Factors Associated with Physical Activity in Primary Spousal Caregivers of Men with Cancer

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Abstact

Spousal caregivers for men living with cancer engage in less physical activity (PA) than their non-caregiving peers. Studies have suggested that caregivers experience factors both positively and negatively associated with their PA which are both unique to caregiving, and common to older adults in general. However, no study has explored these factors using a qualitative methodology, nor has sought to tease out how they may change for different forms of PA. For this qualitative study, participants were seven women above the age of 50 who were caregivers for their spouse with cancer. The caregivers were interviewed regarding the factors which they perceived to be associated with their PA. Content analysis was performed on the transcribed interviews, which revealed that caregivers report a variety of factors associated with their PA. Caregivers described structural, interpersonal, and intrapersonal factors, as well as some unique to the caregiving role. The most critical barriers to PA were directly part of the caregiving role, and centered around the tremendous time commitment and burden of caring for their spouse. Caregivers also reported a clear distinction between leisure time physical activity (LTPA) and their physical activities of daily living (ADLs). The findings suggest that interventions seeking to improve caregiver PA should encourage dyadic PA where possible, and build upon existing PA habits.

Résumé de Recherche

Les proches-aidants conjoints aux hommes vivant avec un cancer font moins d'activité physique (AP) qu'autres adultes du même âge. Des études suggèrent que les proches-aidant vivent des facteurs associés (de façon négative et positive) à leur AP qui sont unique à leur rôle d'aidant, mais aussi des facteurs communs aux autres adultes. Cependant, aucune étude à date n'a exploré ces facteurs avec une méthode qualitative, ni en explorant comment ces éléments pourraient changer pour différentes formes d'AP. Pour cette étude qualitative, les participants furent sept femmes âgées de 50 ans ou plus qui étaient proches-aidants pour leur conjoint vivant avec un cancer. Les proches-aidants furent interviewé concernant les facteurs qu'elles percevaient comme étant associé à leur AP. Les entrevues transcrites furent analysées suivant une analyse de contenu qualitative, révélant une variété de facteurs associées à l'AP des proches-aidants. Les participants ont discuté des facteurs structurels, interpersonnels, et intrapersonnels, ainsi que des facteurs uniques au rôle de proche-aidant. Les facteurs plus importants quant à leur impact sur l'AP furent directement basés sur le rôle de proche-aidant. Le temps requis comme proche-aidant ainsi que l'impact émotif sont ressortis comme éléments importants. Les participants ont aussi discuté une distinction rigide entre leur AP en temps libre et leurs activités physiques de tâches quotidiennes. Les résultats suggèrent que les interventions cherchant à améliorer l'AP des proches-aidant devraient encourager l'AP en couple si possible, et encourager les proches-aidants à augmenter le niveau des activités qu'elles font déjà.

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Preface

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Introduction

In Canada, approximately 102 900 men are diagnosed with cancer each year, with prostate, colorectal, and lung cancers representing the three most common cancer loci in men (Canadian Cancer Society [CCS], 2016). The risk of developing cancer increases with age, and primarily affects middle-age to older men, with 89% of new cancer cases occurring in people over the age of 50 (CCS, 2016). In addition to physical symptoms such as pain, fatigue, and adverse effects of treatment regimens (Wells & Sandlin, 2012), living with cancer can also engender a variety of social, emotional, and psychological issues in patients (Costa, Mercieca-Bebber, Rutherford, Gabb, & King, 2016). In some uncommon circumstances, physical and psychological issues acquired during the acute treatment phase can continue and become chronic issues for patients long after treatment has successfully ended (Stein, Syrjala, & Andrykowski, 2008).

With high rates of cancer among men over the age of 50 and the issues associated with such a diagnosis comes a considerable need for caregiving. Primary family caregivers are family members of a person with an illness who tend to the majority of the patient's needs in a non-professional setting. For men living with cancer, their caregiver is most often their spouse (e.g. Nijboer et al., 1998; Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013). Cancer remains the most frequent reason for spousal caregiving, with 17% of all spousal caregiving attributable to cancer in the other spouse. Generally, caregivers may provide help with the patient's transport within and outside the home, household tasks and management, medical needs (such as adherence to a pharmacological regimen), and emotional support (Girgis et al., 2013). However, compared to caregivers with other relationships to the care recipient, spousal caregivers spend the most hours providing care, with a median of 14 hours a week spent

uniquely on caring for their spouse (Sinha, 2013). The caregiving role may be placed upon spouses involuntarily, due to potentially sudden diagnoses. Spousal caregivers are most often untrained and unpaid and are often only minimally supported by the healthcare system (Girgis et al., 2013). The confluence of these responsibilities, tasks, and additional labor can result in adverse health impacts among caregivers (Lambert et al., 2016).

Spousal caregivers can experience substantial amounts of stress and anxiety from the diagnosis and treatment, as well as the burden of caring for the patient (Lambert et al., 2016). Caring for someone with cancer involves more time-consuming and intense care, and is more likely to cause personal financial expenses compared to caring for other illnesses (Kent et al., 2016). Additionally, cancer therapies can result in a high variety of patient symptoms, which increase the difficulty of the caregiver's tasks. As cancer treatments improve, an increasing number of patients enter the survivorship period where cancer can reoccur with little notice, the risk of which can weigh heavily on caregivers as well. The survivorship period can also be exacerbated by long-term effects of the treatment (Kent et al., 2016). These various stressors and responsibilities create a difficult role that caregivers must face with little support.

In order to address the unique physical and psychological health challenges of caregivers (of many chronic disease types), some researchers have used physical activity (PA) in an attempt to improve caregiver health (Lambert et al., in press). Physical activity has been conclusively shown to greatly improve a multitude of physical and mental health outcomes, many of which are especially important for caregivers for men with cancer, who tend to be women over the age of 50 (CCS, 2016). Such benefits include improved cardiovascular and metabolic function, reduced risks of major chronic illnesses, better functional capacity, as well as enhanced cognition and improved mental health (Penedo & Dahn, 2005; Warburton, Nicol, & Bredin, 2006). The

effects of PA could directly improve a variety of health issues faced by caregivers including age-related disease (e.g., osteoporosis) as well as problems brought on by the caregiving role, such as depression and anxiety (Lambert, Jones, Girgis, & Lecathelinais, 2012). Despite this evidence, few PA studies conducted with caregivers noted consistent improvement to physical health indicators. This lack of consistent effect could be explained by the PA used in the studies, which were generally very mild activities (Lambert et al., in press) performed at a level that is insufficient to reach the Canadian PA guidelines (CSEP, 2011). The results of these studies may also have been influenced by a failure to identify and address the various barriers and facilitators to PA that caregivers may experience.

The shortcomings of current intervention literature can be encapsulated in two points: First, caregivers are not performing enough PA, nor at intensities most associated with health benefits. Second, the factors that may help or impede their ability to engage in larger amounts and higher intensities of PA are not fully understood. Only a small number of studies have attempted to improve caregiver PA, and although several were successful in significantly increasing caregiver PA, there were no significant improvements to indicators of caregiver physical health. This suggests that caregivers mostly increased their levels of low intensity PA while accruing little additional moderate-to-vigorous PA (MVPA), which are the PA intensities most associated with health benefits (Penedo & Dahn, 2005). The results of these interventions suggest a need for further investigation into the factors associated with caregiver PA in order to better develop interventions which can increase caregiver MVPA, and increase the likelihood of imparting PA-related health benefits. Such factors could include intrapersonal issues such as motivation or self-efficacy, interpersonal associations such as social group or family norms, or structural issues such as low neighbourhood walkability or poor urban design. These factors may

further compound other elements unique to the caregiving role, including emotional burden and fatigue. However, no study to date has investigated factors associated with PA among caregivers for men living with cancer using a qualitative methodology. Although several studies have reported factors associated with caregiver PA (Connell & Janevic, 2009; Farran et al., 2008; Hill, Smith, Fearn, Rydberg, & Oliphant, 2007), these data were collected quantitatively as either part of the intervention evaluation or as participants responded to the prescribed interventions. This document will therefore provide a review of relevant literature and propose a methodology to answer the two following research questions:

1) What structural, interpersonal, and intrapersonal factors are associated with PA in primary spousal caregivers of men with cancer?
2) How do these associations change for different types and intensities of PA? ("types" meaning the three main categories of PA for older adults as defined by the CSEP (2011), which are aerobic, resistance, and mobility-enhancing).

By exploring these questions, more information will be gleaned on the unique experiences of caregivers for men with cancer, and what factors are associated with their respective PA behaviours. The resulting perspectives could be used to inform intervention development to improve the health of this unique population.

Chapter 1: Literature Review

Caregivers and Health

Cancer represents a significant illness among Canadian men, with approximately 102 900 new diagnoses in this population every year (CCS, 2016). As the risk of developing cancer increases with age, men who are diagnosed with cancer often turn to their spouse to adopt a caregiving role, as cancer represents the most frequent reason for spousal caregiving (Romito et al., 2013). Spousal caregivers provide care for long hours, and are generally untrained and minimally supported by the healthcare system (Girgis et al., 2013), which can significantly impact their own physical and mental health.

Impact of caregiving role. Rates of stress, anxiety, and depression are higher in caregivers than the general age-matched population, with up to 56% of caregivers (across chronic illnesses) reporting anxiety and up to 52% reporting depression (Lambert et al., 2012). These psychological difficulties can be brought on by the initial diagnosis, ongoing treatments, as well as the daily burden associated with caregiving. For example, in a study of caregivers for men with prostate cancer, the rates of caregiver depression and anxiety were found to exceed the patient's rates of these conditions twofold (Couper et al., 2006). Such psychological distress can impact the caregiver-patient relationship, as caregiver anxiety and depression may increase these feelings in the patients themselves (Ko et al., 2005; Lambert et al., 2012). Anxiety and depression can also impact marital satisfaction between the caregiver and patient, exacerbating psychological difficulties (Zhou et al., 2011). Though the severity of depression and anxiety symptoms in caregivers peak shortly after a diagnosis then slowly decline, the scores often remain past the threshold of clinical significance for years, indicating that the psychological recovery of caregivers is a slow process (Lambert et al., 2012; Romito et al., 2013).

The overall burden of the caregiving role, combined with the physical and psychological health risks of caregivers, can lead to a variety of poor health outcomes among caregivers. Such outcomes can include pain, fatigue, sleep loss, loss of work hours, social isolation (Lambert, Girgis, Lecathelinais, & Stacey, 2013; Romito et al., 2013; Yabroff & Kim, 2009), and diminished quality of life (Fletcher et al., 2008). Because of the additional stressors and responsibilities associated with caregiving, many caregivers report unmet needs (Sklenarova et al., 2015). These needs can be tangible, such as a need for financial aid or physical healthcare, as well intangible, including social and emotional needs. In a recent study, over 40% of cancer caregivers reported more than 10 unmet needs, with unmet emotional needs reported most frequently (Sklenarova et al., 2015). Caregivers with more unmet needs were more likely to exhibit higher depression and anxiety scores. However, the impact of caregiving can extend into the domain of physical health as well.

Physical health risks. Caregivers for men with cancer are generally the man's spouse or partner, and are therefore mostly women over the age of 50 (CCS, 2016). They represent an important population for study, as they are already at risk for diseases associated with their age and sex. Notably, older Canadians (65 years older and more) of all sexes are at elevated risk for cardiovascular diseases, diabetes, osteoporosis, and falls (Health Canada, 2010). Comorbidities are also common, with one quarter of older adults living with four or more chronic conditions (Health Canada, 2011). In addition to the physical health risks associated with the demographic characteristics of this population, the act of providing care itself may exacerbate physical ailments.

Notably, spousal caregivers are the most likely of all family caregivers to report injury and seek medical assistance for their caregiving tasks (Turcotte, 2013). They are also the most

likely group of family caregivers to report overall decreases to physical health, with 38% of spousal caregivers reporting a decline (Turcotte, 2013). Together, the physical and psychological health risks that caregivers face are compounded by their unmet needs, and contribute to an overall decline in a variety of health indicators. Interventions attempting to address and improve caregiver health have begun to be implemented in many forms, such as dyadic coping programs (Lambert, Girgis, McElduff, et al., 2013). Some of these interventions have examined the use of PA to improve physical and mental health indicators in caregivers of individuals with a variety of chronic illnesses (Lambert et al., 2016), due to the wide variety of health benefits PA could potentially confer to the caregiver population.

Physical Activity and Health

It is well established that PA is associated with physical and mental health benefits (Penedo & Dahn, 2005; Warburton et al., 2006), and although the precise relationships between PA amount, intensity, and related health outcomes are not yet completely understood, it is generally agreed upon that higher intensity PA yields larger health improvements (Lee & Paffenbarger, 2000; Penedo & Dahn, 2005; Rehn, Winettb, Wisløffa, & Rognmoa, 2013). This consensus has helped shape the current Canadian Society of Exercise Physiology (CSEP, 2011) guidelines which recommend at least 150 total weekly minutes of MVPA for older adults. These minutes can be accumulated in multiple bouts of 10 or more minutes at a time, if appropriate intensities and types of PA are used. The guidelines also encourage resistance training, and recommend at least two bouts per week.

Physical activity intensity. The myriad forms of PA can be categorized based on many criteria, such as type and intensity. PA intensity is based on the rate of energy expenditure required to perform that activity and is generally divided into low, moderate, and vigorous

categories. It is important to note that the type of activity does not dictate intensity – both aerobic and resistance forms of exercise can be done at a variety of intensities, but are only strongly associated with health benefits when performed at moderate-to-vigorous intensities.

Despite the general consensus expounding the superiority of MVPA for health promotion, low intensity PA has been used with older populations due to the ease of performance and low injury risk, but such interventions have not conclusively demonstrated health improvements using such PA protocols (Buman et al., 2010). As such, current position statements from a variety of institutions (such as the American Heart Association and the American College of Sports Medicine) still recommend MVPA for older adults (Nelson et al., 2007). Older adults can accumulate their weekly minutes of MVPA through a variety of different types of PA, such as aerobic or resistance exercise.

Physical activity type. The Public Health Agency of Canada officially endorses the latest PA recommendations published by the CSEP (2011) which include special guidelines for different age groups, including older adults. These guidelines differentiate between three types of PA: aerobic, resistance, and mobility-enhancing. Briefly, aerobic PA primarily taxes the cardiovascular system, resulting in increased heart rate and heavier breathing for the duration of the exercise. Activities such as running, jogging, swimming, and cycling are all emblematic of aerobic PA, but leisure activities such as sports, gardening, walking, and housework can all incur an aerobic training stimulus (Penedo & Dahn, 2005). Resistance training primarily taxes the musculoskeletal system, usually incurred by pushing, pulling, or lifting a load. This form of PA is often portrayed by weightlifting or bodyweight exercises (e.g., push-ups) but can also be performed through manual labour tasks or daily tasks involving load-bearing (e.g., carrying groceries) (Warburton et al., 2006). Finally, mobility-enhancing PA is generally discussed in

regards to older populations, and describes activities which focus on maintaining or developing balance, gait, or direction change, usually with the goal of fall prevention (Faber, Bosscher, Chin, & van Wieringen, 2006).

Aerobic physical activity. Epidemiological studies have found that higher levels of physical activity are inversely associated with overall mortality risk (Warburton et al., 2006). In inactive populations, even small increases in aerobic MVPA have been associated with significant decreases in all-cause mortality, with the most active populations demonstrating the lowest rates (Warburton et al., 2006). Cardiovascular disease risk is particularly affected by aerobic MVPA. A longitudinal study of over 40 000 older adult participants found that even small amounts of MVPA conferred cardiovascular health benefits when compared to inactive, healthy weight controls, but also found that participants who accumulated less PA but performed it at a higher intensity were also associated with large reductions in risk for the same diseases (Soares-Miranda, Siscovick, Psaty, Longstreth, & Mozaffarian, 2016). Importantly, this study suggests that the cardio-protective effects of aerobic MVPA readily apply to older adult populations, improving the health of older men and women alike, which highlights the importance of aerobic MVPA for the health of spousal caregivers. However, aerobic MVPA may not effectively confer enough health benefits to be the sole prescription for healthy aging and overall health; the benefits of also incorporating resistance training are being increasingly touted for adult and older adult populations (Bauman, Merom, Bull, Buchner, & Fiatarone Singh, 2016).

Resistance physical activity. Though resistance PA can contribute to a person's MVPA and improve one's cardiovascular health, it is also an effective preventive measure for chronic illnesses such as osteoporosis and diabetes (Warburton et al., 2006). Resistance PA is also

associated with reduced fall risk and therefore lower rates of fall-related injury in older populations (Cadore, Rodriguez-Manas, Sinclair, & Izquierdo, 2013). Additionally, resistance training can increase daily functioning, which can not only improve an older adult's independence but may also improve a spousal caregiver's ability to perform daily activities and provide care (Warburton et al., 2006).

Mobility-enhancing and multimodal physical activity. This final category of the three types of PA recommended for older adults by the CSEP (2011) encompasses a variety of kinds of PA which primarily impact coordination, proprioception, balance, and gait. Though many forms of aerobic and resistance PA improve these functions, mobility-enhancing PA targets these functions directly, often with exercises that mimic daily activities of living.

The CSEP's older adult PA guidelines are therefore firmly rooted in literature connecting PA to health, and more importantly, healthy aging. This literature supports the use of PA as a health promoting tool among spousal caregivers for men with cancer. Despite the research recommending multiple types of MVPA for optimal health, many interventions attempting to improve caregiver health did not employ multimodal PA. In many cases, participants did not meet the 150 minutes of MVPA recommendation, even with one form of PA only (Lambert et al., 2016). This discrepancy is important, as it underlines that current attempts to improve caregiver health through PA are implementing suboptimal interventions. This could be due to a variety of factors, such as feasibility or resources, but it warrants further investigation regardless. Reaching the recommended amounts and types of MVPA in caregivers is essential, as the physical benefits are well-documented (Penedo & Dahn, 2005; Warburton et al., 2006). The health impacts of PA extend past the physical realm, however, as more recent studies have also begun to explore the substantial links between PA and other aspects of holistic health.

Physical activity and psychological health. Various studies have found that engaging in MVPA can improve multiple facets of psychological health, such as cognition and affect (Hogan, Mata, & Carstensen, 2013; Peluso & de Andrade, 2005) reduce symptoms of depression and anxiety (Bridle, Spanjers, Patel, Atherton, & Lamb, 2012; Ranjbar et al., 2015; Warburton et al., 2006), and slow the progression of age-related cognitive decline (Lautenschlager, Almeida, Flicker, & Janca, 2004). PA appears to be particularly effective at improving the symptoms of depression, though much like the physical health benefits, a PA intensity of moderate (or higher) is needed to elicit changes (aan het Rot, Collins, & Fitterling, 2009). Dunn, Trivedi, Kampert, Clark, and Chambliss (2005) found that when performed at the recommended guidelines (150 minutes of MVPA per week), MVPA was effective at improving symptoms of major depressive disorder, but little effect was found among people who performed low-intensity PA (Schuch et al., 2016). Interestingly, similar effects were produced in studies using either only aerobic or resistance MVPA, suggesting that the mental health benefits of PA are more closely tied to intensity rather than type of physical activity (aan het Rot et al., 2009). Other studies have found that MVPA and mental health follow a dose-response relationship, with greater amounts or intensity resulting in better general mental health outcomes (Hamer, Stamatakis, & Steptoe, 2009). MVPA also has an anxiety-reducing effect, though its impact on anxiety is less marked than its impact on depression (Stonerock, Hoffman, Smith, & Blumenthal, 2015). These mental health benefits further underline the importance of adequate MVPA for caregivers, who experience elevated rates of anxiety and depression (Lambert et al., 2012).

Despite the lack of clear consensus on the exact mechanisms underpinning the relationship between PA and mental health, it appears to be affected in some way by total amount and intensity of PA as well as the social context in which the activity takes place (aan het

Rot et al., 2009; Asztalos et al., 2009; Mason & Holt, 2012; Stonerock et al., 2015). Research examining the effects of PA on mental health specifically among older adults have found that increasing PA has been associated with improved cognitive function, mood, daily functioning and independent living skills (Hogan et al., 2013; Lautenschlager et al., 2004), as well as improving symptoms of depression among older adults with and without clinical depression (Bridle et al., 2012; Patel, Keogh, Kolt, & Schofield, 2013). Few studies have examined PA as a way to reduce anxiety in older adults, though Katula, Blissmer, and McAuley (1999) found that both low intensity and high intensity PA groups reported decreased anxiety symptoms when confounding items of the anxiety inventory were controlled. These studies further support the use of MVPA for improving spousal caregiver mental health.

Overall, the evidence that PA is beneficial to health is significant, and could be used to improve the health of spousal caregivers for men living with cancer. A position paper by Knapen, Vancampfort, Morien, and Marchal (2015) supported the promotion of PA specifically among older adults because of the higher rates of physical and psychological comorbidities associated with aging, which can be addressed simultaneously by PA. Adequately performed PA holds promise as a way to effectively address most of these issues simultaneously, be it heart disease (Soares-Miranda et al., 2016; Wen & Balluz, 2011), osteoporosis (Hinriksdóttir, Arngrímsson, Misic, & Evans, 2013), diabetes and obesity (Warburton et al., 2006), cognitive decline (Hogan et al., 2013), or depression and anxiety (Bridle et al., 2012; Katula et al., 1999). Despite this plethora of health benefits, spousal caregivers do not engage in adequate levels of PA and report a variety of barriers and facilitators associated with this behaviour.

Older Adults and Physical Activity

Though the exact rates of PA among caregivers for men with cancer are not currently known, the PA rates among older Canadians generally will be used as an estimate of caregiver PA rates for the purposes of this review, as 89% of cancer occurs in people over the age of 50. Caregivers of men with cancer are therefore likely to be at risk for age- and sex-related diseases, and are likely engaging in PA at rates similar or lower to non-caregivers of the same age. Older Canadians perform the least weekly MVPA compared to adults in all other age groups. A study using accelerometers found that Canadian men aged 60 and up engage in MVPA approximately 17 minutes a day, and women of the same age even less, accruing on average 12 minutes of MVPA a day (Colley et al., 2011). The average weekly MVPA of older women is therefore estimated to total 84 minutes of activity, still far lower than the CSEP (2011) guideline of 150 minutes of weekly MVPA. Colley et al. (2011) also found that on the high end of the older women MVPA distribution, only 12.6% of older Canadian women meet the CSEP (2011) guidelines.

Though no study has performed accelerometry research with caregivers with such a large sample (Colley et al. (2011) recruited almost 3000 participants), some studies using PA with a caregiving population measured baseline PA in intervention and control groups. For example, King, Baumann, O'Sullivan, Wilcox, and Castro (2002) found that at baseline, women aged 49-82 years old assigned to an intervention or control groups self-reported approximately 168 weekly minutes of total PA, though this number includes low-intensity PA, which is not associated with significant health benefits (Lee & Paffenbarger, 2000). Assuming that these participants follow the trend found by Colley et al. (2011), it is likely that very few of those 168 minutes were MVPA. In contrast, Colley et al. (2011) found that total PA in older Canadian,

non-caregiver women was 218 minutes per week. Other interventions measured caregiver PA, but did not report total minutes as their PA measurements employed other self-report PA scales (Connell & Janevic, 2009; Hill et al., 2007; Hirano et al., 2011). With such low levels of older adult PA, and the assumption that caregivers engage in even less PA (Colley et al., 2011; King et al., 2002), several interventions have sought to increase caregiver PA in an attempt to improve caregiver mental and physical health.

Caregivers and Physical Activity: Interventions to Date and Limitations

A recent systematic review (Lambert et al., 2016) found that most interventions using PA for caregivers (of patients with a variety of chronic diseases) did not result in improved physical health among the participants, though many reported improved mental health outcomes. This lack of physical health improvement may be due to the intensity and systemic demands of the intervention exercises – most of the studies employed yoga or walking as PA, which are low intensity exercises (Lambert et al., 2016). These forms of PA were likely chosen for the ease of intervention, as no equipment is needed and they can be safely performed by participants with little guidance, training, or supervision.

The review by Lambert et al. (2016) suggests that PA interventions for caregivers are still relatively novel, with little extant research in place to guide the field forward. The reviewed studies focused more on the feasibility of implementing PA interventions rather than maximizing the health impact of PA in this population. Though many studies demonstrated that increasing caregiver PA was feasible through a variety of interventions, and rates of attrition were low (ranging from 0 to 31% across studies), the increases to MVPA were insufficient for reaching the CSEP guidelines. This suggests that even in the context of a controlled intervention, significant barriers to caregiver PA are at play. Studies were inconsistent in their prescription and

measurement of PA, with many different forms of PA employed, but with little attention to accurate measurement of PA levels in participants. The interventions were still reasonably effective, with many studies reporting significantly improved mental health outcomes (Lambert et al., 2016), but were generally unsuccessful in increasing MVPA in this population by amounts and intensities that would confer physical health benefits. Fortunately, certain caregiver PA intervention studies also measured the barriers and facilitators of PA reported by participants.

Barriers and Facilitators to Caregiver PA

Three studies in particular warrant further attention due to their collection of reported barriers and facilitators, as well as the methodologies employed to gather these data. Hill et al. (2007) sought to improve caregiver PA through a directed exercise program in which caregivers participated in physical activity in classes in small groups for six months. The mean age of participants was 64 years old, and 73% provided care for their spouse. Though many forms of exercise were offered, including Tai Chi and yoga, participants generally selected the strength-training option, and participants most frequently attended approximately 75% of the courses, which were offered twice a week. Although participants improved on various measures of physical and mental health, caregiver burden scores were unchanged throughout the intervention. The barriers and facilitators to participating in the intervention were measured through a questionnaire, with caregivers reporting that the exercise classes were enjoyable, energizing, and socially beneficially. However, some participants noted transportation difficulties, the health issues of both the care recipient and themselves, as well as their inability to leave the care recipient alone. These barriers and facilitators may not fully represent the myriad factors associated with caregiver PA, as the questionnaire was developed *a priori* and was therefore

limited in its breadth. Further, this study was a structured PA intervention with instructors and facilities – caregivers engaging in autonomous PA may experience different factors.

In order to promote more autonomous, home-based caregiver PA, Farran et al. (2008) administered a six-month home-based PA intervention with family caregivers (67% were spouses of the care recipient, and the mean age was 65 years old) for people living with Alzheimer's disease, in which participants received telephone-based support from researchers in order to address their informational caregiving needs. The telephone calls also served to encourage LTPA and to perform goal-setting and self-monitoring activities with the participants. Caregiver total weekly minutes of different intensities of PA were measured at baseline, three months, and six months via self-report and pedometers. Less than half of the caregivers in this study successfully increased their total moderate PA, and no caregiver increased their levels of vigorous PA at post-intervention. Despite high adherence to the intervention components (phone calls, goal setting, physical activity self-report), caregiver PA remained low. This suggests that although caregivers may want to increase their PA, they may be facing barriers to doing so. During intervention phone calls, the person administering the intervention took note of any reported barriers to PA mentioned by participants. These barriers included heavy caregiving and non-caregiving responsibilities, mental and physical health issues, as well as the hot weather. Farran et al. (2008) did not note any procedures for thoroughly exploring these barriers however, as the phone calls were focused on delivering the support intervention. As such, it is unlikely that these reported barriers, discussed as a subcomponent of a broader intervention, truly represent the breadth of the factors associated with caregiver PA.

A similar intervention was undertaken by Connell and Janevic (2009) among women caring for their spouse living with dementia. Participating caregivers received phone calls in

which a person trained in motivational interviewing helped them set goals and engage in self-selected and self-directed PA, over a period of six months. The weekly frequency of sessions for different forms of PA was measured, which included aerobic, stretching, and strengthening forms of PA, but not PA intensity. As well, self-reported health, exercise self-efficacy, self-care self-efficacy, caregiver burden, and depressive symptoms were also measured. Measurements were taken at baseline, immediately post-intervention (six months after baseline), and six months post-intervention. Though post-intervention exercise self-efficacy was higher, total PA was only increased significantly among caregivers who reported median PA levels or lower at baseline, and increased only by up to 30 weekly minutes. The impact of these 30 additional minutes is difficult to assess because PA intensity was not recorded. Importantly, Connell and Janevic (2009) administered one open-ended question at post-intervention asking about perceived barriers and facilitators to exercise, and performed a qualitative content analysis on participant responses. Participants reported factors associated with their PA which were summarized as either issues related to the caregiving role and issues related to their own health and wellbeing. Unfortunately, the authors did not further discuss these categories. It is likely that the qualitative data were inherently limited due to the use of only a single question.

Although these studies did not investigate barriers and facilitators to caregiver PA as a primary goal, many reported similar findings. Many caregivers (across chronic conditions) reported that their PA was impeded by the caregiving role, including the health issues of the care recipient, or the recipient not wanting the caregiver to leave. This latter barrier was one of the most highly rated by caregivers in all three studies (Connell & Janevic, 2009; Farran et al., 2008; Hill et al., 2007). Caregivers also reported struggling to engage in PA because of their own health issues, including disease, weakness, frailty, depressive symptoms, and fatigue (Connell &

Janevic, 2009; Farran et al., 2008; Hill et al., 2007). Other barriers unrelated to the caregiving role included poor weather, difficulty accessing facilities and programs, and other responsibilities in their lives (Farran et al., 2008; Hill et al., 2007). Caregivers also reported some facilitators to PA, including increased energy, positive social impacts, and in some cases, supportive care recipients (Hill et al., 2007). However, many of these reported factors are not unique to caregivers, which suggests that caregivers experience barriers and facilitators both unique to their role as a caregiver as well as some common to other older adults.

PA barriers and facilitators common to other older adults. Several authors note that caregivers are likely encountering barriers and facilitators to PA similar to the non-caregiver older adult population (Connell & Janevic, 2009; Farran et al., 2008). Franco et al. (2015) systematically reviewed qualitative studies investigating the barriers and facilitators that older adults report in regards to PA, and summarized the findings into the following categories: Social influences, physical limitations, competing priorities, access difficulties, personal benefits of PA, and intrapersonal factors (such as motivation and beliefs).

One way to classify factors associated with PA is to group them according to their proximity to the individual, beginning with distal, structural factors. Examples of structural factors include the built environment, public health policies, sociocultural norms, and elements of the local community. Interpersonal factors encompass all interactions and influences of people external to the individual, including friends, family members, and their spouse. Finally, intrapersonal factors represent all factors internal to the individual, including psychological and motivation elements. This classification is loosely based on the ecological model proposed by McLeroy, Bibeau, Steckler, and Glanz (1988). Together, caregivers for men with cancer may be experiencing factors associated with their PA which are common to non-caregivers of the same

age, as well as factors specific their unique role as a spousal caregiver. Such factors could include changes to their relationship with their spouse because of the cancer diagnosis, difficulties navigating the healthcare system, or a lack of support from family in friends. These myriad elements may contribute to the low rates of higher PA intensity among caregivers and older adults generally, which may offer an understanding of why PA interventions among caregivers have had poor results.

To date, no study has examined precisely what associated factors caregivers report when asked about their PA habits (or lack thereof). Caregivers experience a uniquely difficult challenge as they must balance their new caregiving role with their regular demands of life. It is therefore possible that their levels of MVPA are impacted by unique barriers and facilitators, beyond those faced by the general population. In order to plan interventions which can address caregivers' levels of physical activity (and, thus, their physical health and mental health needs), it is essential to investigate the various factors that may be associated with different forms of PA.

Rationale and Purpose

Despite the wide variety of health benefits that PA can confer to caregivers (Penedo & Dahn, 2005), caregivers still struggle to meet the CSEP (2011) guidelines, and accrue less PA than non-caregiver women of similar age (Colley et al., 2011; King et al., 2002). Recent interventions seeking to promote PA among caregivers have had inconsistent physical health associations, though mental health was improved in many studies (Lambert et al., 2016). The current state of caregiver PA interventions reveals a need for an in-depth exploration of the structural, interpersonal, and intrapersonal factors associated with PA among caregivers for men with cancer. Furthermore, these factors may also be associated with specific levels of PA intensity or particular types of PA (i.e., resistance or aerobic), an exploration of which could help

increase health-promoting MVPA in this caregiver population. Although some studies have reported preliminary measures of barriers and facilitators to caregiver PA, these data were collected using either quantitative or very limited qualitative methods, and were also collected in the frame of an existing PA intervention evaluation rather than a primary study purpose. Despite such limitations, these findings suggest that caregivers experience factors both unique to the caregiving role and some common to other older adults, though the precise nature of these factors and their interrelationships are not known. Thus, the purpose of the proposed study was to explore any factor related to the PA of primary spousal caregivers of men living with cancer, as well as how such factors may also be associated with different types and intensities of PA. This was accomplished using a qualitative methodology in which spousal caregivers for men living with cancer were interviewed. Participants were asked about the factors they perceived to be associated with the PA, and content analysis was performed to accurately represent the complex reported experiences.

Chapter 2: Methods

The methods for this study were modified after the pilot interview and subsequent pilot data analysis. Originally, this study was to be conducted using a qualitative deductive methodology in which caregivers for men living with cancer were interviewed about their experiences and perceived factors associated with the PA behaviours. The data generated were to be analysed following a directed content analysis approach as described by Hsieh and Shannon (2005) and understood in the context of a theoretical framework to aid future intervention development.

In brief, directed content analysis begins with a deductive phase in which data are matched to the constructs of the chosen model. To that end, the Behaviour Change Wheel model (Michie, van Stralen, & West, 2011; Appendix 1) was selected based on its simplicity of application as well as its relevance to intervention development, as the results of this study were foreseen to help inform the development of a dyadic physical activity intervention for caregivers and men living with cancer. Specifically, the COM-B subcomponent was intended to guide the data analysis by categorizing data into **C**apability, **O**pportunity, and **M**otivation constructs to describe the factors associated with **B**ehaviour (i.e., caregiver PA). We predicted that, for example, that caregivers would report barriers pertaining to their built environments (Opportunity), their own motivation, and their physical abilities (Capability). After this first deductive coding pass, uncoded data are coded inductively to determine whether the existing model constructs need to be modified or whether these data truly represent concepts outside the scope of the model.

After the first interview was completed and transcribed, attempts to analyse the data suggested that the chosen data analysis method was inappropriate. Participants reported complex

experiences that could not be consistently matched to the COM-B constructs used for deductive coding. As such, a large amount of data was relegated to the second inductive phase. Continuing with directed content analysis would have resulted in large changes to the model in order to fit the data, which was deemed unreasonable. Instead, we decided that the model was inappropriate for the purposes of this research.

To represent the data as credibly as possible, the decision was made to alter the research questions, the interview guide, and the data analysis to more accurately represent the breadth of experiences reported by caregivers moving forward in the study. Specifically, the research questions were reworded to maintain their intended meaning but no longer be directly bound to the constructs of the COM-B model. Originally, the research questions were the following:

1) How is capacity, opportunity, and motivation associated with PA in primary spousal caregivers of men with cancer?
2) How do these associations change for different types and intensities of PA? ("types" meaning the three main categories of PA for older adults as defined by the CSEP (2011), which are aerobic, resistance, and mobility-enhancing).

Upon revision, the research questions became those stated in the introduction to this document:

1) What structural, interpersonal, and intrapersonal factors are associated with PA in primary spousal caregivers of men with cancer?
2) How do these associations change for different types and intensities of PA? ("types" meaning the three main categories of PA for older adults as defined by the CSEP (2011), which are aerobic, resistance, and mobility-enhancing).

The revised research questions were crafted to be similar to the original questions to ensure that our data collection tools could still accurately address the research questions. As such, the

questions were simply reworded to encompass broader experiences without using pre-existing model constructs. The interview guide was minimally changed, as the original guide had been written to ask about COM-B constructs, but using non-specific, open-ended questions. Given the richness of the data collected at this point in the study, we determined that the interview guide would still generate data appropriate for an inductive analysis, as the guide did not name any model-specific constructs. The revised interview guide (Appendix 2) can be compared with the original interview guide (Appendix 3). Only one introductory question was added, and two questions were placed later in the guide, but the interview guide was otherwise untouched. Additional prompts were also added, but without modifying the base question.

Finally, the data analysis method was changed from directed content analysis to conventional content analysis as described by Elo and Kyngas (2008). As the data from the first interview were largely being set aside for the secondary, inductive phase of directed content analysis (Hsieh & Shannon, 2005), we felt that the data could be more wholly analysed using an entirely inductive approach.

In summation, the study was designed as a deductive process, hoping to match caregiver experiences to a framework which could then help inform intervention development, but the reported experiences were intricate and dense, which no longer suited this deductive process. Thus, rather than fit data into the model which would entail a loss of meaning from the experiences, we chose to modify our analyses to better represent the lived experiences of these caregivers. With the above changes in mind, the following procedures were employed.

Researcher Involvement and Personal Influences

The principal investigator for this study was intimately involved with every stage of this study, including the original inquiry development and the study design. He performed every

interview and performed the majority of the data analysis. He approached the inquiry from an interpretivist perspective, believing that physical realities are ascribed meaning through myriad sociocultural processes and ultimately may be evaluated differently by each individual. This ontology guided the development of the interview guide, which sought to explore how participants thought and felt about their physical activity.

In contrast, the researcher was very different from participants in age, gender, and life experiences – as such, the data analysis was far more objectively driven. Due to this inherent difference between researcher and participant experiential lens, the data were taken at face value, with little additional interpretation ascribed by the researcher. This was done to avoid inserting the researcher's own biases into the data as much as possible. Therefore, the emotions and experiences described by participants were coded to accurately represent what they reported without further interpreting their thoughts, or creating conceptual links which they did not describe themselves. The researcher drew upon his experiences with older women in his personal life to help him understand the participants' responses. He was able to sympathize with the experiences of the participants as they described levels of physical activity and self-reported health comparable to those experienced by older women in his personal life. For example, a close family member of the researcher struggled to be active due to her chronic pain caused by fibromyalgia. As such, the challenges she faced helped him relate to participants who also reported pain as a barrier to PA. Conversely, the researcher avoided viewing participants in a personal way and ascribing to them characteristics of the older women in his life. He relied on the objective evaluation of the data to maintain the trustworthiness of the analysis and the integrity of the participants' statements.

Participants, Eligibility, and Recruitment

Seven spouses of men living with cancer were recruited. There were three eligibility criteria for this study, pertaining to the caregiving role, the date of diagnosis of the cancer, and the individual's current levels of physical activity (See Appendix 4). Participants were current primary spousal caregivers for men with cancer above the age of 60, and the cancer diagnosis had been within the past 12 months. All participants identified as women, though spousal caregivers of other ages and genders would not have been excluded. Participants were also screened based on their current levels of physical activity; individuals achieving meeting or exceeding the current Canadian MVPA guidelines of 150 minutes a week were excluded (PHAC, 2011). This inclusion criterion was to ensure that the study sample was more homogeneous with the desired population (caregivers with low levels of PA). Recruitment occurred through various channels including:

1. Recruitment posters (Appendix 5) placed in key Montreal-area locations (through research contacts), including messages boards, locations where support groups meet, etc.
2. Classified ads (Appendix 6) posted on internet classified sites (e.g., Kijiji) and online caregiver support forums.
3. The principal investigator (PI) was physically present at a booth representing the Groupe de Soutien du Cancer de la Prostate, a Montreal-based prostate cancer support group, at an information soirée for men living with prostate cancer and their caregivers.
4. Targeted recruitment through the Peri-operative programme (POP) at the Montreal General Hospital. Eligible caregivers for men participating in this cancer care program were approached directly by a member of the POP and referred to the principal investigator if they expressed interest in participating.

Measures

Data were collected using semi-structured, individual, face-to-face, audio-recorded interviews in which caregivers were asked questions about the various factors they perceive as being associated with their physical activity behaviours, as well as how such factors are associated with different forms or intensities of PA. Three additional questionnaires were also administered to assess current PA levels of participants, to collect basic demographic data, and to obtain a measure of caregiver strain.

Interview guide. The interview guide (Appendix 2) was structured to first ask open, broad questions about the participants' experiences with caregiving and PA, with both improvised and prepared prompts used to delve deeper into the reported experiences. Later questions enquired directly about the research question, asking participants if they felt their levels of PA or their health had changed since taking on the caregiving role. In line with the research questions, the interview included sections pertaining to more structural factors, such as the built environment, as well as inter- and intrapersonal factors, such as motivation, desire, and spouse and peer influences.

Demographic questionnaire. Basic demographic information (Appendix 7) was also collected via questionnaires administered prior to beginning the interview. The demographic information allowed a more complete description of the participants and shed light on additional sociodemographic factors which may have contributed to their experiences. The questionnaire collected information on factors such as education level, employment status, and marital status.

PA questionnaire. The PA measure chosen for the study was the Godin-Shephard Leisure-Time Physical Activity Questionnaire, which is commonly used in cancer research contexts (Amireault, Godin, Lacombe, & Sabiston, 2015). The questionnaire (Appendix 8)

served to re-verify the participant eligibility (participants meeting or exceeding the current PHAC guidelines were ineligible). This questionnaire asked participants to report their weekly number of PA sessions, categorized according to intensity. Three different categories of intensity were presented to the participants, with examples of activities for each category to help participants select categories accurately. Participants were asked to note the number of times in a typical week they engage in a particular intensity of PA, and the approximate number of minutes each bout lasts. A total weekly MVPA value in minutes was then calculated from these responses.

The Caregiver Reaction Assessment (CRA). The third questionnaire (Appendix 8) was a tool originally developed as a measure of caregiver burden and reaction to the caregiving role for family caregivers of individuals with chronic physical and/or mental impairments (Given et al., 1992). It has since been validated as a reliable tool for assessing reactions to caregiving for spouses of individuals with cancer (Grov, Fossa, Tonnessen, & Dahl, 2006; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). The CRA consists of 24 items categorized into five subscales: disrupted schedule; financial problems; lack of family support; health problems; impact of caregiving on self-esteem. Each item is scored on a five-point Likert scale, ranging from 1 (*strongly agree*) to 5 (*strongly disagree*), with 3 acting as a neutral response (*neither agree nor disagree*). The CRA is scored by calculating a mean score for the items of each subscale. The CRA was administered in order to shed light on the interview data, as a participant scoring more severely on the CRA subscales may have reported different experiences during the interview. Further, Grov et al. (2006) suggested that a sum CRA score can also be a useful metric, as they found a correlation between total CRA score and scores on Short Form 36 (SF-36) and The Hospital Anxiety and Depression Scale (HADS) in primary cancer caregivers.

Procedure

Interactions between the research team and the participants began once individuals interested in the study contacted the principal investigator or were referred by the members of the POP. All recruitment media included the principal investigator's university email address, as well as his laboratory office phone number as means of contact. Once contact with the investigator was established, four screening questions were administered by the principal investigator using whichever form of communication the potential participant preferred in order to determine participant eligibility (See Appendix 4). If the potential participants met all inclusion criteria, they were deemed eligible for the study, and were sent a message briefly explaining the purpose and procedures of the study. They were also sent the consent form (Appendix 10; Appendix 11 for participants recruited from the POP) via email for their initial information/reading.

Data collection procedures. Data collection occurred in a location chosen by the participants (enhancing accessibility and facilitating recruitment), provided it was quiet and secluded. These criteria were to ensure a high-quality interview and audio-recording and to help maintain the privacy of the participant. If participants did not choose a location, a private office in the Department of Kinesiology and Physical Education at McGill University was proposed.

Once participants were screened and deemed eligible for the study, the interview was scheduled. The interviewer greeted the participants and explained the purpose and procedures of the study. After the study procedures were explained, participants were provided an opportunity to ask any questions they had about the research. Once all of their questions had been answered to their satisfaction, they provided written informed consent to proceed, or were withdrawn from

the study if informed consent was not freely given (Appendices 8 and 9). The audio recorder was then turned on and the interview began only after informed consent had been obtained.

During the interview, the interviewer allowed an in-depth exploration of each question, and used both formal and informal probes to glean additional data from each response. Formal probes were predictable clarifications or details that may have been asked, and are presented as sub-bullets in the interview guide (Appendix 2). Informal probes included additional small clarifications that were contextual, based on what the participants said. As they cannot be determined in advance, they were generated as needed in response to what the participants said. Once all interview questions had been answered, participants had the opportunity to ask any remaining questions about the study before being thanked and dismissed. The entire interview process and guide was pilot tested first in order to adjust the interview procedures if necessary.

Data Analysis

The raw audio recordings of the interview were transcribed verbatim, and the resulting transcripts were analyzed using the NVivo 11 software suite (QSR International). Although the coding was performed in English, no formal translation of the French interviews was performed as the researcher was perfectly fluent in both languages. This decision also avoided any semantic loss through the translation process. Each participant transcript was assigned a pseudonym for reporting purposes. The data were analysed according to the tenets of content analysis as stipulated by Elo and Kyngas (2008), which is appropriate for an area of inquiry in which knowledge may be incomplete or fragmented. Traditionally, content analysis is objective in nature: Participants' data were analysed based on their intended meaning, and were not interpreted through an additional philosophical or theoretical lens. Although content analysis has been used extensively in both qualitative and quantitative research, there has been little

consensus on the precise methods until recently. The core process of content analysis is the grouping of data into codes and categories of meaning. Elo and Kyngas (2008) described a more formal process for content analysis, divided into three phases: Preparation, organization, and reporting. During the preparation phase, the data were read through several times in order to become fully immersed in the meaning and to obtain a sense of the whole. The organization phase began with open coding of data, in which notes were ascribed to passages that seemed to encapsulate a concept, thought, or experience. These open codes were then collected and organised into larger categories that represented a group of similar codes, which were then sorted into higher order headings to represent the overarching concepts that summarized and represented the participants' reported experiences. As the coding process progressed, the three highest emerging data categories were iteratively organized visually in order to guide the analysis and reflection about the codes. The final visual representation of the three highest data categories can be found in Appendix 12.

Evidence of Rigor

Several characteristics of this study demonstrate proper qualitative research rigor. First, the methods stipulated asking the same questions (except prompts) to all participants, increasing that likelihood that the data for each question are saturated. Second, the chosen analysis method was minimally interpretive: participant responses were analysed at "face value", without any additional epistemological or theoretical permutations. Third, the supervisor for this study acted as a critical other throughout the data analysis, as the emerging codes and categories were questioned and challenged in order to strengthen their trustworthiness and reduce the likelihood of uncoded or poorly coded data. Finally, as a premier indicator of data saturation, data collection was continued until no new codes emerged. This indicator, along with the above

characteristics, support the assertion that data saturation was achieved per the criteria laid out by Fusch and Ness (2015).

Chapter 3: Results

Overview of Participants

The participants in this study were all women between the age of 60 and 90 years old, and from a variety of ethnocultural backgrounds. They all self-identified as the primary caregiver for their spouse. The participants spouses had a variety of cancer types (colon and lung were the most common site), and the large majority had a diagnosis of Stage 2 or earlier. Due to recruitment through the Peri-Operative Program, the spouse's treatment course was always surgical, but participants were each interviewed at different timepoints along the treatment path. Some caregivers' spouses had not yet had surgery, some had recently undergone their operation, and some had been in recovery for a few months and were awaiting follow-up appointments to know whether or not the cancer had been successfully removed. All spouses had been diagnosed within the last year.

Caregiving role. Although the caregiving experiences reported by caregivers will be discussed in depth later in this document, a brief overview of the difficulties of the role will help frame the remainder of the results section. In terms of concrete actions, participants reported providing emotional support for their spouse, as well as a supervisory role as they felt compelled to accompany their spouse to his appointments and other outings. Many participants discussed a lack of support from family members, which worsened the burden and responsibility of the role. Caregivers discussed a wide range of emotional reactions, including anger, stress, anxiety, and fear. These emotions were compounded by the time commitment of caring, as caregivers needed to devote much of their time to their spouse. The combination of these emotional and time commitments resulted in widely reported fatigue and exhaustion from the omnipresence of the role.

Descriptive quantitative results. The quantitative measures of this study were used to better understand each participant's weekly PA as well as the impact of the caregiving role. The most salient descriptive results have been presented in Table 1 to provide an overview of each participant's reported MVPA and CRA subscale scores. CRA scores were within normal ranges for every participant, and as such were not used as part of the data analysis.

Although no quantitative data analysis was performed, a cursory glance reveals that many caregivers accrued over 100 minutes of MVPA, although several were completely inactive. In addition, the positive impact of caregiving on their self-esteem was generally high, suggesting that caregivers adapted well to the role. Furthermore, caregivers generally reported moderately low impacts on the Family support and Financial problems subscales, suggesting that participants felt well-supported, both socially and financially. Though these findings are descriptive and only serve to provide the reader with additional insight into the experiences of the women quoted below, these data suggest that the caregivers adapted well and had fairly supportive social networks. Such details can help provide context for the various PA factors reported by participants.

The spousal caregivers in this study reported a wide variety of experiences and factors associated with their PA behaviours. Broadly, these experiences were categorized during the final steps of content analysis into the following higher-level headings: Structural factors, interpersonal factors, non-caregiving intrapersonal factors, caregiving-specific intrapersonal factors, and descriptions of PA (See Appendix 12 for a visual organization of the results). An overview of the PA behaviours described by caregivers will be provided before summarizing the different levels of factors, beginning with structural and ending with caregiving-specific intrapersonal factors.

Table 1

Participant Demographics, MVPA, and CRA Subscale Scores

Pseudonym	Age	Weekly MVPA (Min)	CRA Subscales				
			Caregiver esteem	Disrupted schedule	Lack of family support	Financial problems	Health problems
Heather	63	120	4.3	3.0	2.6	2.3	3.0
Katherine	76	0	4.5	3.4	2.2	2.7	2.8
Rachel	77	105	3.8	2.0	2.4	2.0	2.5
Vanessa	81	100	4.0	2.6	2.6	3.0	3.0
Sarah	69	0	4.3	2.0	1.8	2.0	2.8
Sharon	65	105	4.0	2.2	2.4	2.0	3.0
Christina	85	0	3.8	1.8	1.2	1.3	2.0
Mean	73.7	53.8	3.9	2.1	2.1	2.2	2.6

N.B. Scored on a scale from 1 (*strongly disagree)* to 5 (*strongly disagree).* High scores on the esteem subscale represent a *positive* impact on caregiver esteem, whereas high scores on all other subscales represent a net *negative* impact on the caregiver (Nijboer et al., 1999).

Types of Physical Activity Reported by Caregivers

In the interview guide (Appendix 2), participants were asked what they thought when hearing the term "physical activity", before the interviewer provided a more inclusive definition of the term in a subsequent question. This was done to first capture the participants' initial thoughts about the term before expanding upon such impressions when the definition was broadened. In many interviews, participants described additional forms of PA after being provided the more inclusive definition, thereby providing richer data about their own PA habits. Participants described various forms of physical activity, though they generally used the terms "exercise" and "physical activity" interchangeably. To help maintain rapport, the interviewer adopted their preferred terminology. Despite the lack of distinction between these terms, participants described how they engaged in a broad range of different PA behaviours, spanning basic activities of daily living (ADLs) such as cleaning and home maintenance to more structured leisure-time physical activity (LTPA) such as attending a group fitness class or going for a walk.

ADLs. Caregivers reported a variety of ADLs, including cleaning and laundry, cooking, shopping (and carrying purchases), and walking as a form of transportation. These activities were generally performed daily, and the length of time spent on these activities varied in function of the caregiver's employment status, age, and their spouse's health status and illness progression. Though participants did not discuss the intensity of their ADLs, many reported needing breaks throughout the day or feeling fatigued at day's end, suggesting that the intensity of their ADLs may perhaps be sufficient to incur health benefits.

LTPA. Participants also reported many different forms of LTPA, including golf, gardening, dancing, and yoga, with leisure-time walking being most commonly listed. Though commercial gym attendance was mentioned by several caregivers, this was generally discussed as an activity they did in the past, but no longer performed regularly. Walking was described very positively by caregivers, as Sarah (age 69) summarized: "I really like walking. I really really like it. And I find it's very therapeutic for me. I really feel better after I've had a good long walk". All caregivers reported engaging in low intensity LTPA. Four participants engaged in moderate PA on a weekly basis, and only one of those three also performed vigorous PA on a weekly basis.

Together, ADLs and LTPA form a description of all the PA caregivers performed. With such activities such as walking, swimming, and ADLs in mind, the participants also discussed a variety of factors associated with their physical activity, which ranged from elements of their surrounding environment to factors specifically associated with their caregiving role.

Structural Factors

This higher-level heading represents a collection of factors regarding the caregivers' built environment as well as community and sociocultural factors.

Physical environment. Participants reported several physical environment factors, with neighbourhood walkability being the most often reported element in their environment associated with their physical activity. Sarah (age 69) described her neighbourhood as "really the best neighbourhood I think. . . I mean it's not like a crime-ridden neighbourhood, like I'm afraid to walk at night or something like that. . . I feel safe walking everywhere". However, Heather (age 63) described the difficulty of not having even a shoulder on the road where she lived, which became problematic in winter: "Y'a pas d'accotement dans certaines places, et avec

l'hiver, banc de neige, ben tu te tasses quand l'auto passe là. . . mais sinon faut prendre la voiture pis aller marcher ailleurs" [There's no shoulder in some places, and with winter, snow banks, well, you move over when cars pass. . . but otherwise you'd have to first drive to walk anywhere else].

Other physical environmental factors included whether or not their apartment building contained fitness facilities, whether or not their home had staircases, and the distance required to travel to fitness facilities or exercise activities. Although less commonly reported than physical factors, caregivers also reported some sociocultural elements.

Sociocultural environment. The primary reported sociocultural factor concerned language barriers for community-based fitness classes for older adults. One participant described how few programs were offered for strict anglophones in her area of Montreal:

> I'm in an English community; there's a lot for the French community. They have a lot of activities, a lot of centers; this [class] was started because we didn't have one that was principally English. Like, anybody can go to anything, but this operates in English, so there was a need in the South for that. (Sarah, age 69)

Though these elements of caregivers' physical and sociocultural environments were not described as being significant impediments to their PA, perturbations to their environment were often associated with a loss of habits, as Vanessa (age 81) described during her move from a house to an apartment:

> Quand on marchait [in her three storey house], c'était un environnement qui nous poussait à marcher et je le faisais avec plaisir mais en arrivant ici [in the apartment], je ne sais pas. Je ne sais pas. Je monte, je prends les escaliers pour monter mais on est au deuxième étage, ce n'est pas un gros exercice,

> [When we walked (in her three storey house), it was an environment which pushed us to walk, and I did it with pleasure, but when we arrived here (in the apartment), I don't know. I do not know. I go up, I take the stairs to go up, but we're on the second floor, it's not a big exercise.]

In this case, Vanessa described how a change to her environment caused her to lose her enjoyment of walking stairs in her home, and engage in less PA in her new apartment. Examples like this suggest that structural factors may cascade and impact more proximal factors, such as motivation and PA enjoyment. However plausible this cumulative impact of distal factors may be, the net impact of structural factors was lower than that of interpersonal elements.

Interpersonal Factors

Caregivers spoke at length about how the people in their lives could be associated with their own PA habits. Generally, they discussed how their spouse, their families, and their friends and broader social circles could aid or impede their efforts to engage in PA.

Spouse and relationship factors. As this was a study of spousal caregivers, it is logical that one of the most important social bonds in their life is to their spouse. Caregivers described a variety of instances in which their spouse or the bounds of the relationship itself had an impact on their PA habits. In some cases, despite living with cancer, the spouse helped the caregiver's attempts to engage in PA. Sarah (age 69) reports how encouraging her husband was: "I mean my husband is always encouraging me. 'Go, go for a walk, you know, go, yeah I'm fine, I'll do this, I'll do that'. . . he's an inspiration because he goes spinning three times a week". However, other caregivers reported that their husbands were less helpful, with Katherine (age 76) explaining how "my husband is not a sport type, so he doesn't help to encourage me or to let me do – he would not say no, but somehow, our life, my life changed".

One marked benefit of the relationship on caregiver PA was when the dyad would engage in activities together. Vanessa (age 81) remarked that "on a besoin l'un de l'autre pour s'encourager, alors je ne suis pas la seule à le faire" [We need one another to encourage each other, so I'm not the only one doing it], and Heather (age 63) noted that "quand on fait des choses ensemble, puis au même temps, c'est plus encourageant" [When we do things together, and at the same time, it's more encouraging]. However, the effect of dyadic exercise seemed to be dependent on whether both members of the dyad had similar abilities or interests in PA. Rachel (age 77) noted "I do mostly stretching, like a yoga type exercise, yeah? Whereas (husband) does physical activity. Like with the bicycling and swimming laps, and . . . so I think of that, people doing their workouts at the gym. I'm not one for the gym". Whereas Rachel felt like she was less capable than her husband, Heather (age 63) experienced the opposite, noting that "[lui il est] plus 'Ben j'm'entraine ou je fais rien, là, je m'entraine au gym'. Faique c'est du laisser-aller. J'suis capable d'en faire plus" [He is more like, 'Well I'm training or doing nothing, I train at the gym'. So it's kinda whatever. I'm able to do more]. These discrepancies between caregiver and spouse physical activity abilities or preferences may preclude the benefit of engaging of PA together. However, even caregivers reporting a difference in ability maintained that walking together was a fun and accessible activity for them both. In addition to the influence of the spouse and the organisation of their relationship, participants also described how their families impacted the PA habits.

Family factors. Some caregivers reported that their children or other family members would encourage them to exercise. Rachel's (age 77) family pushed her verbally: "My family have, they say 'Mom you never go, you're going to be out of shape when you're old'. Other caregivers' families led by example:

> My daughter in Toronto got me the Fitbit, 'Mom you gotta start moving more', you know, so she would be a good influencer. She actually influenced my husband to start spinning, you know, so she- she's really maintained a really active lifestyle and it's helped her a lot, yeah. So I think (daughter) would be one of the main motivators. And my other daughter, (name) who lives in the city, you know she bikes to work . . . I would say the daughter in Toronto would be the biggest motivator.

Despite the potential for positive family influences, caregivers also noted an inactive family could decreased their levels of PA as well. However, the participants' children no longer lived with them, and as such were likely less of an impact on caregiver PA as their more frequent social interactions with friends and social groups.

S**ocial group factors.** Several participants spoke of friends with whom they used to exercise. The experiences reported were positive, but often had ended some time ago. Sarah (age 69) described how she and her friend "just jogged together, that was it. . . she'd call me 'Meet you on Wednesday at 7 in the morning' and we would start running. And then I don't remember what happened but we just stopped". Sometimes, exercising together ended when a friend died:

> I used to golf regularly with my good friend; she passed away, so that ends. As you get older you lose your friends. We were a group of ladies and two have died, and one is in the hospital. So that's sad. And they all had cancer. (Rachel, age 77).

Though none of the participants currently had friends with whom they engaged in PA, some attended group fitness classes and reported that exercising in a group setting was a strong motivator for them to be active:

> My elderly friends, you know they're there [at the group class], they're there and you know, of course you know it's like a social thing also, doing elderly exercises with them. It's a social, you know. Being social with them, we have coffee after. (Sharon, age 65)

Despite Sharon's enjoyment of group classes, other caregivers firmly maintained that they preferred exercising alone. Sarah (age 69) explained how she prefers "to do things alone. I prefer solitary exercise. I don't mind like exercising in a class or something, that's okay if I'm enjoying the class, but I prefer to not exercise with a friend".

Together, these interpersonal factors represent the major social connections in the caregivers' lives, who describe the positive impact of encouraging spouses and family members on their desire to engage in PA. Sarah (age 69) offered a sterling example of how her spouse's encouragement made her consider becoming more active: "[He says] 'Why don't you come try a class? Come!' . . . And I probably will do it. I think I could see myself doing it. See if I go with him, it might be a good start." As described by Sarah, the people surrounding a caregiver can impact their own PA. However, as exemplified by the preferences of certain caregivers to exercise alone, intrapersonal factors may shape a caregiver's experiences with the people around them.

Intrapersonal Factors (Non-Caregiving Specific)

This higher-order heading represents a variety of intrapersonal factors associated with caregiver PA. Participants described several keys factors associated with their PA behaviours. Notably, the impact of aging, their present and past experiences of PA, psychological factors associated with PA, as well as time and opportunity factors were discussed in detail.

Aging factors. Caregivers discussed how age-related physical decline and lingering injuries impacted their PA. Participants reported increased fatigue as they aged, with Rachel (age 77) noting a marked decline in energy in recent years:

> Because before I could just keep going. So the energy is not the same at my age. . . I'll do a crossword puzzle, and do something else. Throw the laundry in, and take a break. That's how I do my life, now. Didn't have to do that maybe even five years ago.

Other caregivers, especially those over the age of 80, discussed other declining functions, such as gait issues, degradation of eyesight, and problems with balance. These factors in particular lead to falls for some, with Vanessa (age 81) discussing how she now fears falling: "Bon je suis tombée. Ça m'a fait peur. Vraiment. Ça m'a beaucoup déçue. Je suis tombée aussi l'hiver, je suis tombée quelques fois en marchant. Et… je crains de tomber. J'ai peur de me casser quelque chose" [Well, I fell. It scared me. Really. It really disappointed me. I'm scared of breaking something]. Vanessa's fear of injury is merited, as other caregivers reported how past injuries continue to impact their current attempts to engage in PA.

> So once I started working full-time, I was sedentary, it was a disaster. I did that for seven years. And I wrecked my back. . . I was going for physio and massage and whatever. . . [Now] sitting this way my back is… (laugh) you know I feel it, my back is kind of [uncertain sound] I have to be careful, so I would say if there was something that makes me worried. . . Anything holding me back physically would be that. (Sarah, age 69)

Such persistent injuries combined with gradual physical decline created a sense of limited physical ability among the participants. In addition, caregivers also reported a variety of psychosocial factors associated with aging. Certain participants felt that they were "too old" to engage in certain activities or to begin a new form of PA late in their lives:

> But I never learned to ride the bicycle. I wish I had. But I didn't push myself. Why I didn't push myself, said "I'm gonna fall down, I'm gonna look stupid" [Laugh] "I'm too old", even when I was young, 'I'm too old' you know, like I'm 35, "I'm going to learn a bike now? Y'all go, you go!" (Rachel, age 77).

However, some women did not feel limited by their age: "I've always done whatever I want to do, age was never a factor. Age was never a factor. It's not a factor with my husband either" (Christina, age 85). Paradoxically, Christina also reported a substantial decline in her physical abilities as she aged, suggesting that despite her waning physical capabilities, she remained optimistic about her ability to accomplish whatever she wished.

In addition to their own preconceptions about their physical abilities as older women, participants also discussed perturbations to their social lives as they aged. Vanessa noted that "pour tous les deux, c'est difficile de garder les amis. J'ai l'impression que les amis, on parle de leurs maladies, on parle de leurs problèmes et quelque fois ils nous oublient, et aussi ils s'éloignent. Les gens s'éloignent" [for both us, it's hard to keep friends. I feel like with friend, they talk about their illnesses, we talk about their problems and sometimes they forget about us, and also they become distant. People become distant]. This loss of social ties may preclude the benefits of exercising with a friend or as a group.

Together, both the physical and psychosocial impacts of aging discourage caregiver PA as a decline in physical capabilities is compounded by caregivers' assumptions about their age and their fears of injury and falls. Beyond aging-related factors, caregivers also described a host of other personality and motivational factors pertaining to PA.

Psychological factors. Participants discussed a variety of lived experiences, appraisals, and motivational factors which impacted how they felt and thought about PA. Many caregivers enjoyed engaging in various activities because of the physical experience of various activities. Heather (age 63) described her experiences with martial arts years ago: "[je me sentais] complètement vidé au niveau physique et calme mentalement. Les jours où je faisais ça je me couchais, euh, tellement fatigué que j'avais des meilleures nuits" [I would feel completely emptied, physically, and mentally calm. The days that I did that, I would go to bed, uh, so tired that I had better night]. Other caregivers used PA as a way to relax and relieve pain. Vanessa (age 81) used water-based exercises to cope with age-related aches and pains: "Ah bien ça me relaxe, toutes les douleurs, surtout dans l'eau, toutes les douleurs disparaissent. Je n'ai pas mal aux jambes, j'ai l'impression que je peux courir, que… oui, c'est très, très agréable." [Ah well, it relaxes me, all the pains, especially in water, all the pains disappear. I don't have pain in my legs, I feel like I can run, that. . . yes, it's really, really enjoyable]. Other participants reported positive experiences with PA, especially in regard to PA with music, the importance of fun activities, as well as doing activities outside. Though one participant noted that she did not enjoy the sensation of being hot and sweating, she still felt a sense of pride when she engaged in PA, as did many other caregivers.

In additional to the physical experience of PA, participants also described a variety of knowledge, motivations, and emotions. Caregivers were unanimously aware of the importance of PA, and most were able to list several health benefits resulting from PA, including improved sleep, functional strength, balance, and healthy weight maintenance. Despite these known beneficial outcomes, participants reported various personal motivational factors which impeded their PA. Many participants self-identified as "not athletic/sporty", which contributed to one of

the lack of volition and need to push oneself that caregivers reported: "Faut que j'me pousse. Faut quelque chose se déclenche!" [I gotta push myself. Something needs to click!] (Heather, age 63). When asked what had to change for her to engage in more PA, Rachel replied "I don't know. The will. I had to want it more. I had to want it more." Similarly, Sarah (age 69) acknowledged that when she finally brought herself to engage in PA, she did so without applying herself: "So I'd rather do it [walking] at my own pace even though I don't push myself very hard. That's a problem too." Sarah noted her own lack of effort, and many participants expressed feelings of guilt regarding their low levels of PA. Conversely, some of the more active caregivers remarked that discipline may be more important than motivation: I think if you have good discipline, you can budget your time, you know, in a way that you're able to do all kinds of activities in the time that you have (Sharon, age 65). These motivational factors were compounded by various time and opportunity factors.

Time and opportunity factors. Several caregivers reported conflicting priorities (not caregiving-related) in their lives, such as spending time with family and friends, tending to their hobbies, and taking care of their home. Rachel (age 77) discussed how PA became less important in her life:

> We get lazy. You'd rather do something else, or you don't have time. I used to always say I had no time, because I had a family and I worked for awhile, and- and you come and you clean and you cook, and say "Oh I have no time for that". So people say you have to make time for our physical, but I never made time.

In addition to household tasks and family time, other participants discussed how they preferred to spend their time on hobbies, including reading, museums, crossword puzzles, and watching television.

Beyond these competing uses of time, some participants who were not retired discussed fatigue from work, and not wanting to leave the comfort of home to exercise after a long day of work. Heather (age 63) described how her retired spouse would make her dinner, after which she would not want to leave: "Quand j'arrive à la maison toute confortable, le feu de foyer, le repas prêt, on s'assoie, on discute, on regarde les nouvelles, pis…c'est juste parce que c'est facile, je me pousse pas". [When I come home, all comfortable, the fireplace, the meal is ready, we sit, we discuss, we watch the news and...it's just because it's easy, I don't push myself]. This participant said that she hoped to engage in more PA once she herself was retired.

Together, participants reported factors relating to their aging as well as personal psychological factors. Although the physical processes of aging made PA more difficult, caregivers also experienced various thoughts and assumptions related to their age which further discouraged PA. Despite reporting feelings of physical and mental wellbeing from PA, participants also discussed issues surrounding volition and motivation, and were also faced with competing uses of their time. In sum, these intrapersonal factors represent a large impediment to caregiver PA. However, the caregiving role itself presented further factors which impacted their ability to engage in PA.

Caregiving-Specific Factors

As the focal point of this study, much of the interview focused on the participants' experiences as caregivers for their spouse living with cancer. This new role was associated with a host of changes to their daily lives and profound emotional reactions. A brief description of their experiences as caregivers will be detailed before exploring reported caregiving factors associated with PA. Many of the things that were discussed in this section do not have direct associations

with PA, but rather provide a context to explore how PA may be impacted by the roles and responsibilities of the caregiver.

Description of caregiving role. Participants frequently reported providing emotional support for their spouse in attempts to help him manage his fears and anxieties regarding his illness and treatment. Caregivers described efforts to cheer up their partners by actively listening to their concerns, and occasionally rebuking more morbid thoughts that their partners may express. Heather's (age 63) partner repeatedly talked about his own death, which she felt compelled to argue against:

> Tout le long il disait 'Oh, euh, fais-toi en pas, quand j'vais être mort tu pourras faire ça' . . . y'a été un mois à penser comme ça. . . Pis moi là-dedans, c'était 'Ben voyons!'. Tsé, moi j'ignorais, ou en d'autre temps . . . j'lui disais que tsé, moi je pensais positivement. [The whole time he said 'Oh, don't worry about that, when I'm dead you can do that' . . . he spent a month thinking like that. . . and me in all of this, it was 'Now, come on!'. Y'know, I'd ignore it, or other times . . . I'd tell him that, y'know, I was thinking positively].

Other participants described how they would document their partners' recovery and accompany them to their appointments to help shoulder any news. Caregivers noted that their presence during appointments was crucial, because they also took on more direct roles in managing their spouses' recovery. One participant whose husband has colon cancer began monitoring his food consumption and coaxing him to make changes to his diet that could help his recovery and treatment. Another caregiver spoke of helping her husband wean himself off morphine after his surgery by writing down his dosages and gradually reducing them over time. Several other

caregivers discussed how they ensured that their spouse did not over-exert himself after treatment.

Adapting to the caregiving role was challenging for some, as many caregivers could not rely on their families to help them. Many participants' children had moved to different cities or had families of their own to manage. Facing this role mostly alone, caregivers reported a significant amount of burden and stress from this sudden change in lifestyle.

Burden and responsibility of role. Many participants reported strong emotional reactions to the caregiving role, especially in the period between initial diagnosis and treatment commencement. Sarah (age 69) shared some of her feelings, stating "I mean I'll be honest; I'd rather not be doing it. I'd rather things were different. I want to take care of him. At the same time, I'm terrified what's ahead. You know. It's tough." Other emotions discussed by participants included stress, worry, anger, disappointment, fear, and sadness.

With this emotional burden came a significant time and resource burden, as caregivers felt compelled to be physically near their spouse much more frequently. Heather (age 63) described how she felt responsible for her spouse and did not want to leave him alone for long periods of time:

> On se sent assez responsable que, c'est l'abandon de la personne seul à la maison qu'on souhaite pas faire longtemps. . . Si on part, euh, pour des courses ou des choses comme ça, ben c'est bien placé, ou la personne te suit, mais de la laisser, au début surtout là, euh, on se sent tellement responsable. [One feels so responsable that, it's abandoning the person alone at home that one doesn't wish to do for long. . . if one leaves, uh, for errands or things like that, well, it's well-placed, or the person comes with you, but to leave them, especially in the beginning, uh, one feels so responsable].

Other caregivers voiced similar concerns by describing their need for a break from caregiving, or additional help from another person. Rachel (age 77) expressed a need for a concrete respite care system to help her get some time away from caring: "They need some system where they [caregivers] can be relieved from their duties for a little while. . . you can't be there all the time. You need to be totally at ease with the free mind, for a while." As caregivers had far less time to themselves, many reported going to much greater lengths to organize daily activities in order to minimize the amount of time spent away from their spouse. Together, both the emotional and tangible burden of caregiving greatly increased feelings of fatigue among participants.

Fatigue. Caregivers reported an accumulation of fatigue from various care-related sources, including emotional fatigue and sleep loss. Heather (age 63) described her fatigue as an emotional exhaustion: "C'est de l'épuisement, un peu d'épuisement de le chapeauté dans son anxiété, d'essayer de le sortir de ça." [It's exhaustion, a bit of exhaustion to take care of his anxiety, to try and get him out of it]. Similarly, Rachel (age 77) shared her sense of being drained from "giving all their energy to the partner, you know? . . . and then you're tired, because it's draining eh? It's draining. I've been there a little bit . . . You're there [with the spouse] first." Caregivers therefore described an emotional and physical sense of fatigue, which was compounded by a loss of sleep.

Perturbations to their regular sleeping patterns were described by many participants. Some caregivers were awoken by the spouse who was in pain or ill from the treatment, and in other instances, caregivers slept more poorly due to anxiety and stress. Heather (age 63) discussed how her anxious spouse impacted her sleep, especially when he was in pain: "Mon autre changement a été aussi vu les douleurs la nuit, de mal dormir, parce qu'il était très anxieux, ses nuits coupées ont été mes nuits coupées aussi, alors, j'ai manqué de sommeil là." [My other

change was also because of the [his] pains at night, to sleep poorly, because he was anxious, his shortened nights were also my shortened nights, so I lost sleep]. Rachel (age 77) also discussed how her own stress impacted her sleep: "I would say like, you don't sleep as well because it's on your mind." This frequently reported sleep-loss further contributed to the general sense of fatigue reported by participants.

The caregiving role represented one of the most important disruptions in the caregivers' lives. The emotional and tangible burden combined with fatigue created a constellation of stressors which impede PA behaviours in caregivers. Sarah (age 69) succinctly summarized this effect when she said "I'm wondering you know, maybe I should do more [physical activity], but I just feel like everything's on hold right now, you know, like I can't. I feel like, frozen in a way." Though every higher-order heading of factors impacted caregiver PA in some way, the caregiving role itself was by far the most significant contributor to the changes in PA reported by participants. However, the impact of these factors on PA was not uniform across forms of PA.

Changes to PA Behaviours

The confluence of structural, inter- and intrapersonal factors, as well as factors unique to the caregiving role, impacted caregiver PA in a variety of ways. Caregivers reported changes to both their ADLs and their LTPA as a result of becoming a caregiver.

Changes to ADLs. Due to the increased time spent providing care, many participants reported increased amounts of ADLs, mostly in the form of additional chores and home maintenance. This increased in activity occurred for different reasons. Sharon (age 65) took over many small tasks, like driving and carrying items:

> He's not supposed to drive for a certain duration of time. He wasn't supposed to- to pick up heavy things, after surgery. So I was really like aware of that very much. I'd say 'Oh

> oh oh, you can't pick it up, I'm doing this' like 'I'm carrying this load', you know 'You're not carrying this load'.

In contrast, other participants performed more ADLs because their spouse was unable to do any: "it [her physical activity] has changed. Completing too housework and caring around [husband]. So uh only few times the gardening, weaving not at all, so I would say (pause) the household is my life in the moment, around [husband]" (Katherine, age 76). Many other caregivers reported engaging in more ADLs for similar reasons. Sarah (age 69) described how she did the same chores as before, but they were more burdensome now that she had to care as well:

> I did all of the above, before. And maybe just more so now . . . there's more appointments, there's more things to tend to, there's more things to remember, you know, encouraged him to get his bag ready for surgery . . . I did it before, it's true. But just it's a lot more concentrated and the urgency just seems more, it's there.

In some circumstances, caregiver ADLs did not change significantly. This was due to the dyad's existing division of labour which helped each spouse maintain their usual activities despite the impact of treatment:

> Very little, very little [change to ADLs]. Sometimes he'd say "Oh I'm going to let you do that". . . we have a system at home where he calls himself the sous, I'm a cook, but he cuts things up and cleans up after. So sometimes he was too tired to do those things, but… that's not difficult. He does things outdoors, I do things indoors. I'm mostly the Carol Burnett with the mop. (Rachel, age 77)

Together, the participants unanimously reported either an increase or no change to their levels of ADLs, which was dependent on the physical capability of their spouse and the intensity of the

caregiving role. However, caregivers reported different patterns of change to their levels of LTPA.

Changes to LTPA. Though not all participants engaged in LTPA prior to their spouse's diagnosis, those who did reported a significant reduction in LTPA after becoming a caregiver. Sarah (age 69) explained that " prior to . . . (husband) getting sick, I was going to the Y pretty regularly, I was going in two-three times a week". Other caregivers who used to engage in LTPA described similar decreases in their habits. This reduction in LTPA was directly related to the caregiving role and the shift of priorities in the participants' lives. Rachel (age 77) aptly described how she no longer felt comfortable taking time for her LTPA:

> My duties… being a caregiver - I spend time at the hospital. Like I have activities, but I didn't go to all my activities in the space of this time because you're not going to line dancing when someone's going for an X-ray for cancer, you know?

Similarly, Sarah (age 69) felt guilty about no longer engaging in LTPA but continued to prioritize her spouse's needs:

> "All this started happening with [husband], I said 'Well, I'm not going to the Y now, because I've got too much on my plate' . . . it's something that I should be doing but I'm putting everyone else's needs ahead of my own."

For these participants, LTPA lost much of its important in the face of their spouse's need for support and care. As such, caregivers who previously engaged in LTPA likely faced greater reductions to overall PA than caregivers who only performed ADLs, as this latter form of PA was less impacted by caregiving.

Chapter 4: Discussion

Caregivers in this study reported a variety of factors associated with their PA habits, which were categorized into structural, interpersonal, and intrapersonal factors, both caregiving-specific and general. Previous studies measured factors associated with caregiver PA, but generally as part of an intervention (e.g., Connell & Janevic, 2009; Farran et al., 2008; Hill et al., 2007) and not as an *a priori* exploration of lived experience. As such, the data from this study can serve to corroborate and broaden these previous findings, especially as caregivers in this study were not influenced by the content of a program or intervention.

Though these previous studies were not specific to caregivers of men with cancer, the samples were predominantly female and similar in age (average age of 65 years in all three studies). In line with previous research, this study found that the largest barrier to caregiver PA was the caregiving role itself. Notably, participants described the large time commitment of caring, and their reluctance to leave their spouse alone. This confirms the findings of previous caregiver PA interventions (Connell & Janevic, 2009; Farran et al., 2008; Hill et al., 2007), which reported similar barriers to PA.

Factors unrelated to the caregiving role present an intriguing avenue for comparisons, as they can be compared to the barriers and facilitators reported by non-caregiving older women. Franco et al. (2015) reported several key factor categories in their systematic review of qualitative studies investigating older adult PA. Though this review was not specific to older women, the main categories are still similar to the non-caregiving factors found in the present study, including the importance of social influences, physical limitations, competing priorities, and intrapersonal factors. As such, this study effectively confirms that older female spousal

caregivers experience a confluence of factors associated with the PA habits, which consist of both factors unique to the caregiving role and factors general to older adults.

Therefore, policies and interventions addressing the general older adult factors may also affect caregiver PA. As some participants stated in this study, community older adult fitness classes were a good source of PA for them, while also increasing PA in the general older adult population as well. Addressing even broader factors, such as neighbourhood walkability, may further improve PA for the entire community, regardless of age. However, these broader factors were described as less impactful than the more proximal, intrapersonal factors. Therefore, although a strong multimodal caregiver PA intervention should include community or organizational elements, the focal point should be addressing intrapersonal factors and factors unique to the caregiving role.

In line with the first research question of this study, intrapersonal and caregiving factors were the most significantly associated with caregiver PA. In addition, the second research question involved exploring how these associations changed for different forms of PA. Though the CSEP categorizations of PA (cardiovascular, resistance, and mobility-enhancing) were used to develop this study, the results were structured around the categories of ADLs and LTPA. This was done for several reasons. First, although participants understood the difference between aerobic, resistance, and mobility-enhancing PA, they overwhelmingly performed aerobic exercise. As such, there were not enough data on these three forms of PA to warrant a division in the results section. Second, the participants themselves categorized their PA as either LTPA or ADLs, as caregivers simply distinguished between PA they *had* to do (ADLs) and PA they *wanted* to do (LTPA). This participant-based categorization underpinned key findings in the data, and suggests several important points for future research.

LTPA and ADLs: Different Factor Associations, Different Implications

One of the more salient findings of this study was that caregiver PA was not uniformly associated with the reported structural, interpersonal, intrapersonal and caregiving factors. Participants most frequently reported a reduction in LTPA, as the constraints of the caregiving role limited their time, energy, and motivation to engage in leisure activities. However, no caregivers reported reductions to their ADLs, and in some cases, these activities were performed more frequently or intensely to compensate for the reduced involvement of the spouse. This is not likely caused by a lack of consideration for ADLs as a form of PA – the interview guide (Appendix 2) explicitly includes ADLs in the definition of PA. The distinction seems to be that the end goal of ADLs is not to be active, but rather to complete a task, whereas LTPA is inherently PA for the sake of PA. As such, when leisure time becomes limited due to caregiving, only LTPA becomes curtailed. This is reflected in how participants discussed the various barriers and motivational factors related to their PA – in response to these topics, only LTPA was mentioned. Furthermore, participants who did not engage in LTPA prior to their spouse's diagnosis did not report a decrease in total PA – they had no LTPA to reduce, and their ADLs were maintained. The distinction between LTPA and ADLs is therefore not merely perceived, as the caregiving role differentially impacted these two categories of PA.

This categorization of PA into either LTPA or ADLs may also reflect a lack of knowledge or conscious reflection by caregivers about other forms of PA as distinguished by the CSEP, such as resistance training. Dividing all activity into either ADLs or LTPA may preclude a more nuanced perception of one's own PA forms, which in the case of the participants, were almost exclusively cardiovascular and mobility-enhancing. As such, very few women in this

study were benefitting from resistance training, which is critical for bone health and daily functional ability, among other benefits (Warburton et al., 2006).

This difference between ADLs and LTPA suggests many further possible avenues for intervention development. ADLs seem to be the most resistant to the caregiving role, as they were generally maintained at similar levels before and after the spouse's diagnosis. This stability makes ADLs a notable target for interventions, as it may be simpler to increase or modify existing behaviours than to form new ones during a stressful life event. ADLs can be modified to become more strenuous (and therefore more health promoting) by adding additional resistance in the form of ankle weights, for example. However, when considering that many caregivers reported needing a break from caring, making ADLs more difficult may needlessly complicate their lives further. Therefore, making ADLs more strenuous may only be appropriate with caregivers who report fairly low burden and distress.

Further, the division between caregivers who engage in both ADLs and LTPA and those who solely perform ADLs also suggests differences in ideal intervention development. Participants who did not engage in LTPA prior to becoming a caregiver may require additional informational support, access to resources, or other forms of assistance in order to create a new PA habit. In contrast, caregivers who used to regularly engage in LTPA may only require brief respite from the caregiving role in order to increase their PA levels back to their pre-diagnosis baseline or beyond. They may also be well-placed for interventions aiming to introduce new forms of PA, such as resistance training, as they already perform other forms.

However, the most significant barrier reported by caregivers was unequivocally the time commitment of caring and the need to be present with their spouse far more than before. As such, any intervention seeking to improve caregiver PA must directly address this fundamental

aspect of the caregiver's lives. One possible way to do so is through dyadic interventions, in which both the caregiver and the spouse engage in the PA intervention together. Though dyadic interventions are contingent on the care recipient's physical condition, they effectively circumvent the need for the caregiver to find time apart from their spouse. Dyadic interventions are not a panacea, however, as the findings of this study suggest that dyads prefer exercising together when they have similar PA abilities. Further, certain participants simply reported a preference for exercising alone. Despite these considerations, dyadic PA interventions are a potential way to increase both caregiver and care recipient PA, and can be used to model positive PA behaviours for older adults.

What do MVPA Measures Describe?

Though the quantitative data in this study were descriptive in nature, they suggest a number of areas for future inquiries. Notably, of the four participants over the age of 75, two reported engaging in 100 or more minutes of weekly MVPA which, at face value, is a considerable achievement. These data alone would suggest that these two participants have better physical abilities than the two women above the age of 75 who reported zero weekly minutes of MVPA. However, the interviews described a different account. Vanessa (age 81) reported significant mobility issues and a few falls in the past, and had to move out of her home to live in a more accessible apartment. She discussed the time she spent in her building's shallow pool, which helped her relieve chronic pain. Because these activities were moderately strenuous for her, she correctly listed them in her Godin-Shephard LTPA, which totalled approximately 100 minutes of weekly MVPA. In contrast, Heather (age 63) accrued 120 minutes of weekly MVPA, but this was performed with walking around the neighbourhood and along the trails in the woods near her home. Such activities would be very difficult for Vanessa – yet they both had similar

weekly MVPA totals. Although the Godin-Shephard LTPA questionnaire includes lists of activities that are representative of each level of PA intensity, it also provides a description of perceived exertion: vigorous activity is described as "heart beating rapidly", moderate as "not exhausting" and mild as "minimal effort" (Appendix 8). PA intensity is individually variable as it is dependent upon the person's level of fitness, and these two participants correctly categorized their activity despite the vast difference in objective difficulty between the two activities performed (outdoor trail walking vs shallow pool wading). Though higher levels of PA intensity are associated with improved health outcomes, intensity is not analogous to objective physical ability and may be a poor measure when attempting to quantify how capable a person may be for providing care to a spouse.

From a health promotion perspective, increasing and maintaining the self-management and independent living skills of older adult caregivers is a critical goal, and future research should therefore consider employing measures of independent living rather than PA intensity. For example, a list of basic independent living skills (i.e., I can go shopping for groceries alone and put them away when I get home) may provide a better representation of the participant's physical abilities. To that end, a questionnaire such as the Community Healthy Activities Model Program for Seniors (CHAMPS) tool may have provided a greater sense of participants' functional abilities and independent living (Stewart et al., 2001).

Limitations

The implications of this study should be understood in the context of its limitations. The recruitment strategies employed for this study engendered some limitations. Caregivers recruited through the Peri-Operative Program all had spouses whose cancer treatment consisted of surgery. As such, the findings may not be representative of a caregiver whose spouse is being treated with

chemo- or radiotherapy. However, as caregivers were recruited at different stages of their spouse's participation in the program, not all spouses had undergone surgery yet. Therefore, there was still a rich variety in experiences reported by caregivers, as some had only recently known of their spouse's diagnosis, and others had been caring for their spouse post-surgery.

Furthermore, there may have been a recruitment self-selection bias at play. As the caregiving role is emotionally burdensome, caregivers experiencing large amounts of distress may not have wanted to participate in a study. During recruitment, some caregivers who were approached refused, stating that they did not feel "up to it" given their spouse's recent diagnosis. The caregivers who participated may therefore have been somewhat less burdened by the caregiving role than others who did not participate. However, participants still reported a broad range of emotional responses including worry, depression, and anger, which suggests that the caregivers in this study still were still deeply upset by their spouse's illness.

There are also limitations in terms of the caregiver's own cognisance of factors. For example, the eligibility criteria for this study included only caregivers who did not reach the CSEP physical activity guidelines. With that in mind, they may have been unable to discuss facilitators to PA based on their own experiences. Findings may therefore be skewed towards factors which act as barriers to PA. Similarly, structural factors such as zoning laws could have impeded the development of fitness facilities near the home of caregivers, reducing accessibility. Caregivers may not have been aware of this and may have simply reported a low desire to engage in PA because they were not presented opportunities to do so. Thus it is important to specify that the data collected represent the *perceived* factors associated with PA among spousal caregivers for men with cancer. Future research should engage with other data and populations,

such as public health experts, oncologists, or community nurses to develop a stronger understanding of the factors associated with PA in this population.

Conclusion

This was a novel study investigating a field that has not yet been studied in detail. Though some studies have examined factors associated with PA in caregivers, none have employed this particular methodology. For example, Gordon-Larsen et al. (2004) studied barriers to PA among caregivers, but only studied household factors among younger adult caregivers. Suttanon, Hill, Said, Byrne, and Dodd (2012) explored barriers associated with PA in caregivers as well, but caregivers were a secondary population, and the PA used was a dictated balance program, not general PA. As such, this in-depth exploration of any factors associated with any form of PA among spousal caregivers for men with cancer was a novel and valuable approach.

This study highlighted some key considerations for future research and interventions for caregiver PA. First, the distinct impact of caregiver on ADLs and LTPA is worthy of further examination. Because these two categories of PA were affected differently by caregiving, future studies should also examine changes to PA since becoming a caregiver, in addition to total current caregiver PA levels. A caregiver whose current levels of PA may meet or exceed the CSEP guidelines may still have experienced a significant loss of activity if they were significantly more active before becoming a caregiver. Examining current levels of PA alone may not fully capture how caregiving has impacted the individual's health behaviours. Second, the perceptions of spousal caregivers regarding other forms of PA, such as resistance training, remain somewhat unknown, as the caregivers in this study did not generally perform this activity. Future studies investigating this arear may employ more specific questions in order to more fully understand the barriers unique to resistance training in this population. Finally,

interventions seeking to improve caregiver PA should emphasize dyadic PA to circumvent the time commitment of caring and to extend the benefits of PA to the care recipient. Caregivers who already engage in some amount of LTPA are also an ideal population for learning other forms of LTPA, such as resistance training for the health and functional benefits it confers.

In conclusion, this study confirmed that spousal caregivers for men living with cancer experience factors associated with the PA behaviours that are both unique to the caregiving role, and common to other older adults. The use of a qualitative methodology generated rich and thorough findings, thereby creating a more complete representation of caregiver experiences with PA than previous attempts to do so (e.g. Connell & Janevic, 2009; Farran et al., 2008; Hill et al., 2007). This research contributes to the growing body of literature on caregiver health, and supports the assertion that caregivers are impacted by factors both proximal and distal to themselves. The results may also guide further intervention development for caregiver PA, and potentially improve the performance of future interventions over those reviewed recently by Lambert et al. (2016). Ideally, interventions should address multiple levels of factors in order to truly change the person, those around them, and the environment in which they live. By doing so, interventions may help promote additional MVPA among caregivers and incur the plethora of health benefits associated therewith.

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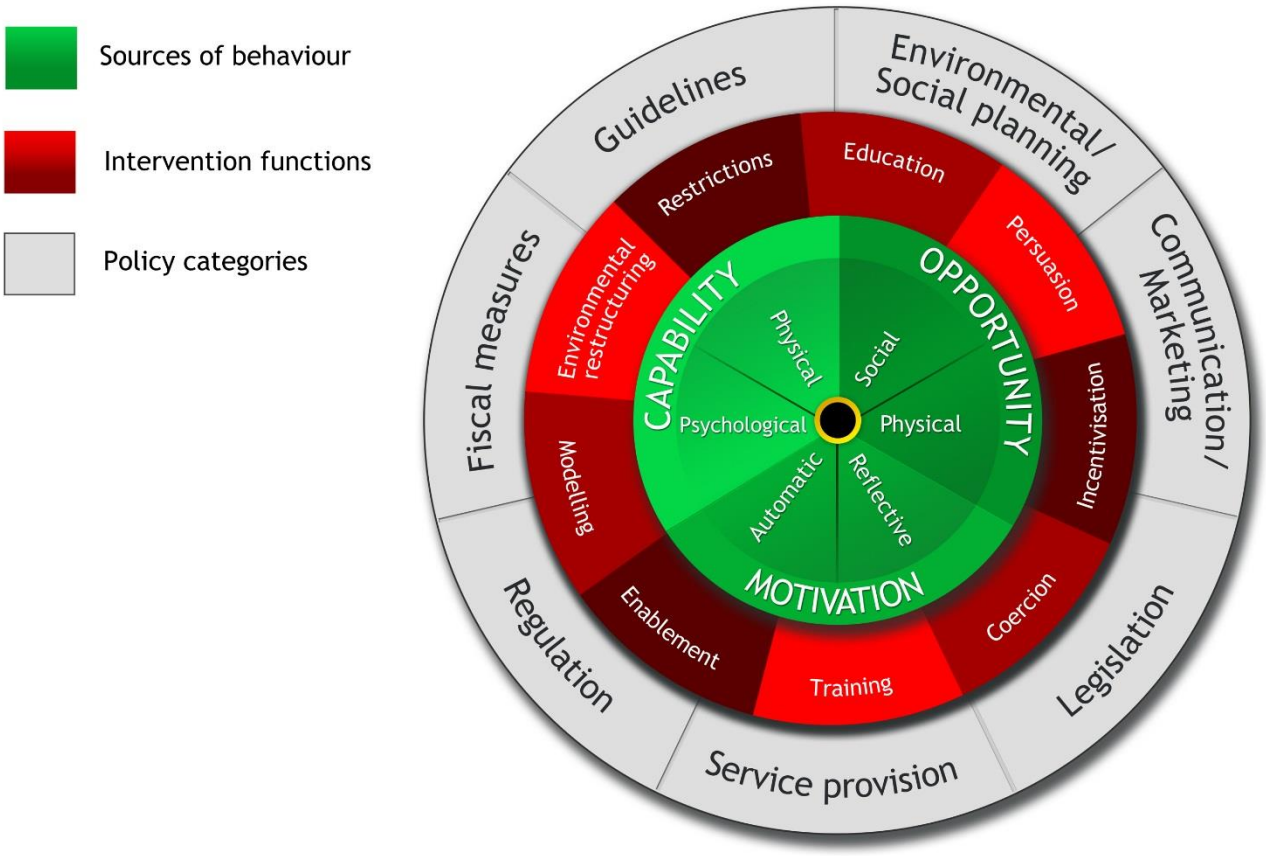
Appendices

Appendix 1: BCW Framework

(COM-B subcomponent in green)



(Michie et al., 2011)

Appendix 2: Revised Interview Guide

English version

1. So, how are things?
2. Tell me about your role as a caregiver. What kinds of things do you do for (insert name of patient) on daily basis?
    a. Roughly how much time do you spend on each of those things?
    b. Did you do similar tasks before the diagnosis or are these new tasks for you?
3. Let's talk about physical activity. What comes to mind when you hear that term?
4. By 'physical activity' I mean any kind of movement in your day. This can be any kind of walking, picking things up, doing housework, yard work...anything where you're moving. What do you think about that definition?
    a. What types of physical activities do you do?
    b. What is it that you like about these physical activities?
    c. How do these physical activities make you feel?
    d. How do you feel after you do these activities?
    e. How intense are those activities?
5. What comes to mind when you hear the words 'resistance training' or 'weight training'? How do those words make you feel?
    a. Have you ever done this kind of physical activity? Why or why not?
    b. If yes to a, tell me about what you do
    c. How intense are those activities? How do they make you feel physically? How does your heart rate change?
    d. Tell me about any lifting or carrying you do.
6. How do you incorporate physical activity into your life?
    a. What gets in the way?
    b. What helps?
7. How do you feel about the amount of physical activity you get?
    a. How intense would you describe your exercise or daily physical activity?
    b. How does that make you feel?
    c. How do you judge the quality of the PA you get?
8. Tell me about a time you did something that was very demanding physically. How did that make you feel? What was it?
    a. How capable do you feel, physically?
    b. How mentally prepared do you feel to be physically active?
9. Often, people will start getting more physical activity but have trouble keeping at it, and sometimes stop altogether. Why do you think this is?
    a. Have you ever experienced this?
    b. Why did you want to start exercising?
    c. How did you start?
    d. What made it difficult to maintain?
    e. Looking back, what would have made it easier for you to stick with it?
10. Can you tell me about a time you wanted to do a particular kind of physical activity, but didn't?

11. Sometimes, people will start doing physical activity because a friend or someone they know helps them. What kind of experience do you have with situations like this?
    a. Tell me about a moment in your life when the people you knew made it harder to be physically active
12. Sometimes, people have trouble being active because of where they live. It may be hard to walk in their neighbourhood, or gyms may be far away. Tell me something about where you live that makes it harder to be physically active. Something that makes it easier?
    a. Have you ever experienced something in your neighbourhood that makes it easier to be active?

13. Tell me about how your physical activity has changed since you took on the role of caregiver.
    a. How did your life change?
    b. What was your lifestyle like before the diagnosis?
14. Tell me about how your own health has changed since you took on the role of caregiver.
15. Some research has shown that caregivers have a hard time staying physically active, what do you think about that?
    a. What would you say are the biggest challenges in your life that make it more difficult to be active?
        i. How could your own physical ability impact your physical activity?
        ii. How could the people around you or where you live impact your physical activity?
        iii. How could your personality impact your physical activity?
16. We're trying to understand what factors might help or prevent physical activity participation among caregivers of people with prostate cancer. Considering everything we've talked about today, is there anything you think we've missed, or anything you want to add?

French version

1. Donc, comment allez-vous, en général?
2. Expliquez-moi votre rôle en tant que proche aidant. Quelles tâches accomplissez-vous quotidiennement pour (insert name of patient)
    a. Environ combien de temps passez-vous à faire ces activités?
    b. Faisiez-vous des activités similaires avant que le diagnostic a été posé?
3. Parlons d'activité physique. À quoi pensez-vous quand vous entendez ce terme?
4. Quand je dis « activité physique », le terme englobe tous les mouvements dans votre journée. Cela peut inclure la marche, ramasser des objets, accomplir des tâches ménagères, jardiner... n'importe quel mouvement. Que pensez-vous de cette définition?
    a. Quels genres d'activité physique faites-vous?
    b. Quels aspects de ces activités aimez-vous?
    c. Comment ces activités vous font-elles sentir?
    d. Comment vous sentez-vous après ces activités?
    e. À quelle intensité pratiquez-vous ces activités?
5. À quoi pensez-vous quand vous entendez les mots « entraînement de résistance » ou bien « entraînement avec des poids »? Comment vous sentez-vous?

   a. Avez-vous déjà pratiqué ce genre d'exercice? Pourquoi?
   b. Si oui, pratiquez-vous actuellement ce genre d'exercice?
   c. À quelle intensité sont ces activités? Comment vous sentez-vous physiquement pendant ces activités ? Est-ce que votre pouls change?
   d. Parlez-moi de tous les moments dans une journée typique où vous ramassez ou transportez des objets ou des poids.
6. Expliquez-moi comment vous incorporez l'activité physique dans votre vie.
   a. Qu'est-ce qui vous empêche de pratiquer l'activité physique?
   b. Qu'est-ce qui vous aide à pratiquer l'activité physique?
7. Comment vous sentez-vous face au niveau d'activité physique que vous pratiquez?
   a. Comment décririez-vous l'intensité de votre activité physique ou de vos exercices quotidiens?
   b. De quelle façon ces exercices vous font-ils sentir?
   c. Comment juger-vous la qualité de ces activités physiques?
8. Pouvez-vous parler d'un moment où vous avez fait une activité très exigeante? Comment vous êtes-vous senti après? Quelle était cette activité?
   a. À quel point vous sentez-vous capable physiquement?
   b. À quel point êtes-vous prêts mentalement pour l'activité physique?
9. Souvent, les gens commencent une routine d'exercice, mais ils ont de la difficulté à la maintenir. Selon vous, pourquoi est-ce le cas?
   a. Avez-vous déjà vécu cette expérience?
   b. Pourquoi avez-vous voulu commencer une routine d'exercice?
   c. Comment l'avez-vous commencée?
   d. Pourquoi était-elle difficile à maintenir?
   e. En y repensant, quels facteurs auraient pu vous aider à maintenir votre routine?
10. Pouvez-vous me décrire un moment où vous avez voulu essayer un type d'exercice, mais que vous ne l'avez pas fait?
11. Parfois, les gens commencent à pratiquer un exercice parce ce qu'un ami ou quelqu'un qu'ils connaissent les aide. Avez-vous déjà vécu cette expérience?
   a. Avez-vous vécu une situation où les gens dans votre vie vous ont empêché de faire de l'exercice?
12. Parfois, les gens ont de la difficulté à faire de l'exercice dû à l'endroit où ils habitent. Leur quartier pourrait être difficile à parcourir à pied ou, les salles d'entraînement sont loin. Que pensez-vous de votre quartier et comment pourrait-il affecter votre activité physique?
   a. Est-ce qu'il y a quelque chose dans votre quartier qui facilite l'activité physique pour vous?
13. Pouvez-vous expliquer comment votre activité physique a changé depuis que vous êtes proche aidant?
   a. Comment votre vie a-t-elle changé?
   b. Comment décririez- vous votre style de vie avant le diagnostic?
14. Pouvez-vous décrire comment votre santé a changée depuis que vous êtes proche aidant?
15. Des études récentes ont conclu que les proches aidants ont de la difficulté à faire de l'exercice. Que pensez-vous de ceci?
   a. Quels sont les plus grands défis dans votre vie qui vous empêchent de faire de l'exercice?

   i. Comment vos habiletés physiques pourraient-elles avoir un impact sur votre activité physique?
   ii. Comment les personnes qui vous entourent et votre quartier pourraient-ils avoir un impact sur votre activité physique?
   iii. Comment votre propre personnalité pourrait-elle avoir un impact sur votre activité physique?

16. Nous voulons comprendre les facteurs qui pourraient aider ou empêcher l'activité physique parmi les proches aidants d'hommes atteint du cancer de la prostate. Est-ce que vous auriez d'autres idées, anecdotes ou détails que vous aimeriez partager à ce sujet?

Appendix 3: Original Interview Guide

Used for first interview only

English version

1. Tell me about your role as a caregiver. What kinds of things do you do for (insert name of patient) on daily basis?
    a. Roughly how much time do you spend on each of those things?
2. What kind of activities do you do during your free time? This can be anything so long as it doesn't relate to work!
3. Tell me about the physical activity you do in your free time.
    a. What types of physical activities do you do?
    b. What is it that you like about these physical activities?
    c. How do these physical activities make you feel?
    d. How do you feel after you do these activities?
    e. How intense are those activities?
4. What comes to mind when you hear the words 'resistance training' or 'weight training'? How do those words make you feel?
    a. Have you ever done this kind of exercise? Why or why not?
    b. If yes to a, tell me about what you do
    c. How intense are those activities?
5. Tell me about how you incorporate physical activity into your life.
    a. What gets in the way?
    b. What helps?
    c. How does caregiving change your exercise?
6. How do you feel about the amount of exercise you get?
    a. How intense would you describe your exercise or daily physical activity? How does that make you feel?
7. Tell me about a time you did something that was very demanding physically. How did that make you feel? What was it?
8. Tell me about how your physical activity has changed since you took on the role of caregiver.
9. Tell me about how your own health and physical activity changed since you took on the role of caregiver.
10. Often, people will start an exercise routine but have trouble keeping at it, and sometimes stop altogether. Why do you think this is?
    a. Have you ever experienced this?
    b. Why did you want to start exercising?
    c. How did you start?
    d. What made it difficult to maintain?
    e. Looking back, what would have made it easier for you to stick with it?
11. Can you tell me about a time you wanted to do a particular kind of exercise, but didn't?
12. Sometimes, people will start exercising because a friend or someone they know helps them. Have you ever experienced this?

    a. Have you ever experienced a moment in your life when the people you knew made it harder to exercise?
13. Sometimes, people have trouble exercising because of where they live. It may be hard to walk in their neighbourhood, or gyms may be far away. Have you ever experienced something about where you live that makes it harder to exercise?
    a. Have you ever experienced something in your neighbourhood that makes it easier to exercise?
14. Some research has shown that caregivers have a hard time staying physically active, what do you think about that?
    a. What would you say are the biggest challenges in your life that make it more difficult to exercise?
15. We're trying to understand what factors might help or prevent physical activity participation among caregivers of people with prostate cancer. Considering everything we've talked about today, is there anything you think we've missed, or anything you want to add?

French version

1. Expliquez-moi votre rôle comme proche-aidant. Quels genres de choses faites-vous pour (insert name of patient) régulièrement?
2. Quels genres d'activités faites-vous pendant votre temps libre? Ça pourrait être n'importe quoi sauf votre emploi.
3. Pouvez-vous m'expliquer l'activité physique que vous faites dans votre temps libre?
    a. Quels genres d'activités faites-vous?
    b. Qu'aimez-vous de ces activités?
    c. Vous vous sentez comment en faisant ces activités?
    d. Vous vous sentez comment après ces activités?
    e. Quelle intensité sont ces activités?
4. À quoi pensez-vous quand vous entendez les mots "entraînement de résistance" ou bien "entraînement avec des poids". Vous vous sentez comment?
    a. Avez-vous déjà fait ce genre d'exercice? Pourquoi ou pourquoi pas?
    b. Si oui, faites-vous présentement ce genre d'exercice?
    c. Quelle intensité sont ces activités?
5. Expliquez-moi comment vous incorporez de l'activité physique dans votre vie.
    a. Qu'est-ce qu'il vous empêche?
    b. Qu'est-ce qu'il vous aide?
    c. Comment votre rôle de proche aidant impacte votre activité physique?
6. Comment vous vous sentez de votre niveau d'activité physique?
    a. Comment décrierez-vous l'intensité de votre activité physique ou exercice quotidienne? Ces exercices vous font sentir de quelle façon?
7. Pouvez-vous me raconter un moment que vous avez fait une activité très forçant. Comment vous vous avez senti par après? C'était quoi l'activité?
8. Pouvez-vous me raconter de quelle façon votre activité physique a changé depuis que vous êtes proche-aidant?
9. Pouvez-vous me raconter de quelle façon votre santé a changé depuis que vous êtes proche-aidant?

10. Souvent, les gens débuteront une routine d'exercice mais auront de la difficulté à la maintenir. Pourquoi pensez-vous que c'est le cas?
    a. Avez-vous déjà vécu cette expérience?
    b. Pourquoi vous vouliez débuter une routine d'exercice?
    c. Comment avez-vous commencé?
    d. Pourquoi était-ce difficile à maintenir?
    e. En y repensant, quels facteurs auraient-pu vous aidez à maintenir votre routine?
11. Pouvez-vous me décrier un moment où vous avez voulu essayer un type d'exercice, mais vous ne l'avez pas fait?
12. Parfois, les gens commencent à faire de l'exercice qu'un ami ou quelqu'un qu'ils connaissent les aident. Avez-vous déjà vécu cette expérience?
    a. Avez-vous vécu une situation où les gens dans votre vie vous ont empêché de faire de l'exercice?
13. Parfois, les gens ont de la difficulté à faire de l'exercice à cause d'où ils habitent. Leur quartier pourrait-être difficile à parcourir à pied, ou les salles d'entraînement peuvent être loin. Que pensez-vous de votre cartier et comment ceci pourrait affecter votre activité physique?
    a. Est-ce que votre cartier vous a déjà aider à faire de l'exercice?
14. Des études récentes ont conclu que les proches-aidants ont de la difficulté à faire de l'exercice. Que pensez-vous de ceci?
    a. Que sont les plus grands défis dans votre vie qui vous empêche de faire de l'exercice?
15. Nous voulons comprendre quels facteurs pourraient aider ou empêcher l'activité physique parmis les proches-aidants des hommes avec le cancer de la prostate. Est-ce que vous avez autres idées, anecdotes ou détails que vous aimerez partager par rapport à ce sujet?

Appendix 4: Eligibility Screening Questions

English:

1. "Are you currently the primary family caregiver to someone living with prostate cancer?" (Inclusion: Yes, Exclusion: No)
2. "What was the date of the cancer diagnosis for that person?" (Inclusion: Within the last twelve months on the day the screening question is administered. Exclusion: More than twelve months before the day the screening question is administered.)
3. In an average week, how often do you do a physical activity that makes you breathe harder and sweat a little bit? For how long do you do that activity?
4. In an average week, how often do you do a physical activity that makes you breathe very hard and sweat a lot? For how long do you do that activity? (Inclusion: Sum of reported minutes from questions 3 and 4 totals less than 150 minutes per week of moderate-to-vigorous PA. Exclusion: Sum of reported minutes from questions 3 and 4 totals or exceeds 150 minutes per week of moderate-to-vigorous PA)

French:

1. "Êtes-vous présentement la personne principale dans la famille qui s'occupe d'un homme vivant avec un cancer de la prostate? (Inclusion : Oui, Exclusion : Non)
2. "Quelle était la date du diagnostic du cancer pour cette personne?" (Inclusion: Within the last twelve months on the day the screening question is administered. Exclusion: More than twelve months before the day the screening question is administered.)
3. Dans une semaine typique, combien de fois faites-vous un activité physique qui vous fait respirer plus fort et suer un peu? Pendant combien de temps faites-vous ces activités?
4. Dans une semaine typique, combien de fois faites-vous un activité physique que vous fait respirer très fort et suer beaucoup? Pendant combien de temps faites-vous ces activités?

(Inclusion: Sum of reported minutes from questions 3 and 4 totals less than 150 minutes per week of moderate-to-vigorous PA. Exclusion: Sum of reported minutes from questions 3 and 4 totals or exceeds 150 minutes per week of moderate-to-vigorous PA)

Appendix 5: Recruitment Posters

English version

Do you care for someone with prostate cancer?

Are you a family member doing most of the work at home to care for someone with prostate cancer?

Was the diagnosis in the last year?

If you answered YES to all, you are invited to take part in a research study conducted by researchers in the department of Kinesiology and Physical Education at McGill University

- ✓ **We are looking to understand the physical activity habits of family caregivers for men with prostate cancer.**
- ✓ **You will be asked to take part in an individual interview lasting 60-90 minutes.**

To participate, contact Eric Hutt:
eric.hutt@mail.mcgill.ca
514-398-4184 ext. 0481

The supervisor is Dr. Lindsay Duncan
lindsay.duncan@mcgill.ca
(514) 398-4184 ext. 0919
Department of Kinesiology and Physical Education, McGill University

To learn more contact Eric Hutt at eric.hutt@mail.mcgill.ca 514-398-4184 ext. 0481

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French version

Vous prenez soin de quelqu'un avec le cancer de la prostate?

Êtes-vous un membre de la famille qui s'occupe de quelqu'un avec le cancer de la prostate à la maison?
Est-ce que le diagnostic a été pose dans la dernière année?

Si vous avez répondu OUI aux deux questions, vous êtes invité à participer dans une étude entrepris par des chercheurs du département de Kinésiologie et Éducation Physique à l'Université McGill

- ✓ **Notre étude explore les habitudes d'activité physique des proches-aidants familiaux des hommes avec le cancer de la prostate**
- ✓ **Vous participerez à une entrevue durant entre 60 et 90 minutes.**

Pour participer, contactez Eric:
eric.hutt@mail.mcgill.ca
514-398-4184 ext. 0481

Le superviseur est Dr. Lindsay Duncan
lindsay.duncan@mcgill.ca
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Appendix 6: Classified Advertisements

Text used in online recruitment forum

English version

Title: Family caregivers needed for research study!

Description: Are you caring for someone in your family who has prostate cancer? Was the diagnosis in the last year? If you answered yes to both questions, you are invited to take part in a research study looking to understand the physical activity habits of family caregivers for men with prostate cancer. This research is being conducted by researchers from the Department of Kinesiology and Physical Education at McGill University. This project is under the supervision of Dr. Lindsay Duncan.

Participating involves meeting one-on-one with a researcher for an interview that will last approximately minutes. If you would like to participate in this study, or just want to learn more, please contact Eric Hutt at eric.hutt@mail.mcgill.ca, or at 514-398-4184 ext. 0481

Contact: Principal Investigator, Eric Hutt, eric.hutt@mail.mcgill.ca

The supervisor, Dr. Lindsay Duncan, can be reached here:
Lindsay.duncan@mcgill.ca
(514) 398-4184 ext. 0919
Department of Kinesiology and Physical Education, McGill University
French version:

Title: Nous cherchons des proches-aidants pour une étude scientifique!

Description: Vous prenez soin d'un homme dans votre famille qui a le cancer de la prostate? Est-ce que le diagnostic a été posé dans la dernière année? Si vous avez répondu oui aux deux questions, vous êtes invité à participer dans une étude qui explore les habitudes d'activité physique des proches-aidants familiaux des hommes avec le cancer de la prostate. Cette recherche est entreprise par des chercheurs du Département de Kinésiologie et Éducation Physique à l'Université McGill. Ce projet est supervisé par Dr. Lindsay Duncan.

Vous participerez à une entrevue durant entre 60 et 90 minutes. Si vous souhaitez participer, ou si vous avez des questions, veuillez contacter Eric Hutt (eric.hutt@mail.mcgill.ca) ou au 514-398-4184 ext. 0481

Contact: Investigateur Principal, Eric Hutt, eric.hutt@mail.mcgill.ca

Le superviseur, Dr. Lindsay Duncan, peut être contacté ici :
Lindsay.duncan@mcgill.ca
(514) 398-4184 ext. 0919
Département de Kinésiologie et Éducation Physique, Université McGill

Appendix 7: Demographic Questionnaire and Caregiving Tasks

English version:

Demographic information

Date of Birth (YYYY/MM/DD): _____ / _____ / _____

Sex: ☐ Female ☐ Male ☐ Other

Marital Status:
☐ Single ☐ Married ☐ Divorced/Separated
☐ Common-law ☐ Other: _____

Ethnic group : ❑ Caucasian ❑ Asian ❑ Indo-Asian ❑ Hispanic
❑ African ❑ First Nation ❑ European
❑ other _____

Spoken/written language : ❑ French ❑ English ❑ other _____

Preferred language: ❑ French ❑ English ❑ other _____

Employment : ❑ full time ❑ part time ❑ unemployed
❑ retired ❑ homemaker ❑ disability
❑ other _____

Care recipient's cancer type: _____

Cancer stage: ❑ Stage 1 ❑ Stage 2 ❑ Stage 3 ❑ Stage 4

Education: Please indicate the highest degree/certificate you obtained (Check ONE).

❑ No diploma or certificate
❑ High school degree
❑ Apprenticeship or trades certificate
❑ College or CEGEP degree (1 year or less)
❑ College or CEGEP degree (1 year or more)
❑ Some university studies (minimum of 1 year)
❑ Bachelor's degree

- ❑ Master's degree
- ❑ Degree in medicine, dentistry, veterinary medicine or optometry
- ❑ Doctorate degree

Your role as a partner or caregiver might range from providing company or emotional support to taking on more physical activities such as cooking, or helping with transport to and from appointments. The types of activities and how much time you spend doing them are likely to change depending on a range of factors. Below is a list of some of the tasks you might do in your role as a partner/caregiver. Even if you do not assist with any of these tasks, we are still interested in your experiences.

During the last 4 weeks, about how often have you performed the following tasks in your role as a partner/caregiver of someone diagnosed with cancer: ***(circle one number on each line)***

	Daily	***At least once per week***	***Less often than once per week***	***Not at all***
Personal tasks				
a. Assist with personal care (eg. bathing, toileting, dressing)	1	2	3	4
b. Help with mobility (eg. getting in and out of bed)	1	2	3	4
c. Provide emotional support	1	2	3	4
Household tasks				
d. Perform household tasks (eg. cooking, cleaning, laundry)	1	2	3	4
e. Doing other odd jobs around the house (eg. minor repairs, painting)	1	2	3	4
Practical assistance				
f. Provide financial assistance	1	2	3	4
g. Transportation (eg. to and from medical appointments, shopping)	1	2	3	4
h. Manage money (eg. household bills, healthcare payments)	1	2	3	4
Medical tasks				
i. Organise appointments (eg. with healthcare providers)	1	2	3	4

k. Manage medications	1	2	3	4
l. Liaising with doctors and finding out information	1	2	3	4
m. Assess need for medication or treatment	1	2	3	4

French version

Informations démographiques

Date de naissance (AAAA/MM/JJ): _____ / _____ / _____

Sexe: ☐ Féminin ☐ Masculin ☐ Autre

État civil:
☐ Célibataire ☐ Marié(e) ☐ Divorcé(e)/Séparé(e)
☐ Conjoint(e) de fait ☐ Autre : _____

Groupe ethnique : ❑ Caucasien ❑ Asiatique ❑ Indo-Asiatique
❑ Hispanique ❑ Africain ❑ Autochtone
❑ Européen ❑ Autre _____

Langue parlée/écrite : ❑ Français ❑ Anglais ❑ Autre_____

Langue préférée: ❑ Français ❑ Anglais ❑ Autre_____

Statut d'emploi : ❑ Temps plein ❑ Temps partiel ❑ Sans emploi
❑ À la retraite ❑ Personne au foyer ❑ Handicapé(e)
❑ Autre_____

Type de cancer de la personne: _____

Stade du cancer: ❑ Stade 1 ❑ Stade 2 ❑ Stade 3 ❑ Stade 4

Éducation: Veuillez indiquer le plus haut niveau d'éducation complété (Cochez UNE case)

❑ Pas de diplôme ni certificat

- ❑ Diplôme d'école secondaire
- ❑ Certificat en apprentissage ou métier
- ❑ Diplôme de collège or CEGEP (1 an ou moins)
- ❑ Diplôme de collège or CEGEP (Plus d'un an)
- ❑ Des cours universitaires (minimum d'un an)
- ❑ Baccalauréat
- ❑ Maitrise
- ❑ Diplôme en médecine, médecine dentaire, médecine vétérinaire, or optométrie.
- ❑ Doctorat

Votre rôle comme proche-aidant peut inclure des tâches de support émotif, ou des aspects plus tangibles, tels la gestion ménagère ou le transport de votre époux. Ces tâches peuvent varier. Cette liste ci-dessous contient des tâches que vous faites probablement comme proche-aidant.

Durant les <u>4 dernières semaines</u>, environ combien de fois avez-vous fait les tâches suivantes dans votre rôle de proche-aidant pour votre partenaire avec le cancer :
(choisissez un numéro par ligne)

	Chaque jour	***Au moins une fois par semaine***	***Moins de une fois par semaine***	***Pas du tout***
Tâches personnelles				
a. Assister avec des tâches personnelles telles que l'hygiène, la toilette, l'habillement	1	2	3	4
b. Les aider à se déplacer (e.g. sortir de leur lit)	1	2	3	4
c. Donner du support émotif	1	2	3	4
Tâches ménagères				
d. Tâches générales (cuisson, ménage, lessive)	1	2	3	4
e. Tâches moins communes (peinture, réparations)	1	2	3	4
Assistance pratique				
f. Support financier pour votre partenaire	1	2	3	4

g. Transport hors de la maison (vers un rendez-vous, e.g.)	1	2	3	4
h. Gestion financière (payer les factures, aller à la banque, etc.)	1	2	3	4
Tâches médicales				
i. Organiser des rendez-vous au médecin	1	2	3	4
k. Gestion des médicaments	1	2	3	4
l. Contacter le médecin pour des renseignements	1	2	3	4
m. Évaluer la santé de votre partenaire	1	2	3	4

Appendix 8: The Godin-Shephard Leisure Time Physical Activity Questionnaire

English version

Physical Activity

1) STRENUOUS/VIGOROUS PHYSICAL ACTIVITY (HEART BEATS RAPIDLY)
(e.g., running, jogging, hockey, football, soccer, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming, vigorous long distance bicycling)

A) Considering A TYPICAL WEEK in the past month, how many times on average have you done strenuous/vigorous physical activity for more than 15 minutes during your free time **(write the appropriate number of times per week in the circle).** ◯ times a week

B) For approximately how many minutes do you participate in each strenuous physical activity session? _____ # of minutes

2) MODERATE PHYSICAL ACTIVITY (NOT EXHAUSTING)
(e.g., fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing)

A) Considering A TYPICAL WEEK in the past month, how many times on average have you done moderate physical activity for more than 15 minutes during your free time **(write the appropriate number of times per week in the circle).** ◯ times a week

B). For approximately how many minutes do you participate in each moderate physical activity session? _____ # of minutes

3) MILD PHYSICAL ACTIVITY (MINIMAL EFFORT)
(e.g., yoga, archery, fishing from river band, bowling, horseshoes, golf, snow-mobiling, easy walking)

A) Considering A TYPICAL WEEK in the past month, how many times on average have you done mild physical activity for more than 15 minutes during your free time **(write the appropriate number of times per week in the circle).** ◯ times a week

B). For approximately how many minutes do you participate in each mild physical activity session? _____ # of minutes

French version

Activité Physique

1) ACTIVITÉ PHYSIQUE D'INTENSITÉ ÉLEVÉE (FRÉQUENCE CARDIAQUE ÉLEVÉE)
(exemples : jogging ou course à pied, ski de fond, hockey, football, soccer, squash, basketball, judo, patin à roulettes, nage intensive, bicycle intensif sur une longue distance…)

A) Considérez une période d'**une semaine typique**. Combien de fois, en moyenne, vous adonnez-vous aux types d'activités physiques précédentes pendant **plus de 15 minutes** durant vos temps libres ? (Inscrivez le nombre approprié dans le cercle). ◯ fois par semaine

B) Pour environ combien de minutes faites-vous chaque session activité d'intensité élevée? (Inscrivez le nombre de minutes par session sur la ligne) _____ # de minutes.

2) ACTIVITÉ PHYSIQUE MODÉRÉE (SANS ÊTRE EXTÉNUANTE) (exemples : marche rapide, tennis, badminton, motoneige, danse, volley-ball, bicycle de promenade, nage facile, …)

A) Considérez une période d'**une semaine typique**. Combien de fois, en moyenne, vous adonnez-vous aux types d'activités physiques précédents pendant **plus de 15 minutes** durant vos temps libres ? (Inscrivez le nombre approprié dans le cercle). ◯ fois par semaine

B) Pour environ combien de minutes faites-vous chaque session activité d'intensité modérée? (Inscrivez le nombre de minutes par session sur la ligne) _____ # de minutes.

3) ACTIVITÉ PHYSIQUE D'INTENSITÉ FAIBLE (EFFORT MINIMAL)
(exemples : yoga, tir-à-l'arc, pêche, quilles, jeu de fers à cheval, golf, motoneige, marche tranquille, etc.)

A) Considérez une période d'**une semaine typique**. Combien de fois, en moyenne, vous adonnez-vous aux types d'activités physiques précédentes pendant **plus de 15 minutes** durant vos temps libres ? (Inscrivez le nombre approprié dans le cercle). ◯ fois par semaine

B) Pour environ combien de minutes faites-vous chaque session activité d'intensité faible? (Inscrivez le nombre de minutes par session sur la ligne) _____ # de minutes.

Appendix 9: The Caregiver Reaction Assessment

Caregiver Reaction Assessment

Title of the research study: **Subproject:** Formative research with spousal caregivers

Questions	*Strongly Agree*	*Agree*	*Neither Agree nor Disagree*	*Disagree*	*Strongly Disagree*
I feel privileged to care for_____.	1	2	3	4	5
Others have dumped caring for__onto me.	1	2	3	4	5
My financial resources are adequate to pay for things that are required for caregiving.	1	2	3	4	5
My activities are centered around caring for_____.	1	2	3	4	5
Since caring for____it seems like I'm tired all the time.	1	2	3	4	5
It is very difficult to get help from my family in taking care of____.	1	2	3	4	5
I resent having to care for____.	1	2	3	4	5
I have to stop in the middle of work.	1	2	3	4	5
I really want to care for _____.	1	2	3	4	5
My health has gotten worse since I've been caring for_____.	1	2	3	4	5
I visit family and friends less since I have been caring for_____.	1	2	3	4	5
I will never be able to do enough caregiving to repay_____	1	2	3	4	5

Questions	***Strongly Agree***	***Agree***	***Neither Agree nor Disagree***	***Disagree***	***Strongly Disagree***
My family works together at caring for _____	1	2	3	4	5
I have eliminated things from my schedule since caring for_____	1	2	3	4	5
I have enough physical strength to care for_____	1	2	3	4	5
Since caring for___I feel my family has abandoned me.	1	2	3	4	5
The constant interruptions make it difficult to find time for relaxation.	1	2	3	4	5
I am healthy enough to care for___.	1	2	3	4	5
Caring for___is important to me.	1	2	3	4	5
Caring for___has put financial strain on my family.	1	2	3	4	5
My family (brothers, sisters and children) left me alone to care for _____	1	2	3	4	5
I enjoy caring for_____.	1	2	3	4	5
It's difficult to pay for_____'s health needs and services.	1	2	3	4	5

French version

Instrument d'évaluation de la réaction du proche

Title of the research study: **Student subproject:** Formative research with spousal caregivers

Questions	*Totalement d'accord*	*D'accord*	*Plus ou moins d'accord*	*En désaccord*	*Tout à fait en désaccord*
Je me sens privilégié de prendre soins de_____.	1	2	3	4	5
Les autres se sont déchargés des soins de____sur moi.	1	2	3	4	5
J'ai les ressources financières adéquates pour payer pour les choses dont j'ai besoin pour m'occuper de_____.	1	2	3	4	5
Toutes mes activités sont centrées sur les soins de____.	1	2	3	4	5
Depuis que je m'occupe de___, je me sens toujours fatigué.	1	2	3	4	5
C'est très difficile d'avoir de l'aide de ma famille pour s'occuper de_____	1	2	3	4	5
Ça me déplait de soigner _____ .	1	2	3	4	5
Je dois arrêter en plein milieu de mon travail.	1	2	3	4	5
Je veux vraiment soigner	1	2	3	4	5

Questions	*Totalement d'accord*	*D'accord*	*Plus ou moins d'accord*	*En désaccord*	*Tout à fait en désaccord*
___.					
Ma santé va moins bien depuis que je soigne_____	1	2	3	4	5
Je vois moins ma famille et mes amis depuis que je prends soin de_____.	1	2	3	4	5
Je ne pourrai jamais soigner___autant que je lui dois.	1	2	3	4	5
Toute ma famille travaille ensemble pour s'occuper de_____.	1	2	3	4	5
J'ai dû éliminer des activités de mon horaire depuis que je prends soin de_____.	1	2	3	4	5
Je suis assez fort physiquement pour prendre soin de_____.	1	2	3	4	5
Depuis que je soigne_____, je sens que ma famille m'a abandonné.	1	2	3	4	5
Les interruptions constantes rendent le repos difficile.	1	2	3	4	5
Je suis assez en santé pour prendre soin de_____.	1	2	3	4	5
Prendre soin de___est important pour moi.	1	2	3	4	5

Questions	*Totalement d'accord*	*D'accord*	*Plus ou moins d'accord*	*En désaccord*	*Tout à fait en désaccord*
Prendre soin de____a eu un impact financier sur ma famille.	1	2	3	4	5
Ma famille (mes frères, sœurs, et enfants) m'ont laissé seul pour prendre soin de_____	1	2	3	4	5
Je suis content de prendre soin de____.	1	2	3	4	5
C'est difficile de payer pour les besoins et les services de santé de_____	1	2	3	4	5

Appendix 10: Consent Form for Participants Recruited Outside of the Peri-Operative Program

English version:

Research Informed Consent

Factors Associated with Physical Activity among Primary Family Caregivers of Men with Prostate Cancer.

Principal Investigator: Eric Hutt, B.Sc.
Supervising Professor: Lindsay Duncan, Ph.D.

Purpose:
We are conducting a research study to find out about the things that help or get in the way of physical activity in primary family caregivers to men living with prostate cancer, using interviews. The overall objective is to learn about the experiences of prostate cancer caregivers in relation to physical activity. Your input and ideas will help us design and adapt effective initiatives to increase physical activity motivation among cancer caregivers.

Procedures:
We are inviting you to take part in a one-on-one interview with a member of the research team. If you accept, you will meet with a member of our research team for a one-on-one interview. During the interview you will answer questions about you, your experiences caring for someone with cancer, and your experiences engaging in physical activity. If you do not wish to answer a question during the interview, you may say so. You are not required to answer any question that you do not want to. The information you share with us during the interview is confidential, and no one other than the interviewer and the McGill research team will have access it. The interview will last approximately one hour.

Audio Recording
The interview will be audio recorded to ensure that we capture your responses as accurately as possible. By signing this consent form, you are giving us your permission to be audio recorded during the interview. The information that is recorded is confidential and no one else except the interviewer and the McGill research team will have access to it.

Risks and Benefits
There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics; however, we do not wish for this to happen. You do not have to answer any question or take part in the interview if you feel the questions are too personal or if talking about them makes you feel uncomfortable.

There will be no direct benefit to you, but the information you provide will be used to help us to find out more about the things in the lives of caregivers that help or get in the way of their physical activity. Information gained from this study may be used in the development of programs to increase physical activity participation among prostate cancer caregivers. Given the

benefits of physical activity for mental and physical health, this research has the potential to have a positive effect on the stress and health of cancer caregivers.

Confidentiality and Privacy:
All of your responses will be held in confidence by the researchers. We understand that information about you or your partner's health is personal, and we are committed to protecting the privacy of that information. If you decide to be in this study, the researcher will get information that identifies you and your partner, and may include personal health details. This will include information that might directly identify you such as your name. This information will be de-identified at the earliest reasonable time after we receive it, meaning we will replace your identifying information with a unique ID code that does not directly identify you. The principal investigator (PI) will keep a link that identifies you to your coded information. This link will be kept secure (i.e., stored in a separate locked file cabinet) and available only to the PI and the project supervisor.

The interview will be transcribed and your unique ID (rather than your name) will be included on the transcript. The interview transcripts will be password-protected and saved on a computer. The research team will only give this coded information to others if it is necessary for the purposes of carrying out this research study. The link to your personal information will be kept secure for 5 years, after which time the link will be destroyed and the data will become anonymous. The data will be kept in this anonymous form indefinitely, and may be used for future studies. If you do not wish for your data to be kept, you may select the option below for your data to be destroyed after the study is complete. You can still participate if you choose for your data to be destroyed.

In this study we will collect some basic demographic information about you (i.e., your age, race, ethnicity, education, income, marital status, employment status, stage of cancer, types of treatment, and date of diagnosis).

Sharing the results
The knowledge that we gain from this research will be shared with you and the other interview participants before it is made available to the public. Each participant will receive a summary of the results. Following the distribution of the results to you and the community, we will publish the results so that other interested people may learn from the research.

Voluntary Participation:
You are free to choose not to take part in this study. The health care of your loved one outside the study, the payment for their health care, and their health care benefits will not be affected if you do not agree to participate.

If you do become a participant, you are free to stop and withdraw from this study at any time during its course. This authorization to use and disclose the health information of your loved one will never expire; however, you have the right to change your mind and revoke it. To do so, you must contact the researchers listed on this form.

Questions:
If you have any questions you can ask them now or later. If you wish to ask questions later, you may contact Eric Hutt at:

Eric Hutt
Graduate Student
Department of Kinesiology and Physical Education
McGill University
Eric.hutt@mail.mcgill.ca

If you have any questions or concerns regarding your rights or welfare as a participant in this research study, please contact the McGill Ethics Manager at 514-398-6831 or lynda.mcneil@mcgill.ca

Agreement to use Data in Future Studies (OPTIONAL):
I accept for my data to be kept indefinitely and used in future studies. I understand that my decision on this matter will not prevent me from participating in this study.

□ I accept

□ I do not accept

Agreement to Participate:
I have read the above information, have had the opportunity to have any questions about this study answered and agree to participate in this study. I also agree to be audio recorded.

_____ _____
(printed name) (date)

_____
(signature)

French version:

Formulaire de Consentement Éclairé
Titre du projet: **Primary Family Caregivers of Men with Prostate Cancer: Factors associated with physical activity.**
Investigateur principal: Eric Hutt, B.Sc.
Professeur en supervision: Lindsay Duncan, Ph.D.

But du projet :
Nous faisons une étude de recherche afin d'explorer les obstacles et éléments facilitateurs envers l'activité physique parmi les proche-aidants familiaux des hommes avec le cancer de la prostate. Nous utiliserons des entrevues pour obtenir ces informations. L'objectif principal est d'étudier les expériences de ces proches-aidants avec l'activité physique. Vos histoires, idées, et expériences nous aideront à développer des programmes et interventions afin d'améliorer les taux d'activité physique chez les proches-aidants du cancer.

Procédures :
Nous vous invitons à participer à une entrevue en personne avec un membre de l'équipe de recherche. Si vous consentez, vous seriez demandé de faire les choses suivantes :

Rejoindre un membre de l'équipe de recherche pour une entrevue individuelle. Durant l'entrevue vous serez demandé de répondre à une série de questions portant sur vous, vos expériences d'aide et support pour quelqu'un avec le cancer, et vos expériences avec l'activité physique. S'il y a des questions que vous préférez ne pas répondre, vous pouvez le dire sans conséquence, et aucune question est obligatoire. L'information partagé pendant l'entrevue est confidentielle, et aucune personne hors de l'équipe de recherche aura accès à ces informations. L'entrevue durera environ une heure.

Enregistrement audio
L'audio de l'entrevue sera enregistré afin d'assurer que nous captons vos réponses avec précision. En signant ce formulaire, vous nous donnez la permission d'enregistrer l'entrevue. L'information enregistrée est confidentielle, et aucune personne hors de l'équipe de recherche aura accès à ces informations.

Risques et bénéfices
C'est possible que vous partagez des informations personnelles et confidentielles, et que vous vous sentez inconfortable à discuter certains sujets, mais nous souhaitons éviter de telles situations. Vous n'êtes pas obligés à répondre à toutes les questions, et vous êtes libres à quitter l'entrevue à tout moment.

Il n'y aura aucun bénéfice direct pour vous, mais les informations que vous partagez lors de l'entrevue seront utilisé pour mieux comprendre les obstacles et les facteurs facilitateurs envers l'activité physique chez les proches-aidants du cancer. L'information obtenue lors de cette étude pourrait-être utilisée pour développer des interventions visant l'augmentation de l'activité physique chez les proches-aidants du cancer de la prostate. Étant donné les bénéfices connus de

l'activité physique pour la santé mentale et corporelle, c'est possible que cette étude ait un impact important dans la vie des proches-aidant en améliorant leur santé.

Protection de la vie privée et confidentialité :
Toutes vos réponses seront confidentielles. Cette confidentialité sera maintenue par les chercheurs. Nous comprenons que les informations que vous partagez sont personnelles, et nous sommes dévoué à la protection de votre vie privée. Si vous acceptez de participer à cette étude, les chercheurs vont obtenir des informations qui vous identifient ainsi que des informations portant sur votre santé et celle de votre partenaire, incluant vos noms. Ces informations seront dés-identifiées aussitôt possible. Ceci veux dire que nous assignerons un nom-code unique à toute information que vous partagerez, cachant donc votre identité. L'investigateur principal (le IP) gardera un document privé qui lie les nom-codes aux informations identifiables. Ce document sera gardé en toute sécurité, à part de l'ensemble des données. Seul le IP et le superviseur de recherche auront accès à ce document.

Votre entrevue sera transcrite et votre nom-code (au lieu de votre vrai nom) sera inclus sur la transcription finale. Ces transcriptions seront protégées par mot de passe et sauvegardées sur un ordinateur. L'équipe de recherche donneront ces transcriptions à autres personnes seulement si c'est essentiel pour les buts du projet. Le document liant votre vrai nom à votre nom-code sera détruit après 5 ans en sécurité. Après cette date, toutes les données seront complètement anonymes et gardées sous cette forme de façon permanente, et seront possiblement utilisées dans de futures études. Si vous ne voulez pas que vos données soient gardées sous cette forme, vous pouvez choisir l'option approprié à la fin de ce document pour que vos données soient détruites après l'étude. Vous pouvez toujours participer peu importe votre choix.

Lors de cette entrevue nous allons vous demander des questions démographiques générales, tel votre âge, race, genre, ethnicité, niveau d'éducation, salaire, emploi, le stage du cancer de votre bien-aimé, le type de thérapie, et la date que le diagnostic a été posé.

Partage des résultats
Les connaissances obtenues par cette étude seront partagées avec vous et les autres participants avant qu'elles soient partagées avec le public. Chaque participant recevra un résumé des conclusions. Après la distribution des données aux participants, nous allons publier les résultats, permettant autres chercheurs et personnes intéressées d'apprendre de notre étude.

Participation volontaire :
Vous êtes libre à ne pas participer dans cette étude. Le traitement médical de votre bien-aimé, les couts de leur thérapie, et leurs assurances médicales ne seront aucunement affectées par votre décision de participer ou non.

Si vous décidez de participer, vous êtes libre d'arrêter l'entrevue à tout moment et quitter l'étude sans conséquence. L'autorisation que vous nous accorder pour utiliser vos informations n'expire pas; cependant, vous pouvez en tout temps changer d'avis et de révoquer votre consentement sans conséquence. Pour faire ceci, vous devez simplement contacter les chercheurs inscrits au bas de cette formulaire.

Questions:
Pour toute question, vous pouvez en tout temps contacter Eric Hutt (le IP) :

Eric Hutt
Graduate Student
Department of Kinesiology and Physical Education
McGill University
Eric.hutt@mail.mcgill.ca

Si vous avez des questions ou inquiétudes concernant vos droits ou votre bien-être comme participant de cette étude, veuillez contact le Gérant d'Éthique de McGill au 514-398-6831 ou lynda.mcneil@mcgill.ca

Consentement d'utiliser les données dans de futures études (FACULTATIF)
J'accepte que mes données soient gardées indéfiniment et utilisées dans de futures études. Je comprends que ma décision n'affectera pas mon droit de participer dans l'étude présente.

□ J'accepte

□ Je n'accepte pas

Consentement à participer
J'ai lu les informations ci-dessus, j'ai eu une réponse à toute mes questions concernant cette étude, et j'accepte de participer. Je consente à l'enregistrement audio de l'entrevue.

_____ _____
(nom en lettres moulées) (date)

_____
(signature)

Appendix 11: Consent Form for Participants Recruited Through Peri-Operative Program

English version

INFORMATION AND CONSENT FORM

Title of the research study:	Initial usability testing of *TEMPO* - a Tailored, wEb-based, psychosocial and physical activity self-Management PrOgram
Student sub-project	Formative research with spousal caregivers
Principal investigators:	**Sylvie Lambert**, RN, PhD, Assistant Professor, Ingram School of Nursing, McGill University; Nurse Scientist, MUHC Nursing Research Centre; Research Associate, St. Mary's Research Centre
	Lindsay Duncan, PhD, Assistant Professor, Kinesiology and Physical Education, McGill University
Student Researcher	**Eric Hutt**, Graduate student, Kinesiology and Physical Education, McGill University
Co-investigators:	**John Wellesley Robinson**, Ph.D., Adjunct Associate Professor, Departments of Psychology and Oncology, University of Calgary; Clinical Psychologist, Tom Baker Cancer Centre
	Nicole Culos-Reed, Ph.D., Associate Professor, Health and Exercise Psychology, Faculty of Kinesiology, University of Calgary & Adjunct Professor, Department of Oncology, Faculty of Medicine, University of Calgary; Research Associate, Health and Exercise, Psychosocial Resources, Tom Baker Cancer Centre, University of Calgary
	Carmen G. Loiselle, R.N., Ph.D., Joint Associate Professor, Ingram School of Nursing and Department of Oncology, Faculty of Medicine, McGill; & Co-Director, Segal Cancer Centre Jewish General Hospital; Scientific Director, Hope & Cope, Jewish General Hospital
	Daniel Santa Mina, CEP, Ph.D., Assistant Professor, Faculty of Kinesiology and Physical Education, University of Toronto; Clinician-Scientist, Princess Margaret Cancer Centre, & Co-Chair Academic Advisory Committee
	Paramita Saha-Chaudhuri, M.D., Ph.D., Assistant Professor, Department of Epidemiology, Biostatistics and Occupational Health, McGill University
	Stuart Peacock, DPhil, Associate Professor, School of Population and Public Health, University of British Columbia; Co-Director, Canadian Centre for Applied Research in Cancer Control; Scientist, British Columbia Cancer Agency
	Andrew Matthew, Ph.D., Assistant Professor, Faculty of Medicine, Departments of Surgery and Psychiatry, University of Toronto; Senior Staff Psychologist, Department of Surgery, Princess Margaret Cancer Centre
	Larry Goldenberg, M.D., Professor, Department of Urologic Sciences, University of British Columbia; Director of Development and Supportive Care, Vancouver Prostate Centre
	Janet Ellis, M.D., Lecturer, Department of Psychiatry, University of Toronto; Psychiatrist and Director, Psychosocial Care in Trauma, Sunnybrook Health Sciences Centre

Anne Katz, R.N., Ph.D., Adjunct Professor, College of Nursing, University of Manitoba; Clinical Nurse Specialist, Prostate Centre, CancerCare Manitoba

Protocol number: MP-CUSM-15-179 (student sub-project)
Funder: Prostate Cancer Canada

Introduction

You are invited to participate in a clinical research study conducted by Eric Hutt, a Master's student as part of his program at McGill University, Department of Kinesiology. Throughout this project, he will be supervised by co-Principal Investigator, Dr. Lindsay Duncan. This project will help him understand the lived experiences of spousal caregivers for men living with cancer.

The present document contains detailed information about this research study. Its purpose is to explain to you as openly and clearly as possible all of the aspects of this study. Before you accept to participate in the study, please take the time to carefully read all the information below. This form may contain some words or ideas that you do not understand. If you have any questions, we invite you to ask the research assistant or investigators responsible for this study to explain anything that you find unclear. You may take this form with you and discuss the study with a person you trust before making your decision. If you decide to participate, you will be asked to sign the last page of this document (declaration of consent). A copy of this information sheet and the signed consent form will be provided to you for your records.

What is this research about?

The research team will ask between 10 and 15 spousal caregivers for men living with any form of cancer to meet with a member of our research team for a one-on-one interview to find out more about their experiences. This information will contribute to existing knowledge about caregiver health behaviours and experiences with physical activity.

Who can participate in this study?

We are recruiting 10-15 **spousal** caregivers of men with **any form** of cancer

Caregivers are eligible if they:

- Have been identified by the patient as his primary source of support or self-identify as the primary caregiver;
- Have not been diagnosed and have not undergone treatment for cancer in the previous year; and
- Have not previously had any education program to help them manage their caregiving role;
- Engage in less than 150 minutes of moderate-to-vigorous physical activity per week.
- Are aged 50 years or older.

Caregivers will be recruited from the McGill University Health Centre (MUHC).

What are you being asked to do?

1. Consenting caregivers will be asked to meet in person or over the phone with student researcher, Eric Hutt or, and participate in a 60-90

minute audio-recorded interview about their experiences and thoughts about being a caregiver and about their physical activity.
2. Caregivers will also be asked to fill out 2 questionnaires about themselves and their experiences as a caregiver.

How much time will it take?

- Entire duration of study participation: Approximately 60-120 minutes for the questionnaires and interview.

What are the benefits of participating?

You may benefit from participating in this research study, but we cannot guarantee it. The information collected will contribute to our understanding of how caregivers manage the challenges they face and the factors associated with their physical activity behaviours. Also, the information you provide will be used to develop recommendations that may guide cancer organisations as they refine their support services in the future.

What are the risks of participating?

This study does not involve any drugs, blood tests, or physical examination. Therefore, it is expected that you will face minimal risks during this study. During the interviews, you may feel discomfort in openly expressing your opinions to strangers. We only expect you to say what you feel comfortable sharing. You may withdraw from the study at any time. If you have any concerns about participating, we advise you to contact the research team or your doctor. The Canadian Cancer Society also has a helpline that can provide you with any additional support you may need (1-888-939-3333).

What choice do you have?

Your participation in this study is voluntary. Therefore, you may refuse to participate. You may also withdraw from the ongoing project at any time, without giving any reason, by informing either the student researcher or his supervisor (L. Duncan). Your decision not to participate in the study, or to withdraw from it, will have no impact on the quality of care and services to which you are otherwise entitled. You will be informed in a timely manner if any information becomes available that may impact your willingness to continue participating in this study. If you withdraw or are withdrawn from the study, the information already collected about you during the study will be destroyed if it can be identified as yours. If the data has been anonymized or was always anonymous (e.g. does not contain any information that can be used to identify you), the data will continue to be used in the analysis of the study

How will your privacy be protected?

During your participation in this study, the research team will collect and record information about you in a study file. We will only collect the information required to meet the study's scientific goals. All the information collected during this study will remain confidential to the extent provided by law. For auditing purposes your study file may be examined by individuals mandated by the funder, the McGill University Health Centre, or the Research Ethics Board. All these individuals adhere to policies on confidentiality. To protect your identity and the

confidentiality of your personal information, you will only be identified by a code number. The key to the code linking your name to your study file will be kept by the researcher in charge of this study. All study data will be kept for seven years and the destroyed.

All audio-recordings will be transcribed (your words will be written down) in a de-identified fashion (i.e. your name will not appear in the transcripts). The audio-recordings will then be destroyed. It is possible that direct quotes of what you said will be presented in publications and/or conferences. However, precautions will be taken to ensure that it will not be possible identify you.

According to the Quebec *Act respecting Access to Documents held by Public Bodies and the Protection of Personal Information, R.S.Q., chapter A-2.1*, you have the right to consult your study file to verify the information or to have it corrected, if necessary. You may use this right as long as the principal investigator or the institution holds this information. However, to protect the scientific integrity of the research study, there may be certain information that you can only access after this study has ended.

Who is funding this research study?

The larger study is funded by Prostate Cancer Canada.

Is there compensation for participating?

Your participation in this study should not result in any extra costs to you. Given the short nature of the study, there is no compensation for participating.

How will the information collected be used?

The information collected will contribute to overall knowledge about caregiver health behaviours and experiences. The results of this study may be presented at scientific meetings or published in medical journals, but your identity or any other identifying information will not be revealed in any publication or report.

If you would like a summary of the results mailed to you at the end of the study, please indicate this on your consent form.

If I want more information, who should I contact?

If you have questions about the study please contact: Principal investigator and student researcher supervisor, Dr. Lindsay Duncan, at 514-398-4184 ext. 0919 or by e-mail: lindsay.duncan@mcgill.ca, or the student researcher Eric Hutt, at 514-398-4184, ext. 0481, or by e-mail at eric.hutt@mail.mcgill.ca

If you have a problem or question about your rights while taking part in this study or if you have comments or want to file a complaint, please contact the Hospital Complaint Commissioner/

Ombudsman: 514 934 1934 Pascale Valois, ext. 44285, Montreal General Hospital or Daniele Thibodeau, ext. 35655, Glen/Royal Victoria Hospital.

E-mail: ombudsman@muhc.mcgill.ca

Mail: MUHC Office of the Ombudsman, 1650 Cedar Room E6.164, Montreal, Qc H3G 1A4.

Oversight of the ethical aspects of the research study
The Research Ethics Board (REB) of the MUHC approved this research study and is responsible for monitoring it. Any change or amendment made to the research protocol or to the information and consent form must first be approved by the MUHC REB.

Student subproject: Formative research with spousal caregivers

I. Participant's statement of consent
I have reviewed the information and consent form. I acknowledge that the research study was explained to me, that I am satisfied that my questions were answered, and that I was given enough time to make a decision.

I agree to participate in this research study according to the conditions stated above, including having my interviews audio-recorded. I authorize the research team to collect and use my personal information for the purpose of this study and in the manner mentioned above.

Please note that this study does not replace the care and advice you receive from your doctor.

Name *(please print)*:
_____

Signature: _____ Date:
_____

Mailing address:
_____

_____
_____

E-mail: _____ Telephone (optional):
_____

The best time to contact me: *Day:* _____ *Time:*
_____

Would like a copy of the summary of the results to be mailed to you, on completion of this project? (Please indicate your answer with an 'X'.) □ Yes □ No

Our team has several planned and ongoing studies involving cancer caregivers.
Would you like to be contacted in the future regarding these studies? □ Yes □ No

For use by the research team

II. Signature of the person who obtained consent, if different from the study investigator

I have explained the terms of the present information and consent form to the research participant and I answered all his/her questions.

_____

Name and signature of the person who obtained consent Date

III. Signature and commitment of the researcher in charge of the study

I hereby certify that the terms of the present information and consent form were explained to the research participant, that any questions the participant had were answered and that it was clearly indicated that he/she remains free to withdraw from the study, without suffering any prejudice.

I undertake, together with the research team, to respect what was agreed upon in the information and consent form and to give a signed copy of this form to the research participant.

_____

Name and signature of the researcher in charge of the study Date

French version

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

Titre de l'étude	Test initial de la facilité d'utilisation du programme *TEMPO*
Sous-projet étudiant :	Recherche formative avec des conjoints proches aidants
Chercheuses principales :	**Sylvie Lambert**, inf., Ph. D., professeure adjointe, École de sciences infirmières Ingram, Université McGill; chercheuse en sciences infirmières, Institut de recherche du CUSM; chercheuse associée, Centre de recherche de St. Mary **Lindsay Duncan**, Ph. D, professeure adjointe, kinésiologie et éducation physique, Université McGill
Chercheur étudiant	**Eric Hutt**, étudiant à la maîtrise, kinésiologie et éducation physique, Université McGill
Co-chercheurs:	**John Robinson**, Ph. D, professeur agrégé, départements de psychologie et oncologie, University of Calgary; psychologue clinicien, Tom Baker Cancer Centre **Nicole Culos-Reed**, Ph. D, professeure agrégée, kinésiologie et psychologie de l'éxercice, University of Calgary et professeure adjointe, départment d'oncologie, faculté de médecine, University of Calgary; chercheuse associée, Tom Baker Cancer Centre **Carmen Loiselle**, Ph. D, professeure adjointe, École de sciences infirmières Ingram et département d'oncologie, Université McGill; co-directrice, Segal Cancer Centre, Hôpital général juif; directrice scientifique, L'espoir c'est la vie, Hôpital général juif **Daniel Santa Mina**, PEC-SCPE, Ph. D, professeur adjoint, kinésiologie et l'education physique, University of Toronto; clinicien-chercheur, Princess Margaret Cancer Centre **Paramita Saha-Chaudhuri**, Ph. D, professeure adjointe, épidémiologie, biostatistique et santé au travail, Université McGill **Stuart Peacock**, Ph. D, professeur agrégé, l'école de la population et le santé publique, University of British Columbia; co-directeur, Canadian Centre for Applied Research in Cancer Control, chercheur, British Columbia Cancer Agency **Andrew Matthew**, Ph. D, professeur adjoint, départements de chirugerie et psychiatrie, University of Toronto; psychologue principal, Princess Margaret Cancer Centre **Larry Goldenberg**, M.D., professeur titulaire, urologie, département des sciences urologiques, University of British Columbia; directeur, Vancouver Prostate Centre **Janet Ellis**, M.D., professeure, département de psychiatrie, University of Toronto; psychiatre et directrice, Sunnybrook Health Sciences Centre **Ann Katz**, inf., Ph.D, professeure agrégée, école des infirmières, University of Manitoba; infirmière clinicien spécialisée, Prostate Centre, CancerCare Manitoba
Numéro de protocole	MP-CUSM-15-179
Financement:	Prostate Cancer Canada

Introduction
Vous êtes invité à participer à une étude de recherche clinique menée par Eric Hutt, un étudiant à la maîtrise en kinésiologie de l'Université McGill. Professeure Lindsay Duncan supervisera cette étude Le projet, qui fait partie des exigences du programme de sa maîtrise l'aidera à comprendre les expériences vécues des proches aidants (conjoints-es) pour les hommes vivant avec un cancer.

Afin de nous orienter dans le développement du programme, nous souhaitons mieux comprendre les expériences des proches aidants d'hommes atteint de n'importe quel type de cancer.

Ce document comporte des renseignements détaillés sur cette étude. Il vise à vous expliquer le plus clairement possible tous les aspects de cette étude. Avant d'accepter de participer à l'étude, veuillez prendre le temps de lire attentivement toutes les informations ci-dessous. Ce formulaire comprend peut-être des mots ou des idées que vous ne comprenez pas. Si vous avez des questions, n'hésitez pas à les poser à l'adjoint de recherche ou aux chercheurs responsables de cette étude afin qu'ils vous expliquent tout ce qui n'est pas clair pour vous. Vous pouvez apporter ce formulaire afin de discuter de l'étude avec une personne en qui vous avez confiance avant de prendre votre décision. Si vous décidez de participer, on vous demandera de signer la dernière page de ce document (déclaration de consentement). Une copie de cette feuille de renseignements et du formulaire de consentement signé vous sera remise pour vos dossiers.

Sur quoi porte cette recherche?
L'équipe de recherche compte demander entre 10 à 15 proches aidants d'hommes atteints de tout type de cancer de rencontrer un membre de l'équipe pour une entrevue individuelle afin de mieux comprendre leurs expériences. Ces informations contribueront aux connaissances actuelles portant sur les comportements de santé des proches aidants ainsi que leurs expériences avec l'activité physique.

Qui peut participer à cette étude?
Nous sommes en train de recruter 10 à 15 proches aidants partenaires d'un homme atteints d'un cancer.

Les proches aidants sont admissibles si :

- Ils ou elles ont été identifiés par le patient (ou par eux-mêmes) comme sa principale source de soutien;
- Ils ou elles n'ont pas reçu un diagnostic de cancer et des traitements pour le cancer au cours de l'année précédente;
- Ils ou elles n'ont pas suivi un programme d'éducation pour les aider à gérer leur rôle de proche aidant; et
- Ils ou elles bénéficient de moins de 150 minutes d'activité physique modérée ou vigoureuse par semaine
- Ils ou elles sont âgés de 50 ans ou plus.

Les participants seront recrutés au Centre universitaire de santé McGill

(CUSM).

Qu'est-ce que nous vous demandons de faire?

1. Les proches aidants consentant devront rencontrer le chercheur étudiant, Eric Hutt, pour une entrevue enregistrée de 60 à 90 minutes portant sur leurs expériences et ce qu'ils pensent de leur rôle comme proche aidant et leur activité physique. L'entrevue aura lieu en personne ou par téléphone.

2. Les conjoints proches aidants devront également compléter deux questionnaires portant sur eux-mêmes et leurs expériences comme proche aidant.

Combien de temps cela prendra-t-il?

- Durée totale de la participation à l'étude : environ 60 à 120 minutes pour compléter le questionnaire et l'entrevue.

Quels avantages y a-t-il à participer?

Vous pourriez bénéficier de votre participation à cette étude, mais nous ne pouvons pas le garantir. L'information recueillie contribuera à nos connaissances portant sur les façons utilisées par les proches aidants pour mieux composer avec les défis auxquels ils font face, ainsi que les facteurs associés avec leurs comportements d'activité physique. De plus, les renseignements que vous fournirez serviront à mettre au point des recommandations qui orienteront peut-être les organismes à l'œuvre dans le domaine du cancer dans leurs démarches pour offrir de meilleurs services de soutien dans l'avenir.

Quels sont les risques?

Cette étude n'implique aucune prise de médicament, aucune analyse sanguine ni aucun examen clinique. On s'attend donc à ce que les participants soient exposés à des risques minimes. Durant l'entrevue, vous pourriez vous sentir mal-à-l'aise à partager vos expériences avec un étranger. Vous devriez partager que ce dont vous vous sentez capable de dire sans vous sentir inconfortable. Vous pourrez vous retirer de l'étude en tout temps. Si vous avez des inquiétudes au sujet de votre participation, nous vous conseillons de communiquer avec l'équipe de recherche ou votre médecin. La Société canadienne du cancer dispose également d'un service d'assistance téléphonique qui peut vous offrir le soutien additionnel dont vous pourriez avoir besoin (1-888-939-3333).

Ai-je le choix?

Vous êtes entièrement libre de participer à cette recherche ce qui signifie que vous pouvez refuser d'y participer. Vous pouvez aussi vous retirer de l'étude en tout temps, sans avoir à donner de raison, en informant soit l'étudiant chercheur ou son superviseur (L. Duncan). Votre décision de ne pas participer ou de vous retirer n'affectera pas la qualité des soins et des services auxquels vous avez droit. On vous informera en temps opportun si des informations disponibles

sont susceptibles d'avoir une incidence sur votre volonté de continuer à participer à cette étude. Si vous vous retirez de l'étude, les informations déjà recueillies à votre sujet seront détruites si nous pouvons les identifier comme étant à votre propos. Si les données ont été dépersonnalisées ou ont toujours été anonymes (ex. ne contiennent pas d'information qui puisse vous identifier), elles continueront d'être utilisées à des fins d'analyse.

Comment la protection de votre vie privée sera-t-elle assurée?

Tout au long de votre participation à cette étude, l'équipe de recherche recueillera et enregistrera des informations dans un dossier de recherche. Nous recueillerons uniquement les informations requises pour atteindre les objectifs scientifiques de l'étude. Toutes les informations recueillies durant l'étude demeureront confidentielles dans les limites permises par la loi. Pour des fins de vérification, votre dossier de recherche pourrait être examiné par des personnes mandatées par le commanditaire, le Centre universitaire de santé McGill ou le Comité d'éthique et de recherche. Toutes ces personnes adhèrent aux politiques de confidentialité. Afin de protéger votre identité et la confidentialité des renseignements, vous serez identifié par un numéro de code. La clé du code qui fait le lien entre votre nom à votre dossier sera conservée par le chercheur responsable de cette étude. Toutes les données seront conservées pendant sept ans puis, seront détruites. Tous les enregistrements audio seront transcrits (vos mots seront écrits) en mode dépersonnalisé (c.-à-d. votre nom n'apparaitra pas sur les transcriptions). Les enregistrements audio seront ensuite détruits. Il est possible que des phrases que vous avez dites soient citées dans des publications et/ou des congrès. Cependant, nous prendrons des précautions pour que vous ne puissiez être identifié.

Selon la *Loi du Québec sur l'accès aux documents des organismes publics et sur la protection des renseignements personnels, L.R.Q. chapitre A-2.1*, vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis à votre sujet et les faire rectifier au besoin, et ce, aussi longtemps que la chercheuse responsable du projet de recherche ou l'établissement détient ces informations. Cependant, pour préserver l'intégrité scientifique de la recherche, vous pourriez n'avoir accès à certaines de ces informations qu'une fois l'étude terminée.

Qui finance cette étude?

Prostate Cancer Canada

L'étude est financée par Cancer de la prostate Canada.

La participation au projet est-elle rémunérée?

Votre participation à cette étude ne devrait entraîner aucun coût supplémentaire pour vous. Étant donné la nature courte de l'étude, il n'y a aucune compensation pour la participation.

Comment les renseignements colligés seront-ils utilisés?
Les renseignements colligés contribueront aux connaissances générales concernant les comportements de santé des proches aidants et leurs expériences. Les résultats de cette étude pourraient être présentés lors de congrès ou publiés dans des revues médicales, mais votre nom ou toute autre information vous identifiant ne sera pas révélé dans quelque publication ou rapport que ce soit.

Si vous désirez qu'un résumé des résultats vous soit posté à la fin de l'étude, veuillez l'indiquer sur le formulaire de consentement.

Si je veux en savoir plus, avec qui dois-je communiquer?
Si vous avez des questions au sujet de l'étude, veuillez communiquer avec la chercheuse principale, Lindsay Duncan, au 514-398-4184, poste 0919, ou par courriel : lindsay.duncan@mcgill.ca, ou le chercheur étudian, Eric Hutt, au 514-398-4184, poste. 0481, ou par courriel au eric.hutt@mail.mcgill.ca

Pour tout problème ou toute question concernant vos droits en tant que participant à ce projet de recherche ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec le commissaire aux plaintes / ombudsman de l'hôpital : 514 934 1934, Pascale Valois, poste 44285, Hôpital général de Montréal.
Courriel : ombudsman@muhc.mcgill.ca

Par la poste : Bureau de l'Ombudsman du CUSM, 1650 Cedar, bureau E6.164, Montréal, QC H3G 1A4.

Supervision des aspects éthiques de l'étude
L'approbation de ce projet de recherche et son suivi incombent au Comité d'éthique de la recherche du CUSM. De plus, ce dernier approuvera au préalable toute révision et toute modification apportée au protocole de recherche ou au formulaire d'information et de consentement.

Sous-projet : Recherche formative avec des conjoints proches aidants

Pour les besoins du présent document, il est entendu que le masculin comprend le féminin.

I. Déclaration de consentement du participant

J'ai bien pris connaissance du formulaire d'information et de consentement. Je reconnais que l'étude m'a été expliquée, qu'on a répondu à ma satisfaction à toutes mes questions et que j'ai eu assez de temps pour prendre une décision.

J'accepte de participer à cette étude selon les conditions énoncées ci-dessus, ce qui comprend le fait que les entrevues seront enregistrées. J'autorise l'équipe de recherche à colliger et à utiliser des renseignements me concernant pour les finalités de la recherche et de la manière décrites ci-dessus.

Veuillez noter que cette étude ne remplace pas les soins et les conseils que vous recevez de votre médecin.

Nom *(en caractères d'imprimerie svp) :*
_____

Signature: _____ Date:
_____

Adresse postale:
_____

_____

Courriel: _____ Téléphone (facultatif): _____

Le meilleur moment pour me joindre : *Jour :*_____ *Time:* _____

Aimeriez-vous recevoir par la poste une copie du résumé des résultats, une fois le projet terminé? (Veuillez indiquer votre réponse à l'aide d'un 'X'.) □ Oui □ Non

Notre équipe développe plusieurs autres études portant sur les proches aidants. Aimeriez-vous que nous vous contactions dans le futur pour ces études? □ Oui □ Non

À l'intention de l'équipe de recherche :

II Signature de la personne qui a obtenu le consentement si c'est quelqu'un d'autre que le chercheur

J'ai expliqué au participant les conditions de l'étude et le formulaire de consentement et j'ai répondu à toutes ses questions.

_____

Nom et signature de la personne qui a obtenu le consentement Date

III. Signature et engagement du chercheur responsable de l'étude

Je certifie par la présente que les conditions de l'étude et le formulaire de consentement ont été expliqués au participant, qu'il a reçu des réponses à toutes ses questions et qu'il lui a été clairement expliqué qu'il demeure libre de se retirer de l'étude, sans subir quelque désavantage que ce soit.

Je m'engage, tout comme l'équipe de recherche, à respecter ce qui a été convenu dans le formulaire d'information et de consentement et à remettre une copie signée de ce formulaire au participant.

_____

Nom et signature du chercheur responsable de l'étude Date

Appendix 12 : Visual Representation of Three Highest Data Categories