please specify): _____

7. What stage of cancer was the care recipient diagnosed with?
   - ☐ Stage I
   - ☐ Stage II
   - ☐ Stage III
   - ☐ Stage IV
   - ☐ I do not know

8. Please indicate which medical treatments for cancer the care recipient is receiving or received and the month and year of the last treatment, if applicable: (check all that apply)
   - ☐ Surgery (please specify the month and year treatment was complete): _____
   - ☐ Chemotherapy (please specify the month and year treatment was complete): _____
   - ☐ Radiotherapy (please specify the month and year treatment was complete): _____
   - ☐ Hormonal therapy (please specify the month and year treatment was complete): _____
   - ☐ Other treatments (please specify the month and year treatment was complete): _____
   - ☐ I do not know

9. Do you live with the care recipient?
   - ☐ Yes
   - ☐ No

10. How long, in years and months, have you been providing care for the care recipient? _____

11. On average, how many *hours per week* do you spend in caregiver activities (such as, but not limited to, transportation, meal preparation, medication management, personal care, emotional support)? _____

12. In the past 12 months, which of the following activities have you provided help with? (check all that apply)
   - ☐ Transportation (e.g., to do errands, to medical appointments)
   - ☐ Meal preparation
   - ☐ House cleaning and/or laundry
   - ☐ House maintenance and/or outdoor work
   - ☐ Personal care (e.g., bathing)
   - ☐ Medical treatments
   - ☐ Scheduling and/or coordinating care related tasks
   - ☐ Managing finances/banking
   - ☐ Emotional support
   - ☐ Other (please specify): _____

13. In the past 12 months, how physically strenuous on average were your caregiving activities?
    - ☐ Very strenuous
    - ☐ Strenuous
    - ☐ Somewhat strenuous
    - ☐ Not at all strenuous

14. Have your caregiving responsibilities affected the amount of physical activity that you usually get?
    - ☐ Yes, my physical activity increased
    - ☐ Yes, my physical activity decreased
    - ☐ No

15. Have your caregiving responsibilities affected the amount of fruits and vegetables that you usually consume?
    - ☐ Yes, my fruit and vegetable consumption increased
    - ☐ Yes, my fruit and vegetable consumption decreased
    - ☐ No

16. Have your caregiving responsibilities affected your weight?
    - ☐ Yes, my weight increased
    - ☐ Yes, my weight decreased
    - ☐ No

17. Have your caregiving responsibilities affected your overall health?
    - ☐ Yes, my health improved
    - ☐ Yes, my health suffered
    - ☐ No

Post intervention questionnaire

The following questions will gather information so that we can describe the group of people who are participating in this study. At the beginning of the study, we asked you to provide sociodemographic information about yourself such as your employment status and information about your role as a caregiver. Now, we would like to know if any of this information has changed over the past 5 weeks.

1. What is your current weight? _____pounds OR _____kilograms

2. Please describe changes (if any) in your sociodemographic information over the past 5 weeks. Examples may include, but are not limited to, changes in your employment, relationship status, health status, medications, or tobacco use.

3. Please describe changes (if any) in your role as a caregiver over the past 5 weeks. Examples may include, but are not limited to, changes in the number of hours spent caregiving, type of care provided, or changes in your care recipient's treatment.

Physical Activity

Aerobic physical activity

We are interested in finding out about the kinds of aerobic physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the last **7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the vigorous and moderate activities that you did in the last 7 days. Vigorous physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Moderate activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal.

Part 1: Job-related physical activity

The first section is about your work. This includes paid jobs, farming, volunteer work, course work, and any other unpaid work that you did outside your home. Do not include unpaid work you might do around your home, like housework, yard work, general maintenance, and caring for your family. These are asked in Part 3.

1. Do you currently have a job or do any unpaid work outside your home?

   ☐ Yes

   ☐ No → ***Skip to PART 2: TRANSPORTATION***

The next questions are about all the physical activity you did in the **last 7 days** as part of your paid or unpaid work. This does not include traveling to and from work.

2. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, heavy construction, or climbing up stairs **as part of your work**? Think about only those physical activities that you did for at least 10 minutes at a time.

   _____ **days per week**

   ☐ No vigorous job-related physical activity → ***Skip to question 4***

3. How much time did you usually spend on one of those days doing **vigorous** physical activities as part of your work?

   _____ **hours per day**
   _____ **minutes per day**

4. Again, think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads **as part of your work**? Please do not include walking.

_____ **days per week**

☐ No moderate job-related physical activity → ***Skip to question 6***

5. How much time did you usually spend on one of those days doing **moderate** physical activities as part of your work?

_____ **hours per day**
_____ **minutes per day**

6. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time **as part of your work**? Please do not count any walking you did to travel to or from work.

_____ **days per week**

☐ No job-related walking → ***Skip to PART 2: TRANSPORTATION***

7. How much time did you usually spend on one of those days **walking** as part of your work?

_____ **hours per day**
_____ **minutes per day**

Part 2: Transportation physical activity

These questions are about how you traveled from place to place, including to places like work, stores, movies, and so on.

8. During the **last 7 days**, on how many days did you **travel in a motor vehicle** like a train, bus, car, or tram?

_____ **days per week**

☐ No traveling in a motor vehicle → ***Skip to question 10***

9. How much time did you usually spend on one of those days **traveling** in a train, bus, car, tram, or other kind of motor vehicle?

_____ **hours per day**
_____ **minutes per day**

Now think only about the **bicycling** and **walking** you might have done to travel to and from work, to do errands, or to go from place to place.

10. During the **last 7 days**, on how many days did you **bicycle** for at least 10 minutes at a time to go **from place to place**?

_____ **days per week**

☐ No bicycling from place to place → ***Skip to question 12***

11. How much time did you usually spend on one of those days to **bicycle** from place to place?

_____ **hours per day**
_____ **minutes per day**

12. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time to go **from place to place**?

_____ **days per week**

☐ No walking from place to place → ***Skip to PART 3: HOUSEWORK, HOUSE MAINTENANCE, AND CARING FOR FAMILY***

13. How much time did you usually spend on one of those days **walking** from place to place?

_____ **hours per day**
_____ **minutes per day**

Part 3: Housework, house maintenance, and caring for family

This section is about some of the physical activities you might have done in the **last 7 days** in and around your home, like housework, gardening, yard work, general maintenance work, and caring for your family.

14. Think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, chopping wood, shoveling snow, or digging **in the garden or yard**?

_____ **days per week**

☐ No vigorous activity in garden or yard → ***Skip to question 16***

15. How much time did you usually spend on one of those days doing **vigorous** physical activities in the garden or yard?

_____ **hours per day**
_____ **minutes per day**

16. Again, think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **moderate** activities like carrying light loads, sweeping, washing windows, and raking **in the garden or yard**?

_____ **days per week**

☐ No moderate activity in garden or yard → ***Skip to question 18***

17. How much time did you usually spend on one of those days doing **moderate** physical activities in the garden or yard?

_____ **hours per day**
_____ **minutes per day**

18. Once again, think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **moderate** activities like carrying light loads, washing windows, scrubbing floors and sweeping **inside your home**?

_____ **days per week**

☐ No moderate activity inside home → ***Skip to PART 4: RECREATION, SPORT AND LEISURE-TIME PHYSICAL ACTIVITY***

19. How much time did you usually spend on one of those days doing **moderate** physical activities inside your home?

_____ **hours per day**
_____ **minutes per day**

Part 4: Recreation, sport, and leisure-time physical activity

This section is about all the physical activities that you did in the **last 7 days** solely for recreation, sport, exercise or leisure. Please do not include any activities you have already mentioned.

20. Not counting any walking you have already mentioned, during the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time **in your leisure time**?
_____ **days per week**

☐ No walking in leisure time → ***Skip to question 22***

21. How much time did you usually spend on one of those days **walking** in your leisure time?

_____ **hours per day**
_____ **minutes per day**

22. Think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **vigorous** physical activities like aerobics, running, fast bicycling, or fast swimming **in your leisure time**?

_____ **days per week**

☐ No vigorous activity in leisure time → ***Skip to question 24***

23. How much time did you usually spend on one of those days doing **vigorous** physical activities in your leisure time?

_____ **hours per day**
_____ **minutes per day**

24. Again, think about only those physical activities that you did for at least 10 minutes at a time. During the **last 7 days**, on how many days did you do **moderate** physical activities like bicycling at a regular pace, swimming at a regular pace, and doubles tennis **in your leisure time**?

_____ **days per week**

☐ No moderate activity in leisure time → ***Skip to PART 5: TIME SPENT SITTING***

25. How much time did you usually spend on one of those days doing **moderate** physical activities in your leisure time?
_____ **hours per day**
_____ **minutes per day**

Part 5: Time spent sitting

The next questions are about the time you spend sitting while at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting

friends, reading or sitting or lying down to watch television. Do not include any time spent sitting in a motor vehicle that you have already told me about.

26. During the **last 7 days**, how much time did you usually spend **sitting** on a **weekday**?

_____ **hours per day**
_____ **minutes per day**

27. During the **last 7 days**, how much time did you usually spend **sitting** on a **weekend day**?

_____ **hours per day**
_____ **minutes per day**

Strength and conditioning activities

The next questions are about the time you spent doing anaerobic physical activities (e.g., strength and conditioning activities) as part of your everyday life. The questions will ask you about the time you spent being physically active in the last **7 days**. Please think about the strength and conditioning activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

1. Have you participated in strength or resistance activities (e.g., free weights, weight machines, resistance bands or exercises using your own body weight) in the past 7 days?
   - ☐ Yes
   - ☐ No

   If "Yes", please answer the following questions:

2. In the past 7 days, how many days did you do strength or resistance activities? _____ days

3. How long did you spend doing strength or resistance activities on those days (i.e., the total time between when you started your first exercise to when you finished your last exercise)? _____minutes

4. What types of activities did you do (please check all that apply)?
   - ☐ Free weights
   - ☐ Bodyweight exercises
   - ☐ Weight machines
   - ☐ Resistance bands
   - ☐ Balance exercises
   - ☐ Plyometrics (i.e., activities that involve jumping or moving quickly and explosively)
   - ☐ Yoga or Pilates
   - ☐ Other (please specify): _____

5. List what activities you did (e.g., push-ups, box jumps, squats):

   _____

   _____

   _____

6. On average, how many times did you do each exercise?

   _____ sets of _____ reps

7. Where do you usually do your strength or resistance activities (please check all that apply)?
   - ☐ Home
   - ☐ Weight room
   - ☐ Gymnasium
   - ☐ Fitness studio
   - ☐ Workplace
   - ☐ Outside
   - ☐ Other (please specify): _____

8. With whom do you usually do your strength or resistance activities (please check all that apply)?
   - ☐ On my own
   - ☐ Care recipient
   - ☐ Friend(s)
   - ☐ Coworker(s)
   - ☐ Spouse or partner
   - ☐ Personal trainer
   - ☐ Others in a fitness class
   - ☐ Teammates
   - ☐ Other (please specify): _____

Fruit and vegetable consumption

These next questions are about the fruits and vegetables you ate or drank during the past week. Think about all meals and snacks, at home and away from home.

1. In the last week, how many times did you drink 100% PURE fruit juices, such as pure orange juice, apple juice or pure juice blends? Do not include fruit-flavored drinks with added sugar or fruit punch. _____ times per week

2. In the last week, not counting juice, how many times did you eat fruit? Please remember to include frozen, dried or canned fruit. _____ times per week

3. In the last week, how many times did you eat dark green vegetables such as broccoli, green beans, peas and green peppers or dark leafy greens including romaine or spinach? Please remember to include frozen or canned vegetables and vegetables that were cooked in soups or mixed in salad. _____ times per week

4. In the last week, how many times did you eat orange-coloured vegetables such as carrots, orange bell pepper, sweet potatoes, pumpkin or squash? Please remember to include frozen or canned vegetables and vegetables that were cooked in soups or mixed in salad. _____ times per week

5. In the last week, how many times did you eat potatoes that are not deep fried? _____ times per week

6. Excluding the green and orange vegetables as well as the potatoes you have already reported, in the last week, how many times did you eat OTHER vegetables? Examples include cucumber, celery, corn, cabbage and vegetable juice. _____ times per week

Motivation

The following questions relate to the reasons why you would either start eating more **fruits and vegetables (FVs)** or continue to do so. Different people have different reasons for doing that, and we want to know how true each of the following reasons is for you. Please indicate the extent to which each reason is true for you, using the following 7-point scale:

The reason I would eat FVs is:	**1** Not at all true	**2**	**3**	**4** Somewhat true	**5**	**6**	**7** Very true
1. Because I feel that I want to take responsibility for my own health							
2. Because I would feel guilty or ashamed of myself if I did not eat FVs							
3. Because I personally believe it is the best thing for my health							
4. Because others would be upset with me if I did not							
5. I really don't think about it							
6. Because I have carefully thought about it and believe it is very important for many aspects of my life							
7. Because I would feel bad about myself if I did not eat FVs							
8. Because it is an important choice I really want to make							
9. Because I feel pressure from others to do so							
10. Because it is easier to do what I am told than think about it							

11. Because it is consistent with my life goals							
12. Because I want others to approve of me							
13. Because it is very important for being as healthy as possible							
14. Because I want others to see I can do it							
15. I don't really know why							

The following question relates to the reasons why you would either start to engage in **physical activity (PA)** or continue to do so. Different people have different reasons for doing that, and we want to know how true each of the following reasons is for you. Please indicate the extent to which each reason is true for you, using the following 7-point scale:

The reason I would engage in PA regularly is:	**1** Not at all true	**2**	**3**	**4** Somewhat true	**5**	**6**	**7** Very true
1. Because I feel that I want to take responsibility for my own health							
2. Because I would feel guilty or ashamed of myself if I did not engage in PA regularly							
3. Because I personally believe it is the best thing for my health							
4. Because others would be upset with me if I did not							

5. I really don't think about it							
6. Because I have carefully thought about it and believe it is very important for many aspects of my life							
7. Because I would feel bad about myself if I did not engage in PA regularly							
8. Because it is an important choice I really want to make							
9. Because I feel pressure from others to do so							
10. Because it is easier to do what I am told than think about it							
11. Because it is consistent with my life goals							
12. Because I want others to approve of me							
13. Because it is very important for being as healthy as possible							
14. Because I want others to see I can do it							
15. I don't really know why							

Basic psychological need satisfaction and frustration

Below, we are going to ask about your actual experiences of certain feelings pertaining to your **physical activity (PA)**. Please read each of the following items carefully. You can choose from 1 to 5 to indicate the degree to which the statement is true for you at this point in your life.

	1 Not true at all	**2**	**3**	**4**	**5** Completely true
1. I feel a sense of choice and freedom in the PA I undertake					
2. Most of the PA I do feels like "I have to"					
3. I feel that the people I care about also care about me					
4. I feel excluded from the group I want to belong to					
5. I feel confident that I can do PA well					
6. I have serious doubts about whether I can do PA well					
7. I feel that my decisions reflect what I really want					
8. I feel forced to do a lot of PA I wouldn't choose to do					
9. I feel connected with people who care for me, and for whom I care					
10. I feel that people who are important to me are cold and distant towards me					
11. I feel capable at what I do					
12. I feel disappointed with many of my performances					
13. I feel my PA choices express who I really am					
14. I feel pressured to do too much PA					
15. I feel close and connected with other people who are important to me					
16. I have the impression that people I spend time with dislike me					
17. I feel competent to achieve my goals					

18. I feel insecure about my abilities					
19. I feel I have been doing PA that really interests me					
20. My daily activities feel like a chain of obligations					
21. I experience a warm feeling with the people I spend time with					
22. I feel the relationships I have are just superficial					
23. I feel I can successfully complete difficult tasks					
24. I feel like a failure because of the mistakes I make					

Below, we are going to ask about your actual experiences of certain feelings pertaining to your **fruit and vegetable (FV) consumption.** Please read each of the following items carefully. You can choose from 1 to 5 to indicate the degree to which the statement is true for you at this point in your life.

	1 Not true at all	**2**	**3**	**4**	**5** Completely true
1. I feel a sense of choice and freedom in the FVs that I eat					
2. Most of the FVs that I eat feels like "I have to"					
3. I feel that the people I care about also care about me					
4. I feel excluded from the group I want to belong to					
5. I feel confident that I can eat FVs					
6. I have serious doubts about whether I can eat FVs					
7. I feel that my decisions reflect what I really want					

8. I feel forced to eat many FVs I wouldn't choose to					
9. I feel connected with people who care for me, and for whom I care					
10. I feel that people who are important to me are cold and distant towards me					
11. I feel capable at what I do					
12. I feel disappointed with many of my performances					
13. I feel my FV choices express who I really am					
14. I feel pressured to eat too many FVs					
15. I feel close and connected with other people who are important to me					
16. I have the impression that people I spend time with dislike me					
17. I feel competent to achieve my goals					
18. I feel insecure about my abilities					
19. I feel I have been eating FVs that really interest me					
20. My daily activities feel like a chain of obligations					
21. I experience a warm feeling with the people I spend time with					
22. I feel the relationships I have are just superficial					
23. I feel I can successfully complete difficult tasks					
24. I feel like a failure because of the mistakes I make					

Autonomy support

This questionnaire contains items that are related to your interactions (e.g., video-calls, phone calls, emails) with your health and wellness advisor. Everyone has different styles in dealing with people, and we would like to know more about how you have felt about your encounters with your health and wellness advisor. Your responses are confidential. Please be honest and candid.

	1 Strongly disagree	**2**	**3**	**4** Neutral	**5**	**6**	**7** Strongly agree
1. I feel that my health and wellness advisor has provided me choices and options							
2. I feel understood by my health and wellness advisor							
3. My health and wellness advisor conveys confidence in my ability to make changes							
4. My health and wellness advisor encourages me to ask questions							
5. My health and wellness advisor listens to how I would like to do things							
6. My health and wellness advisor tries to understand how I see things before suggesting a new way to do things							

Caregiver burden

We are asking you for information about your present situation. The present situation comprises your caregiving deduced from the illness of your care recipient. The following statements often refer to the type of your assistance. This may be any kind of support up to unpaid nursing care. Please select the best description of your present situation.

	1 Strongly agree	**2** Agree	**3** Disagree	**4** Strongly disagree
1. My life satisfaction has suffered because of the care				
2. I often feel physically exhausted				
3. From time to time I wish I could "run away" from the situation I am in				
4. Sometimes I don't really feel like "myself" as before				
5. Since I have been a caregiver my financial situation has decreased				
6. My health is affected by the care situation				
7. The care takes a lot of my own strength				
8. I feel torn between the demands of my environment (such as family) and the demands of the care				
9. I am worried about my future because of the care I give				
10. My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care				

Interview guide

Introduction

- The purpose of this interview is to discuss your thoughts and feelings about your experiences in this self-care program as well as your engagement in self-care and your role as a caregiver.
- If we start talking about something on this topic that is important to you, please feel free to talk openly and honestly about it. If you do not want to talk about a certain topic, that is okay as well. Remember, there are no right or wrong answers for this interview.
- This interview will also be audio-recorded so that I will be able to better listen to you now.
- Your name as well as other names used during this interview will be kept confidential and will be replaced with a pseudonym once the interview is over. This way, your confidentiality and anonymity will be assured.

Opening question:

- What prompted you to sign up for this study?

Part 1: Experiences within the program and health and wellness advisor

- What are your overall impressions of the program that you participated in (delivery mode, content, frequency, length)?
    - What were the most helpful parts of the program?
    - What were the least helpful parts of the program?
    - What techniques learned (e.g., goal setting) did you find most/least useful? And which ones did you apply?
    - What would you change about the program in the future?
        - What would you change to be more applicable to caregivers?
- Did you experience any barriers to participating in the program?
    - Please explain.
        - Would participating in the program with your [care recipient] have been more or less beneficial for you?
    - Do you feel that you were able to prioritize your own self-care [and/or health] during the program? Why/Why not?
- Did participating in the program impact your physical, mental, and/or social health and wellbeing/functioning?
    - Please explain.
- What were your experiences with the health and wellness advisor who lead the program?
    - Do you feel that she supported your engagement in physical activity and fruit and vegetable consumption? Why/Why not?
    - What could she have done differently to make you feel more supported and improve your experience with the program?
    - What did you like/dislike about your interactions with her?
- Would you participate in a similar program again in the future?
    - Would you recommend the program to a friend?

Part 2: Self-care and self-determination theory constructs

[Discuss changes in self-care informed by quantitative results]

- Did your levels of physical activity change? Please explain.
- Did your fruit and vegetable consumption change? Please explain.
    - [If participants self-care increased] Do you plan on continuing to engage in regular self-care following the program?
- What motivated you to want to make changes in your physical activity behaviour?
- What motivated you to want to make changes in your fruits and vegetables consumption?
- Did your motivation for physical activity change since starting the program? How so?
- Did your motivation for fruit and vegetable consumption change since starting the program? How so?
- How did participating in the program affect…
    - your confidence to make changes to your physical activity behaviour;
    - your confidence to make changes to your fruit and vegetable consumption;
    - your sense of control (e.g., over your physical activity, fruit and vegetable consumption, health in general); and
    - social aspects of your life (e.g., sense of connectedness with others [e.g., health and wellness advisor, care recipient, others outside of the program].

Part 3: Self-care and caregiving

- How has participating in the program affected your relationship with your [care recipient]?
- Can you tell me what it has been like trying to engage in self-care while you are a caregiver to a cancer survivor?
- Did you apply any of the techniques learned (e.g., goal setting) to other areas of your life (i.e., areas other than physical activity and fruit and vegetable consumption)? Which ones and why these ones?
    - How did the program affect how you were able to manage your role as a caregiver?
        - Please explain.

Conclusion

- Is there anything else related to the program that you would like to discuss that we have not covered?
- Thank you for your participation!