

Caregivers of long-term cancer survivors: The role leisure plays in  
improving psychological well-being

by

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### **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## **Abstract**

Cancer rates are on the rise and there is also an increase in the number of cancer survivors. This results in an increase of caregivers for those survivors. Many caregivers experience negative impacts of caregiving, including decreased mental health. The purpose of this study is to gain an understanding of how the fulfillment of leisure needs impacts caregivers' mental health. Using data from *The Cancer Support Person's Unmet Needs Survey* (Campbell et al., 2009), secondary data analysis was conducted to examine the relationship between unmet leisure needs and mental health, as well as examining the mediation of social and physical aspects of leisure. The sample consisted of 718 support persons (self-selected by the survivors, who were asked to give their caregivers the survey) from the Cancer Registry run by CancerCare Manitoba. Results revealed that fulfilling leisure needs decreased level of caregiver depression, anxiety, and stress. Fulfilling social needs showed a decrease in caregiver depression, and having higher levels of physical functioning had a positive impact on caregiver's level of depression, anxiety, and stress. This study provided practical applications for practitioners and caregivers on how to improve caregiver mental health through the fulfillment of leisure needs.

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## **Chapter 1: Introduction**

Statistics show cancer rates are on the rise. Approximately 33% of males and 25% of females will get cancer before the age of 75 (Hodgkison et al., 2007). The number of people alive after being diagnosed with cancer has greatly increased over the past decades (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Improvements in cancer detection, diagnostic procedures, advancements in cancer treatment, and improved clinical management have resulted in improved survival rates, and the number of cancer survivors is expected to continue to increase (Hagedoorn et al.; Hodgkison et al.; Sanson-Fisher et al., 2000). The aging population, as well as an increase in life expectancy, also results in an increased number of survivors (Campbell, 2009; Hagedoorn et al.). Although there has been extensive research around cancer patients' and caregivers' quality of life during diagnosis and treatment, there is limited research on the experiences and needs of patients post-treatment or on those providing support to long-term survivors.

These high survival rates have lead cancer to be regarded as a chronic disability, similar to other health and psychosocial concerns (Campbell, 2009). Along with many physical limitations, cancer survivors may also experience many psychological issues including poor emotional well-being, anxiety, and depression (Campbell, 2009; Bedini & Guinin, 1996a). Bedini (2002) reports that two out of every three caregivers experience depression since taking on caregiving responsibilities.

Cancer is a major stressor in the lives of cancer survivors as well as the caregivers involved in the coping and support process. Because of increased survival rates and a greater life expectancy, quality of life is important for both patients and caregivers. Quality of life can be impacted by stress and emotional distress (Hagedoorn et al., 2008). Caregivers often provide

primary emotional support to survivors. Kim et al. (2008) explains that cancer survivors' and caregivers' psychological distress are related, indicating that if a caregiver is experiencing distress, it could impact the level of distress of the one they are supporting. Kim et al. goes on to explain that increased psychological distress among the caregiver may lead to them being less resourceful, impacting the level of emotional support they are able to provide. Therefore, psychological distress and decreased quality of life in a caregiver can have adverse effects on the quality of life of the survivor.

Leisure may play an essential role in the lives of cancer survivors and their caregivers because leisure can improve physical and emotional health (Campbell et al., 2009; Bedini, 2002). Understanding unmet leisure needs of survivors, as well as caregivers, and how to fulfill them is important to improve their quality of life post-cancer. Caregivers are an important part of the life of a cancer survivor, and studies show that they will impact the cancer survivors' quality of life (e.g. Cameron, Franche, Cheung, & Stewart, 2002; Given, Given, & Kozachik, 2001; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). For my research, I will be focusing on caregivers of long-term cancer survivors (one to five years post-diagnosis) and will explore the role that leisure plays in their lives.

Looking at how leisure improves psychological well-being for caregivers, I will investigate various aspects that promote increased quality of life. Extensive research has been done on the needs of cancer patients and their caregivers while in treatment (e.g. Nijboer et al., 2001; Sharpe, Butow, Smith, McConnell, & Clarke, 2005), but very few studies have focused on the needs of long-term survivors and their primary support persons. Hodgkinson et al. (2007) has reported that caregivers are still providing support well after the patient's active treatment is complete. Research conducted by Campbell et al. (2009) focused on the needs of support persons

within 5 years of diagnosis. This research determined that during this period, survivors are perceived to continue to feel stressed, and that this is also likely to occur for those who support them. Long-term cancer survivors and their caregivers still experience unmet needs and challenges in their lives and it is important to explore them to help understand how practitioners can better fulfill these needs through programming and services.

### **1.1 Significance**

Examining the effects that leisure plays in improving quality of life for caregivers' of long-term cancer survivors will be of value to the advancement of the field of therapeutic recreation. Therapeutic recreation is a field of study which promotes leisure participation to achieve positive benefits gained through this participation (Caldwell, 2005) and is described as a "purposeful intervention designed to help clients grow and to assist them to relieve or prevent problems through recreation and leisure" (Austin & Crawford, 2001, p. 45). One study found that caregivers viewed leisure as a privilege rather than a right and participation was a low priority (Bedini & Guinan, 1996a). Bedini and Guinan (1996b) found that caregivers stated that caregiving responsibilities required changes in their leisure. These studies may provide insights to the benefits of leisure and why it is important for caregivers to engage in recreation and leisure activities.

As there has been little research with caregivers of long-term cancer survivors, my research will be of significance to gain a better understanding of how to work with this population. In addition, with increased survival rates, this topic has immediate and lasting social relevance. As the rate of cancer, as well as cancer survivors, is on the rise, having an understanding of the needs of those who care for them will help to improve caregivers' psychological well-being and quality of life, which in turn may have an impact on the survivors'

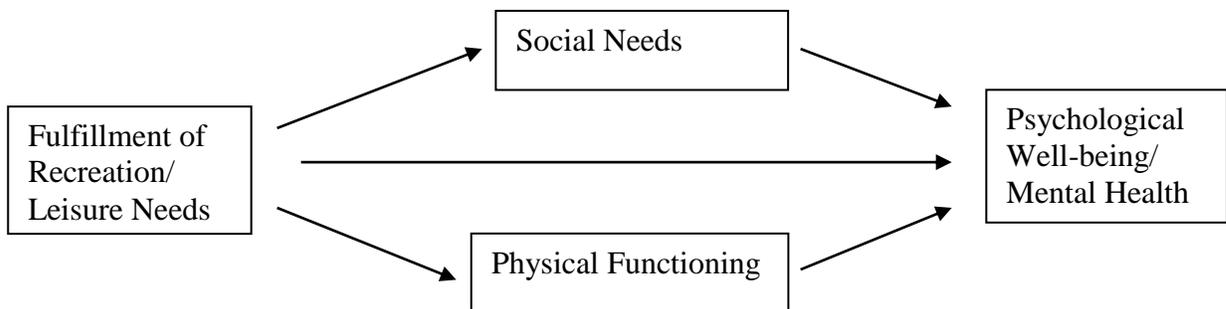
well-being. It is also important to study the needs of caregivers so that practitioners can know where there are unmet needs and how to provide services that will help to fulfill these needs based on the efficacy of these interventions. Caregivers are an important population to study because often times their needs may be disregarded or come second to the needs of the cancer survivor.

Overall, there is much that needs to be discovered about the needs of caregivers because their health and well-being can have an important role in the lives of those whom they support and also to decrease the potential for caregiver burnout. As the population ages and the number of cancer survivors increase, it is becoming increasingly important to meet the needs of caregivers (Roth, Clay, Madan, Mittelman, & Haley, 2005) and discover strategies that potentially impact psychopathology related to a diagnosis of cancer. Understanding the role of leisure and how meeting leisure needs for caregivers offers the opportunity to provide insight on the relationship between caregiving, health, and leisure (Bedini & Guinan, 1996a). Studies have linked caregiver stress specifically to reduced leisure time (Bedini, 2002; Ory et al., 1999; King et al., 2000), so the fact that the absence of leisure can cause a negative impact to the health of caregivers' shows it is of great significance that caregiver leisure needs be explored.

## **1.2 Purpose Statement**

The purpose of this study is to gain an understanding of the recreation/leisure needs of caregivers of long-term cancer survivors and explore how the fulfillment of leisure needs influences psychological well-being. Specifically, I intend to study the role of meeting recreation/leisure needs in cancer survivors' primary caregivers, looking at the role leisure and quality of life post-cancer. Exploring the relationship between recreation/leisure needs and psychological well-being, I will seek to understand how social and physical aspects may explain

any association found between satisfaction of recreation and leisure needs and psychological well-being. The social aspects under examination are fulfilling social needs and the physical aspects include physical functioning and caregiver health. I expect that meeting social needs and having increased physical functioning will have a positive impact on the leisure/well-being relationship and promote increased psychological well-being. I will explore which aspect (social or physical) has a greater impact on this relationship and the extent to which fulfillment of one, or both, impacts psychological well-being. The nature of these relationships is depicted in Figure 1.



**FIGURE 1.** Nature of Association - the relationship between fulfillment of recreation/leisure needs and how social needs and physical functioning will mediate this relationship.

### 1.3 Definitions

#### 1. Caregivers

Walker, Pratt, and Eddy (1994) define caregivers as a person who provides aid and assistance past that required as normal everyday life and explain that the criterion for the requirement of a caregiver is the dependence on another person for any activity that is essential for daily living. Primary caregivers provide a significant amount of primary care, physical and

emotional support (Campbell, 2009), and they are typically spouses, adult children, relatives and friends.

## **2. Long-term Cancer Survivor**

Campbell et al. (2009) has defined a long-term cancer survivor as an individual who is one to five years post diagnosis of cancer.

## **3. Unmet Needs**

Unmet needs have been defined as “a problem or concern for which a person is unable to get the help they need to resolve the problem” (Campbell, 2009, p. 12a) and are “the requirement for some desirable, necessary or useful action to be taken or some resource to be provided, in order for the person to attain optimal well-being” (Campbell, 2009, p. 12d). For this study, unmet leisure needs are defined as a primary caregiver not dedicating time for themselves and not having time to relax or to do things that make them happy.

## **4. Social Aspects**

For the purpose of this study, social aspects of caregivers will be their social needs. Social needs involve having social support, which will be determined as to whether the caregivers feel they have emotional support from friends and family (e.g. being able to tell family and friends how they are feeling emotionally). Also, social needs include meaningful social relationships, which is whether the caregivers feel they have enough time to see their family and friends and may include spending time with others in a leisure activity.

## **5. Physical Aspects**

Physical aspects include the caregiver’s physical functioning. Physical functioning refers to physical functional capacity during daily activities and functional well-being, as well as the

caregiver's level of energy and fatigue. Physical aspects are achieved through physical leisure activities, such as exercise.

## **6. Psychological Well-being (mental health)**

For the purpose of this study, psychological well-being will be a self-reported measure of depression, anxiety, and stress.

## **7. The Propel Centre**

I will be using surveys developed by the Propel Centre for Population Health Impact, which have been completed by primary caregivers' of cancer survivors. Researcher Sharon Campbell of the Propel Centre for Population Health Impact (a partnership between the Canadian Cancer Society and the University of Waterloo) and Propel staff have developed instruments to measure the unmet needs of cancer survivors and their support persons. I intend to analyse the results from the data sets of the study *The Cancer Support Person's Unmet Needs Survey* (Campbell et al., 2009) to explore my research questions.

## 1.4 Questions/Hypotheses

I am using a deductive approach and the research questions I intend to examine are:

1. What is the relationship between meeting leisure needs and psychological well-being of the caregiver of a long-term cancer survivor?
2. To what extent is the association of meeting recreation/leisure needs and psychological well-being explained by (i.e. mediated by) the ability to meet social needs and physical functioning?

My expectations can be described by the following three hypotheses:

*HYPOTHESIS 1:* Meeting leisure needs will be positively associated with increased psychological well-being.

*HYPOTHESIS 2:* Fulfilling social needs will be positively associated with psychological well-being.

*HYPOTHESIS 3:* Fulfilling physical functioning will be positively associated with psychological well-being.

I expect that meeting social needs and physical functioning will have a positive association with psychological well-being. I plan to examine whether meeting social needs has a greater impact on promoting psychological well-being than physical functioning, or vice-versa, and what the impact of meeting both of these needs is. From a therapeutic recreation perspective, it would be beneficial to determine which aspect will have a greater impact on psychological well-being for this population and which pursuits seem to be more effective, so that programming can better improve mental health and quality of life.

## **Chapter 2: Literature Review**

In this section I will review various articles that explore the variables in this study. The variables are fulfillment of recreation/leisure needs (therapeutic benefits of leisure participation), social aspects, physical aspects, and psychological well-being. First, statistics and experiences, as well as the impact that caregiving may have on an individual, will be explored. Then the relationship between recreation and leisure participation and psychological well-being is discussed, as well as how fulfillment of both social needs and physical functioning promote mental health.

### **2.1 Cancer Statistics**

In 2008, there were approximately 12.7 million cancer cases reported worldwide (Jemal et al., 2011). Breast cancer was the most frequently diagnosed cancer among females, and was also the leading cause of cancer death among females. Among males, the most frequently diagnosed cancer, as well as the leading cause of cancer death, was lung cancer (Jemal et al., 2011). The North American Association of Central Cancer Registries projected that a total of 1,638,910 new cases of cancer will occur in 2012 in the United States (Siegel, Naishadham, & Jemal, 2012). Statistics show that the probability of developing cancer increases with age (Siegel et al., 2012) and those aged 60 to 79 have the greatest chance (Jemal, Seigel, Xu, & Ward, 2010). Males are also more likely to develop cancer (Jemal, Seigel, Xu, & Ward, 2010). It has been reported that over the past 10 years, cancer death rates have declined by more than 1% each year (Siegel et al., 2012). It is also noted that there have been sizeable improvements since 1975 in the relative 5-year survival rate for most cancers. Five-year survival rates for all cancers combined from 1975-1977 was 49%; from 1987-1989 it was 56%; and the survival rate from 2001-2007 was 67% (Siegel et al., 2012).

## **2.2 Experience of Cancer Survivors and their Caregivers**

Caring for someone who has been diagnosed with cancer is a unique experience because of the type of care needed based on the trajectory of the illness. Patients may experience multiple symptoms of varying severity and require complex treatment regimens (Given, Given, & Sherwood, 2012).

Following a cancer diagnosis, there is a sudden need for diagnostic and treatment decisions, as well as active involvement by the patient and family members (Given et al., 2012). Because a cancer diagnosis is often sudden, family members are usually unprepared to take on the role of caregiver and have little time for preplanning. Caregivers take on their role immediately and continue throughout the treatment and survivorship stages of the disease (Given et al., 2012).

There is a substantial increase in caregiver burden and depression when the patient has reached a terminal stage of the illness (Grunfeld et al., 2004). Grunfeld et al. (2004) also reports that there are measurable unmet needs for caregivers at early stages of the patient's illness, noted from the large amount of caregivers experiencing anxiety and depression.

Emotional factors can predict caregiver distress (Grunfeld et al., 2004). A cancer diagnosis can be a very emotional experience for an individual as well as for their family. This is due in part to society's negative view of the dreaded word "cancer," as well as the understanding that cancer treatment may be a long, emotional and painful experience. Many variables come in to play during the disease trajectory, such as multiple disease or treatment related symptoms, whether the patient is in a curative phase or palliative phase of treatment, and the patient's response and performance to treatment (Valeberg & Grov, 2012).

While emotional distress impacts caregivers, perceived burden is the largest predictor of caregiver anxiety and depression (Grunfeld et al., 2004). Roles of caregivers to cancer survivors include symptom, medication, and equipment management. Direct care demands include areas such as “physical care, nutrition, spiritual support, symptom management, housekeeping, transportation, and financial support” and care can also include activities such as “wound care, management of infusion pumps, and catheter care” (Given et al., 2012, p. 58). Caregivers are extremely important in coordinating treatment and in the patient’s plan of care.

Given et al. (2012) reports that caregivers continue to assist patients well after initial diagnosis and the active care phase. Role strain and burden can still be present after 12-24 months. Caregivers of long-term cancer survivors may not be actively providing direct care demands, but may still experience an interruption in daily activities or time spent in leisure activities. They may also still be providing financial, emotional, and social support to their care-receiver.

### **2.3 Impacts of Caregiving**

Caregiving has been proven to be a chronic stressor and can lead to financial problems, and physical and psychological health issues (Clipp & George, 1993). Among these issues, specific negative impacts include “increased levels of depression, anxiety, poor perceived health, increased health care utilization, and conflict between caregivers and other family members” (Strawbridge, Wallhagen, Shema, & Kaplan, 1997, p. 505). Haley, Levine, Brown, and Bartolucci (1987) report that numerous studies have found that the high levels of stress experienced by caregiving can result in feelings of burden, social isolation, depression, and health problems. Caregivers have been identified to be in a “high risk category” for physical and psychological ailments because of the stress of their responsibilities (Bedini & Guinam, 1996b).

Bedini and Guinam further explain that caregivers perceive their physical health to be negatively impacted by the responsibilities of caregiving, have experienced negative self-concept, and score high on ratings of depression.

Caregiving has been shown to decrease the amount of time spent in leisure activities among those with caregiving responsibilities (Bedini & Guinan, 1996b; Bedini, 2002). It has been found that there is a decrease in both physical and social leisure pursuits. Leisure time is lost because caregivers give up this time to provide care for the care-receivers. The demands of caregiving greatly reduce a caregiver's opportunity to have time for themselves in which to pursue leisure activities (Losada et al., 2010).

Caregiving is also experienced positively by some and can add meaning to the lives of those in a caring position. Strawbridge et al. (1997) state that caregivers report increased feelings of gratification and usefulness, as well as an increased sense of satisfaction in their own caring abilities. Caregiving can help to improve the relationship between the caregiver and care-receiver. Haley et al. (1987) explain that most caregivers will experience great stress; however, they will vary in their ability to cope with their situation. Not all caregivers will become depressed and those able to cope successfully may view caregiving as something positive in their life.

## **2.4 Therapeutic Benefits of Leisure**

### **2.4.1 Leisure**

Caldwell and Gilbert (1990) list the basic elements of leisure as: enjoyment, relaxation, freedom of choice, intrinsic motivation, commitment, control, and challenge. Experiences in which individuals are intrinsically motivated, feel self-determined, and have perceived control often result in psychological benefits. Leisure offers opportunities for individuals to develop or enhance social relationships, to be self-expressive, develop skills, and to become self-actualized.

Leisure can provide both short- and long-term benefits to mental health (Caldwell & Gilbert). Caldwell and Gilbert further explain that recreational activities may help people develop social skills and allow them to be successful in leisure activities as well as everyday life. The key elements of leisure have been proven to promote mental health elements, which were listed as: psychological and social harmony and integration, quality of life and general well-being, individual empowerment, self-actualization and growth, and effective personal adaptation (Caldwell & Gilbert).

There has been extensive research on the benefits of leisure and its contribution to psychological well-being. Caldwell (2005) explains that leisure is therapeutic. She does this by examining several studies, which show the various protective factors that leisure participation holds. These factors include social support, meaningful activity, competence, feeling relaxed, and self-determination. The author also tells us that leisure coping has been shown to promote mental health and psychological well-being. When coping with illness or disability, leisure helps to improve the health of someone with a serious illness and remediate the negative effects of living with, or caring for someone with, a chronic illness. Caldwell also reports that leisure activities can decrease levels of anxiety and depression and promote mental health through social inclusiveness.

A study completed by researchers from the University of Toronto explores the impact that providing care to cancer patients has on lifestyle and emotional well-being. Providing care may interfere with a caregiver's ability to participate in valued activities (e.g. recreation, social outings). Using statistical analysis, the results indicate that lifestyle interference is a mediator between the amount of care provided and emotional distress. This study showed that increased lifestyle interference resulted in increased emotional distress, regardless of the amount of care

(Cameron et al., 2002). The results of this study suggest that when caregivers are unable to participate in recreation and leisure they have greater emotional distress and suffer negative emotional consequences.

#### **2.4.2 Leisure Coping**

Leisure has been proven to act as a coping resource. Hood and Carruthers (2002) illustrate that coping is related to health and well-being and failure to cope may enhance illness. The process of coping may be difficult for an individual with an illness or disability because new skills may be required. According to Hood and Carruthers, positive resources developed through leisure activities enhance one's ability to cope and promote overall health and well-being. The researchers also explain that the ability to relax is important for successful coping as it allows for the disengagement from stressful situations. Leisure can provide relaxation, and activities that are meaningful, optimally challenging, and intrinsically motivating will allow disengagement from stress and worries.

Iwasaki and Mannell (2000) have also described leisure as means of coping with stress and acknowledge that leisure is important in helping people maintain or improve their health. A person can use leisure to help achieve good health by using leisure activities to take a break from a stressful situation. Leisure can also enhance a person's positive mood or reduce their negative mood. Iwasaki and Mannell have developed *hierarchical dimensions of leisure stress coping* where various dimensions and sub-dimensions of leisure coping are identified at different levels. At the most general level, two dimensions – leisure coping beliefs and leisure coping strategies – are identified. Leisure coping beliefs are people's general beliefs that their leisure can help them cope with stress and can help buffer, or moderate, against stress to maintain good health. Leisure coping strategies are behaviours or cognitions that are present through leisure participation.

Leisure coping strategies help people mediate against the effect of stress on health. For example, when people experience stress, they participate in leisure as a process of coping, with the result being that they are able to maintain their good health. At the next level of the hierarchy, the sub-dimensions identified include leisure autonomy and leisure friendships (sub-dimensions of leisure coping beliefs), and leisure companionship, leisure palliative coping, and leisure mood enhancement (sub-dimensions of leisure coping strategies). At the third level, sub-dimensions of leisure autonomy include self-determination disposition and empowerment, and sub-dimensions of leisure friendships include emotional support, esteem support, tangible aid, and informational support. This hierarchy demonstrates the many ways in which leisure can provide the opportunity to cope with stress.

Looking more specifically at two dimensions of this hierarchy, leisure palliative coping and leisure mood enhancement will be described. Iwasaki and Mannell (2000) define leisure palliative coping as “an escape-oriented coping strategy” (p. 168) where leisure is used to take a break from stressful life events. Leisure can keep a person’s body busy or take a person’s mind off of their problems or stressful situations. This type of coping can leave a person feeling refreshed and better able to handle their problems. Iwasaki, Mackay, and Mactavish (2005) explain that leisure palliative coping can be a time-out from everyday stressors and can allow for the chance to regroup and provide renewed energy and the opportunity to gain a new perspective. This can help a person to better handle stress. Examples of leisure palliative coping include running, taking a coffee break, or going on vacation.

Leisure mood enhancement refers to a coping strategy where the result is an enhancement of positive mood and/or a reduction in negative mood. This can be accomplished through leisure

participation that helps to regulate emotions/mood. Certain types of leisure may have this stress-reducing potential, for example, nature-based recreation.

Iwasaki, Mannell, and Butcher (2002) studied police and emergency response service workers to examine the impact that using leisure to cope with stress has on maintaining good physical and mental health versus the effects of general coping. This study adapted the conceptual framework of leisure coping using Iwasaki and Mannell (2000) *hierarchical dimensions of leisure coping*. The results revealed that leisure coping is positively related to outcomes of stress coping that go beyond the effects of general coping. Leisure coping had a significant and positive impact on both physical and mental health. The findings also revealed that mental health was significantly predicted only by leisure coping and not by general coping. This shows the importance that leisure coping has on maintaining and improving mental health and further demonstrates the use that leisure has on enhancing positive mood and reducing stress.

Iwasaki et al. (2005) conducted focus groups with professional managers to determine how male and female managers cope with stress. Nine common themes of stress-coping methods emerged through these focus groups. These themes include socialization through leisure and leisure-generated social support, deflecting stress-inducing thoughts through leisure, feeling rejuvenated through leisure, leisure as a personal space, humour and laughter, spiritual coping, altruistic leisure coping, and problem-focused coping. The researchers concluded that the findings demonstrate that leisure is an important means to cope with stress.

### **2.4.3. Self-Determination Theory**

Intrinsic motivation and self-determination, the key aspects of leisure activities, are also directly linked to psychological health. Ryan and Deci (2000) define intrinsic motivation as doing an activity for the inherent satisfaction of the activity itself. The self-determination theory,

as explained by Ryan and Deci, states that meeting three psychological needs (competence, relatedness, and autonomy) is important in facilitating optimal functioning and allows for personal growth and integration. Fulfillment of these needs also promotes social development and personal well-being. When these needs are not fulfilled pathology and ill-being can develop and individuals cannot thrive (Ryan & Deci). Thus, contexts where individuals are intrinsically motivated and self-determined, such as leisure participation, are paramount to promote psychological health and well-being.

Coleman (1993) explains that those who are self-determined in their leisure gain a sense that leisure can be a mediator to leisure's health benefits and can contribute to the resilience of life stressors. The findings of Coleman's study showed that self-determination in leisure helped people resist the impact of stress on health and that freely chosen leisure prevented the onset or worsening of stress induced illness.

Therefore, leisure is important to incorporate into anyone's life, and can have many therapeutic benefits for those in a caregiving role. The ability to relax and to find time to participate in activities that bring joy and satisfaction can contribute to decreased stress and depression and can promote increased psychological well-being.

## **2.5 Social Aspects**

### **2.5.1 Social Needs and Social Support of Caregivers**

Next, the relationship between social aspects and psychological well-being will be discussed. As mentioned previously, the social aspects that I will focus on during this study include caregivers' social needs. It has been found that caregivers reduce, or even abandon, social interactions (Bedini & Guinan, 1996a). Bedini and Guinan (1996b) conducted a study on caregivers' of older adults and discovered that caregivers experienced a loss of social life, which included losing the opportunity to visit or socialize with family and friends. These researchers

also noted that caregiving can reduce phone contact with friends and family, decrease participation in church and club activities, as well as result in less time spent doing hobbies and relaxing. Bedini and Guinan concluded that caregiving responsibilities interfered with both the opportunity for social interactions, as well as the nature of these interactions. Tennstedt, Cafferata, and Sullivan (1992) explain that the lack of social support among caregivers has been related to depression and Elliot and Shewchuk (1995) report that depression can have significant effects on both short-term social interactions and long-term relationships. Elliot and Shewchuk go on to explain that depressed individuals rarely engage in pleasurable social activities and report less satisfaction in activities involving others. Thus, it appears that caregiving can lead to decreased social interaction and social support, which in turn can lead to depression. Depression then can lead to impaired social interactions, also decreasing social support. Sharpe, Butow, Smith, McConnell and Clarke (2005) examined available support among caregivers of cancer patients and found that caregivers with low available support consistently reported increased burden (i.e. stress, anxiety, or depression) and more negative consequences of caregiving.

Nijboer et al. (2001) conducted a study to investigate the role that social support and personality play within the caregiving process. Results show that caregivers who reported high amounts of daily support were observed to report lower levels of depression.

Haley et al. (1987) examined social support among caregivers and found that caregivers with a large number of friends, close relationships, and reports of greater satisfaction with their social networks had higher levels of overall life satisfaction. Roth et al. (2005) showed that the caregiving resource of having high levels of social support was associated with lower levels of caregiver depression. Roth et al. continues to explain that strong social support resources can reduce the consequences of stressful life experiences and contribute to preserved psychological

well-being. Helgeson and Cohen (1996) looked at the social environment and its association to the adjustment of cancer. These authors suggest that the social environment has been proven to effect well-being and aspects of the social environment can protect individuals from negative life events, such as cancer. It was found that emotional support plays the strongest role in adjustments and having positive social interactions can also help in psychological adjustment.

### **2.5.2 Benefits of Social Support and Social Integration**

Cohen and Wills (1985) describe social support as a buffer against negative life events. Social support is linked to positive psychological and physical health outcomes. Social support is seen as beneficial because social networks can provide individuals with regular positive experiences and give rewarding roles in the community. A sense of belonging and social companionship can provide emotional support and act as a buffer to stress. Cohen and Wills state that social companionship can be achieved by spending time with others in leisure and recreational activities. Iwasaki et al. (2002) showed that the use of leisure companionship has positive consequences on mental health because leisure provides an opportunity to socialize with others, and socialization through leisure is a form of social support. Russell and Cutrona (1991) also explain that having a social network available permits an individual to avoid experiencing minor stressful occurrences. These researchers conducted a study and found that participants who reported high levels of social support experienced fewer daily hassles and stress. Iso-Ahola and Park (1996) conducted a study using Taekwondo participants to show that social support has a buffering effect on the stress-illness relationship and that companionship in shared leisure activities enhanced psychological well-being. Engagement in social leisure activities helps to maintain and develop healthy relationships with others, which helps to better manage life stress and maintain good health. Thoits (1986) explains that social support can assist with coping

because others can facilitate and strengthen coping attempts by suggesting alternative techniques or helping an individual directly in coping efforts.

Therefore, a caregiving role can decrease one's social support and social network and can result in the loss of one's social life, which may lead to depression. Having social support can help buffer against negative life events. Participation in social leisure activities are a good way to meet new people. These activities allow you to spend time with others and gain the psychological benefits of spending time with family and friends.

## **2.6 Physical Aspects**

### **2.6.1 Physical Health of Caregivers**

Caregiving can also result in decreased physical functioning and physical health. Caregiving responsibilities can place considerable demands on the caregiver, draining them of physical energy (Bedini & Guinan, 1996b). Clipp and George (1993) explain that caregiving leads to chronic stress, which in many caregivers leads to physical health consequences. A study conducted by Kim et al. (2008) showed that among cancer survivors who had breast cancer, the survivor's distress predicted the caregiver's physical health. It appears that the greater the level of distress among the cancer survivor, the worse the caregiver's physical health. Fredman, Bertrand, Martire, Hochburg, and Harris (2006) examined the amount of time caregivers were able to participate in leisure-time physical activity versus non-caregivers. It was found that caregivers report less leisure-time physical activity than non-caregivers of the same age group.

King and Brassington (1997) explain that caregivers are at an increased vulnerability for physical illness and that a third of caregivers in a national survey (in the United States) rated their physical health as "fair" or "poor." King and Brassington conducted a study where a 4-month exercise regime was implemented among caregivers and found that inactivity among

caregivers poses a major risk to their health and those that participated in moderate-intensity physical activity showed a beneficial increase in their physical health.

Physical functioning has been proven to promote psychological well-being among people with depression (e.g. Wells et al., 1989). Mock, Fraser, Knutson, and Prier (2010) show that participation in leisure time physical activity among adults with rheumatoid arthritis results in greater ratings of perceived physical health as well as an increased rating of mental health.

### **2.6.2 Participation in Physical Leisure Activity**

Within cancer research, several studies indicate that participation in physical activity improves mental health as well as overall well-being and quality of life. A study conducted by Lynch, Cerin, Owen, and Aitken (2007) examines the association between physical activity and quality of life among colorectal cancer survivors. Physical activity and functioning were measured among the participants. Functioning was measured using the Functional Assessment of Cancer Therapy – Colorectal (FACT-C). Results indicate that there is a significant difference in quality of life scores among those that are inactive (0 minutes of physical activity/week), compared to those who were insufficiently active (1-149 minutes/week), and sufficiently active (150+ minutes/week). Participants who were sufficiently active had significantly higher scores of quality of life and higher scores on both the physical and functional well-being measures when compared to the two other groups. Participants who were insufficiently active had higher scores than those who were inactive. Results also showed that survivors that did not experience fatigue have FACT-C scores of 64.4% higher than those that did.

Another study examining physical activity shows similar results among non-Hodgkin's lymphoma survivors. Vallance, Courneya, Jones, and Reiman (2005) measured physical activity, in terms of meeting public health guidelines (i.e. at least 150 minutes of moderate-vigorous

exercise/week), and measure quality of life with the Functional Assessment of Cancer Therapy-Anemia (FACT-An). Results reveal that exercise levels are strongly correlated with several domains of quality of life. Off-treatment survivors who meet public health exercise guidelines have less fatigue, fewer anemia symptoms, better physical and functional well-being, and better overall quality of life.

A final study by Rabin, Pinto, Trunzo, Frierson, and Bucknam (2006) shows that breast cancer survivors who completed a 12-week physical activity intervention were able to increase their confidence for engaging in physical activity and increase the number of minutes of activity per week. They were also able to implement behavioural processes that helped them to maintain activity.

Therefore, increased physical activity can have a great impact on level of energy and physical functioning. Because caregivers may experience a decrease in their physical health due to caregiving responsibilities, it would be beneficial for them to engage in physical leisure activities to improve their physical functioning. Increased physical functioning has also been shown to promote an increase in psychological well-being and a higher quality of life.

## **2.7 Psychological Well-Being**

### **2.7.1. Theories**

Current research on [psychological] well-being is derived from two general perspectives: the hedonic approach and eudaimonic approach (Ryan & Deci, 2001). Ryan and Deci define well-being as optimal psychological functioning and experience and not simply the absence of mental illness. The hedonic view focuses on happiness and defines well-being in terms of pleasure attainment and pain avoidance. Subjective well-being is often used as a measure of pleasure attainment by researchers who adopt this approach. The eudaimonic view, on the other

hand, focuses on meaning and self-realization. This view defines well-being in terms of the degree to which a person is fully functioning. Proponents of the eudaimonic approach believe that subjective happiness does not measure well-being, rather well-being is measured objectively in terms of psychological well-being. Psychological well-being assesses aspects of human actualization. The hedonic and eudaimonic approach both overlap and have distinct aspects, showing that the measurement of well-being may be improved by measuring it in different ways by incorporating both approaches into the definition of well-being.

Folkman and Greer (2000) reviewed the interaction between theory, research, and practice regarding psychological well-being during serious illness. The serious illnesses described are cancer and HIV/AIDS. The theoretical model discussed was Lazarus and Folkman's model of stress and coping. This model includes four stages: appraisal, coping, event outcome, and emotion outcome. The authors state that the appraisal process is important in coping. Conceptualizations of theoretical models, which improve psychological well-being during the stress process, falls into three categories. These include personality and dispositional variables (hardiness, dispositional optimism, mastery, and internal locus of control), situational efficacy beliefs (outcome and self-efficacy), and coping processes. Therefore, the outcome of one's psychological well-being is a result of the combination of these three categories and depends on personality, how the situation is viewed, and how one is able to cope with the situation.

### **2.7.2 Psychological Well-being and Caregivers**

Results from a study comparing grandparent, spouse, and adult-child caregivers show that all caregivers experience significantly greater levels of depression and unhappiness than non-caregivers (Strawbridge et al., 1997). Happiness is a measure of subjective well-being.

Subjective well-being is defined as people's evaluation of their lives which included emotions, life satisfaction, happiness, and fulfillment (Diener, Oishi, & Lucan, 2003).

Nijboer et al. (1999) assessed caregiving experiences among caregivers of individuals with colorectal cancer. The researchers use a conceptual research model consisting of these components: characteristics of the caregiver, characteristics of the patient, and characteristics of the situation. The objective of the study was to assess the caregivers' experiences in terms of negative and positive domains, as well as to assess the caregivers' mental health. Statistical analysis revealed that different caregiver and patient characteristics accounted for different types of experiences and mental health outcomes. Performing more care tasks and reporting more changes in activities increases negative experiences of giving care. Results show that patient and care characteristics played a minor role in caregiver mental health compared to the way caregiving was experienced by the caregiver (i.e. the appraisal of the situation). Therefore, when caregivers experience changes in their activities, for example loss of leisure times, they may experience caregiving more negatively.

Depression is common among caregivers and a decrease in leisure-time social and physical activities can play a part in this.

## **2.8 Summary**

Caregiving can be viewed by individuals either positively or negatively, but often times caregiving comes with many issues that can impact one's health. Some of these issues include experiencing depression, a change in social life (impacting the amount of social support received), and physical health problems. Caregiving may also take away time from participation in leisure activities and caregiving responsibilities can interfere with time spent that caregivers would normally take for themselves if they were not in that role.

Participation in leisure activities can have many positive benefits to psychological well-being and overall quality of life. Leisure is a time for individuals to have freedom and choice and be self-determined. Leisure activities can be social and physical in nature. It allows an individual to be self-expressive, develop skills, improve social relationship, and improve physical health. Leisure can also act as a coping resource during stressful times, such as caregiving.

Participation in social leisure activities can lead to the development of new friends, or provide a time to spend with family and friends. Having high amounts of social support can act as a buffer against depression and caregivers with greater satisfaction with their social life have higher overall life satisfaction. Having relationships with others can provide caregivers with emotional support and improve their psychological well-being.

Physical functioning impacts psychological well-being, where an increase in functioning leads to an increase in well-being. Participation in physical leisure activities has been shown to improve physical functioning and overall health. Physical activity can improve energy levels, lower fatigue, and improve mental health.

Changes in activities among caregivers have an impact on psychological well-being, indicating that a loss of leisure activities can lead to negative mental health consequences. Caregivers report higher levels of depression than the general population.

### **2.8.1 Theoretical Framework**

Based on the review of the literature, I am using several theories to help guide my research. First, the self-determination theory will act as a guiding theory to analyze the relationship of leisure participation and psychological well-being. The self-determination theory, applied to leisure (Coleman & Iso-Ahola, 1993), states that self-determination is a key characteristic in leisure participation and that this has a positive influence on psychological well-

being and health. Guiding theories for social aspects include social support as a coping assistance (Thoits, 1986) and social support as a buffer against life stress (Cohen & Wills, 1985), as illustrated previously. Physical aspects will be measured in terms of functioning and how much energy one has. I will be looking at both the hedonic and eudaimonic viewpoints as to improve the measurement psychological well-being of caregivers.

## **Chapter 3: Research Methods**

This section will discuss the procedures, beginning first with the research method. I will also discuss the survey that was used during my secondary data analysis, as well as the research sample. Finally, the questions that will be used from the survey will be looked at and the variables will be explained.

### **3.1 Quantitative Method**

This study used a quantitative research design, with the use of survey research to provide a numeric description of the results. Quantitative research examines the relationship among variables by testing objective theories (Cresswell, 2009). The variables are measured using statistical procedures and the results are achieved through statistical interpretation. Quantitative research allows for the generalization of findings. This study used the method of secondary data analysis. Secondary analysis has been defined by Hakim (1982), as cited in Dale, Arber, and Procter (1988), as “any further analysis of an existing dataset which presents interpretations, conclusions or knowledge additional to, or different from, those presented in the first report on the inquiry as a whole and its main results” (p.3). Thus, secondary data analysis is re-working data that has already been analysed and gaining knowledge on a separate topic than what the original survey had focused on. For the purpose of this study, the focus is on unmet leisure needs and psychological well-being, which differs from the original purpose of the study, which was to develop a tool to measure unmet needs of caregivers.

Quantitative research methods are used when there is a large sampling frame. It is appropriate for this study because of the large number of surveys to analyse and because it draws upon secondary data.

### 3.2 The Survey

The research draws on secondary data from *The Cancer Support Person's Unmet Needs Survey* (Campbell et al., 2009). Using various questions from the survey, I analyzed the relationship between meeting recreation and leisure needs and psychological well-being, as well as how meeting social and physical aspects impact this relationship. The questions that explored leisure needs are from the “Unmet Personal Needs” subscale of the survey.

As previously mentioned, the purpose of the study *The Cancer Support Person's Unmet Needs Survey* (Campbell et al., 2009) was to develop a psychometrically rigorous tool to measure the unmet needs of caregivers. The survey was developed based on extensive literature review and a pilot study. The Canadian Cancer society recruited 74 cancer survivors and their primary caregivers from five provinces in Canada. Fifty-one caregivers completed an open-ended survey that asked them to list their top six unmet needs in the last month. Based on the results, two research staff coded the respondents' needs into themes. Using the results from the pilot study, the final product is entitled the *Support Person Unmet Needs Survey* (SPUNS) and consists of 78 items and six domains. These domains include unmet information needs (27 items), the future (four items), unmet work and financial needs (eight items), unmet needs for access and continuity of health care (nine items), unmet personal needs (14 items), and emotional needs (16 items). Leisure needs are found in the personal care domain. These domains are found in the first section of the survey: About Your Needs. The second section is Your Health and Well-Being and the third section is entitled About You.

### 3.3 Survey Sample

Primary caregivers were self-selected by the cancer survivor. The survivor was given the definition that a primary caregiver is “someone you can count on and who helps you with your needs.”

The sampling frame was the population-based Cancer Registry run by CancerCare Manitoba. This cancer registry consists of persons 19 and older with a histologically confirmed cancer diagnosis in the preceding 12 to 60 months. A cross-sectional, stratified random sample of 1600 survivors was identified by Manitoba Registry based on time of diagnosis (12 to 24 months, 25 to 36 months, 37 to 48 months, and 49 to 60 months) and there were 1128 survivors eligible to participate in the study.

The study received ethical approval from the University of Waterloo and the University of Manitoba, who provided ethical oversight for the Cancer Registry. Only the Cancer Registry staff had access to patient information, so initial and follow-up mailings were done by Cancer Registry staff. The surveys were returned to the Centre for Behavioural Research and Program Evaluation at the University of Waterloo, identified by study number only.

The survey was sent out to eligible survivors with an invitational letter for a follow-up survey they were asked to pass on to their caregiver. The SPUNS was completed independently by caregivers who were asked to return it in a stamped envelope. Once the survey was received, a test-retest survey was sent out.

The population that completed the survey that I will be using for this research study includes 718 support persons (self-selected by the survivors, who were asked to give their caregivers the survey). Along with questions regarding unmet needs, demographic and contextual questions about the acceptability of the questionnaire were also asked of the

caregivers. Gender, age, education, employment status, and geographic residence of the participants were obtained. The nature of the relationship between the caregiver and survivor was asked and whether the caregiver lives with the survivor, when they learned they had cancer, the survivor's age at diagnosis, type of cancer, perceptions of the cancer survivor's current medical state, type of cancer treatment in the last month (if any), out of pocket expenses, and travel distance to survivor's treatment facility. The caregiver was also asked to indicate if they themselves had ever been diagnosed with cancer and if so, when and what type.

### **3.4 Survey Scales and Variables**

For the first section of the survey, caregivers were asked to rate their level of unmet need in the past month for each item on a 5-point Likert-type scale. All questions regarding unmet needs used a scale that ranged from 0 to 4 (no unmet need, low unmet need, moderate unmet need, high unmet need, very high unmet need). The survey included a "no unmet need" option which allowed respondents to indicate where no help was required. This scale provided the option of calculating a score for each domain, and an overall score of unmet needs. The second section on health and well-being used a 4-point Likert-type scale for the first 21 questions (the DASS – 21), ranging from 0-3 (did not apply to me at all, applied to me to some degree/some of the time, applied to me to a considerable degree/a good part of the time, applied to me very much/most of the time). Caregivers were asked about how they have been feeling in the past week. This section also asked caregivers about the views of their health using a number of scales. The third section asked questions about the caregiver and the history of the person whom they are supporting.

### **3.4.1 Demographics**

Demographic variables included age, gender, education, employment status, and nature of relationship. Respondent's age is a continuous variable and gender is denoted by male (0) and female (1). Level of education was coded into secondary school or less, trades, vocational, college or other (0), and university or higher (1). Employment status was looked at in terms of does not do paid work (0) and does paid work (1). Respondents were asked "who gave you this survey" with the choices denoted as: wife, husband, or partner, parent(s), child(ren)/ grandchild(ren), brother(s) or sister(s) or other relative (e.g. aunt, uncle, grandparent, in-law), friend(s), housemate, and other (please specify). Nature of relationship was coded as child (1) and spouse (0). Also looked at is all other relationships (1) versus spouse (0). This compared if there was a significant difference in caring for a parent versus a spouse or other relative, etc. The nature of the relationship may impact the caregiver's health in different ways. For example, a child caregiver to a parent may experience more lifestyle interferences because they may also have their own family and children to care for. Or an older spouse of a cancer survivor may have their own health problems that may impact their psychological well-being and quality of life. I think it is important to control for the nature of the relationship and explore the difference in health based on the type of caregiver.

### **3.4.2 Independent Variable**

The independent variable for this study is fulfillment of recreation and leisure needs. These questions from the survey included the amount of unmet personal needs the caregivers have experienced in the last month. For leisure needs, the items looked at are "finding time to do things that make me happy," "finding time alone, just for myself," and "knowing how to relax." This is based on Caldwell and Gilbert's (1990) and Hood and Carruthers' (2002) research that

leisure activities promote enjoyment and incorporate relaxation. The mean of these three survey questions was calculated ( $\alpha = 0.89$ ) to create a scale of the perceived unmet leisure needs of caregivers and was recoded to produce a measure of very high unmet need (0) to no unmet need (4).

### **3.4.3 Dependent Variable**

The dependent variable is psychological well-being/mental health. Psychological well-being was measured using questions found in the second section asking about health and well-being. This section included the DASS-21 (Depression, Anxiety and Stress Scale – 21 Items, a condensed version of the DASS-42), which is a standardized tool that measures levels of depression, anxiety, and stress (Lovibond & Lovibond, 1995). I looked at the questions from the DASS-21 that focuses on each area separately. The responses of the seven questions pertaining to depression were summed ( $\alpha = 0.91$ ) to create a measure of psychological well-being. Some of these items included: “I found it difficult to work up the initiative to do things” and “I felt life was meaningless.” The seven questions pertaining to anxiety and the seven questions pertaining to stress were also summed ( $\alpha = 0.85$ ,  $\alpha = 0.92$ , respectively) to create a measure of caregiver’s anxiety and stress. Examples of questions measuring anxiety included: “I experienced trembling (e.g., in the hands)” and “I was worried about situations in which I might panic and make a fool of myself.” Questions regarding stress include: “I found it hard to wind down” and “I tend to over-react to situations.” For a full list of questions asked, please refer to Table 5 in Appendix A. Responses for each area were summed and then doubled to match the scoring for the DASS-42. The scales measure the level of severity in terms of “normal” (depression = 0-9, anxiety = 0-7, stress = 0-14), “mild” (depression = 10-13, anxiety = 8-9, stress = 15-18), “moderate”

(depression = 14-20, anxiety = 10-14, stress = 19-25), “severe” (depression = 21-27, anxiety = 15-19, stress = 26-33) and “extremely severe” (depression = 28+, anxiety = 20+, stress = 34+).

#### **3.4.4 Mediating Variables**

The mediating variables included social and physical aspects. To explore social aspects, survey items that were looked at are found in the domain of unmet personal needs and unmet emotional needs. The items analyzed are “finding time to see family and friends,” and “telling family and friends how I was feeling emotionally.” Using these questions from the survey, the mean of the responses was calculated ( $\alpha = 0.93$ ) to create a scale of social support. The items were recoded to produce a measure of the perceived need of unmet social support the caregivers felt they have from a very high unmet need (0) to no unmet need (4), meaning that lower response values indicates greater amount of unmet need.

To analyse physical aspects, I looked at the rating of health and physical functioning that is found in the section asking about health and well-being. Examples of these questions included “In general would you say your health is...” with the response options ranging from “poor” to “excellent,” (on a Likert scale from 1-5) and “During the last month, how much time have you had any of the following problems with your work or other regular daily activities as a result of your physical health (a. Accomplished less than you would like, b. Were limited in the kind of work or other activities)” with the response options ranging from “none of the time” to “all of the time,” using a 5-point Likert scale. Responses were recoded so that lower response values indicated a lower rating of health and physical functioning. The health and physical functioning scores from three survey questions were transformed to z-scores and the mean of the z-scores were computed ( $\alpha = 0.78$ ) to create a measure of physical functioning. Health and physical functioning were measured on different scales, so the standardization of these measures allowed

for the combination into a single variable of physical aspects, where the average score is approximately zero. Higher scores indicated higher levels of perceived health and physical functioning.

### **3.5 Data Analysis**

Statistical analysis was done using PASW software to determine the unmet leisure needs of caregivers and the impact that meeting leisure needs had on psychological well-being. Descriptive statistics (means and frequencies) were used to gain an understanding of the sample, and demographic characteristics were controlled for in the analysis. Four linear regression models for each depression, anxiety and stress were constructed to examine the association of unmet leisure needs and psychological well-being and the impact that social and physical aspects may have on this association. The first model included the demographic characteristics/control variables and the following models introduced meeting leisure needs and the mediating variables. A method called bootstrapping (Preacher & Hayes, 2008) was used to test multiple mediators simultaneously. Baron and Kenny (1986) explain that the mediator acts as another variable, which “represents the generative mechanism through which the focal independent variable is able to influence the dependent variable of interest” (p. 1173). I explored how social and physical aspects mediate the relationship between meeting recreation and leisure needs and psychological well-being among caregivers. The method of bootstrapping allowed for the examination of how multiple mediators independently impact the relationship between the independent and dependent variable, as well as a statistical comparison between mediators (Preacher & Hayes).

### 3.6 Summary

There has been extensive research on caregivers of cancer survivors during diagnosis and treatment, but little research that has explored the needs of long-term caregivers. My research study, which has received ethical approval from the University of Waterloo, used data from the study *The Cancer Support Person's Unmet Needs Survey* (Campbell et al., 2009) to explore the relationship between meeting recreation and leisure needs and psychological well-being among caregivers of cancer survivors. The SPUNS depicts six domains of caregiver needs that are common for caregivers. I further explored the impact of fulfillment that leisure-related social and physical aspects have on psychological well-being. I expect that meeting recreation and leisure needs, as well as social needs and physical functioning, will have a positive impact on mental health. My research will be beneficial to the field of therapeutic recreation because it will help practitioners understand the needs of this population and how to better meet their recreation and leisure needs. It will help practitioners to know which type of intervention (i.e. social or physical) will have more of an impact on a caregiver's psychological well-being and overall quality of life.

Higher survival rates and longer survival times of cancer survivors may equate to the need of continued support from family and friends of survivors. This may result in increasing demand for a caregiver over an extended period of time and have an impact on their mental health and quality of life. My study will address unmet leisure and determine ways to improve mental health and quality of life for caregivers of long-term cancer survivors.

## Chapter 4: Results

The average age group for the sample was 2.59 (SD = 1.0), which corresponds with the age group 50-59 years of age. The sample consisted of 25.8% of the caregivers falling between the age range of 50-59 years and 31.7% falling between 60-69 years. Sixty-six percent of the sample were females and 24% of the sample have obtained a university degree or higher. Approximately half the sample (46%) was employed. In terms of the nature of the relationship, 76% of the sample was the spouse of the cancer survivor and 12% was the child of the survivor/caring for a parent (see Table 1).

**Table 1.** Means, Standard Deviations, and Percentages for Demographic Characteristics

Variable	<i>M/Percent</i>	<i>SD</i>
Age	2.59	1.0
Gender (female)	66%	--
Education (university degree or higher)	24%	--
Employment (does paid work)	46%	--
Nature of Relationship (spouse)	76%	--
Nature of Relationship (child)	12%	--
Fulfilling leisure needs	3.35	0.95
Fulfilling social needs	3.40	0.94
Fulfilling functioning	-0.01	0.84
Depression	8.66	7.29
Anxiety	6.32	5.89
Stress	12.83	8.68

On average, caregivers had a high score of fulfilling leisure needs (M= 3.35, SD = 0.95), as well as fulfilling social needs (M = 3.40, SD = 0.94), which corresponds with “no” to “low” unmet need. The mean for fulfilling physical functioning was -0.01 (SD = 0.84). Looking at the dependent variable of psychological well-being, the means for each item were doubled (in correspondence to the DASS – 42) and were as follows: depression (M = 8.66, SD = 7.29),

anxiety ( $M = 6.32$ ,  $SD = 5.89$ ), and stress ( $M = 12.83$ ,  $SD = 8.68$ ) (see Table 1). These scores fall on the high end of the “normal” range for the scoring of the DASS. Looking at the frequencies for depression, it was found that 81.4% of the caregivers fell within the normal range, 8.4% in the mild, 5.2% in the moderate range, 3.0% in the severe range, and 2.0% qualified as being severely depressed. In terms of anxiety, 88.6% of caregivers fell within the normal range, 2.1% in the mild category, 3.7% moderate, 3.4% severe, and 2.2% fell within the extremely severe range. Lastly, in regards to stress, 85% of caregivers fell in the normal range, 5.3% mild, 5.3% moderate, 3.6% severe, and 0.8% extremely severe. Therefore, in terms of the level of depression, anxiety, and stress, this sample of caregivers were doing relatively well as compared to past research (e.g., Bedini, 2002; Hagedoorn et al., 2008).

Regression analysis was run to determine if the control variables were significantly associated to the meeting leisure, social needs and physical functioning and mental health. Next, bootstrapping was done to reveal the association of the mediators with the relationship between fulfilling leisure needs and psychological well-being. Depression, anxiety, and stress were looked at separately.

#### **4.1 Depression (Table 2)**

When looking at depression, being female was significantly associated with depression. All other control variables were not significant (**Table 2**, Model 1). Regression analyses showed that meeting leisure needs was associated with lower ratings of depression (**Table 2**, Model 2) and greater levels of physical functioning were significantly associated with lower levels of depression (**Table 2**, Model 3). Meeting social needs also showed a reduction in the caregivers' level of depression (**Table 2**, Model 4). The addition of these two mediating variables to the model reduced the association of fulfilling leisure needs with depression (**Table 3**), indicating

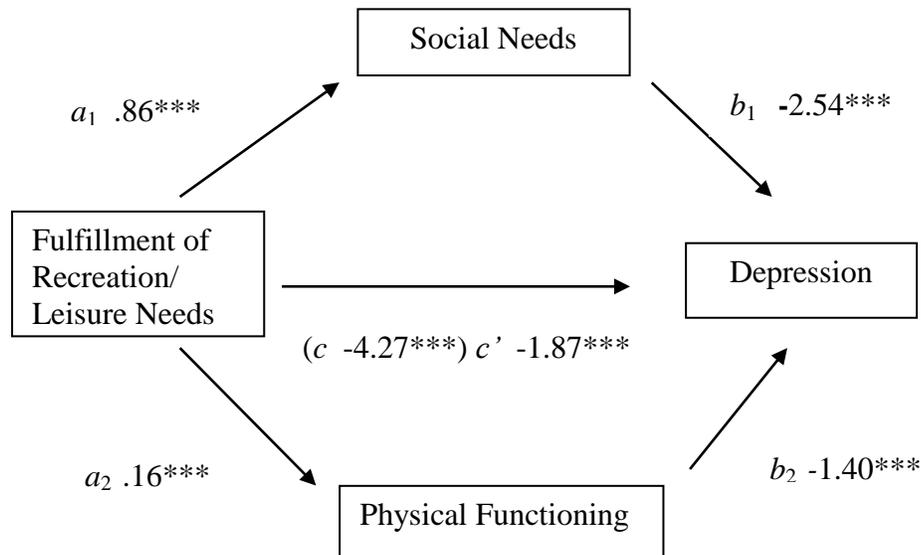
that physical functioning and social support partially explain the association between meeting leisure needs and level of depression. In the test for mediation (Preacher & Hayes, 2008) it was found that the total effect ( $c$ ) of meeting leisure needs and depression was significant ( $B = -4.27$ ,  $p < .001$ ) and compared to the total effect, the direct effect ( $c'$ ) of meeting leisure needs and level of depression was reduced ( $B = -1.87$ ,  $p < .001$ ) with the addition of social needs and physical functioning to the model (**Figure 2**).

The indirect effects ( $a_1b_1$  and  $a_2b_2$  paths) for both mediators were statistically significant (social needs, *point estimate* = -2.18, *SE* = 0.71, *upper confidence interval* = -4.08, *lower confidence interval* = -0.39; physical functioning, *point estimate* = -0.22, *SE* = 0.07, *upper confidence interval* = -0.44, *lower confidence interval* = -0.08). When the two mediators were compared, the contrast between social needs and physical functioning was significant (*point estimate* = 1.96, *SE* = 0.72, *upper confidence interval* = 0.13, *lower confidence interval* = 3.90). This revealed that fulfilling social needs was a significantly greater mediator than fulfilling physical functioning.

**Table 2.** *Unstandardized coefficients for regression models examining associations of demographics, fulfilling leisure needs, physical functioning, and social support status with depression*

<b>DEPRESSION</b>								
Variables	Model 1		Model 2		Model 3		Model 4	
	B	SE	B	SE	B	SE	B	SE
Constant	6.44 **	1.99	18.09 ***	.07	18.64 **	.07	20.42 **	1.77
Age	-.05	.02	.01	.02	-.16	.02	-.02	.02
Gender (Female)	1.34 *	.60	.40	.51	.33	.50	.22	.49
Education	-.21	.65	-.02	.55	.30	.55	.28	.53
Employment	-.11	.65	-.70	.55	-.38	.55	-.42	.53
Relationship (child)	.55	.97	.85	.81	.58	.80	.53	.77
Relationship (other)	-.28	.89	.14	.75	-.11	.74	-.09	.72
Meeting Leisure	--	--	-4.27 ***	.25	-4.03 **	.25	-1.87 **	.45
Physical	--	--	--	--	-1.53 **	.29	-1.40 **	.29
Social Support	--	--	--	--	--	--	-2.54 **	.45
Adjusted R <sup>2</sup>	.01		.30		.32		.35	

*n* = 718; \* *p* < .05; \*\* *p* < .01, \*\*\* *p* < .001



**Figure 2.** Association between fulfillment of leisure needs and depression mediated by the fulfillment of social needs and physical functioning

Note: The value in parentheses is the unstandardized regression coefficient for the association between meeting recreation and leisure needs and depression before the addition of social and physical to the model.

$n = 718$ ; \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

#### 4.2 Anxiety (Table 3)

Statistical output showed that being female was significantly associated with anxiety. All other control variables were not significant (Table 3, Model 1). Results show that meeting leisure needs was associated with lower ratings of anxiety (Table 3, Model 2). Greater levels of physical functioning were significantly associated with lower levels of anxiety (Table 3, Model 3) as was meeting social needs (Table 3, Model 4). The addition of the mediating variables to the model reduced the association of fulfilling leisure needs with caregivers' level of anxiety (Table 3), indicating that physical functioning and social support partially explain the association between meeting leisure needs and level of anxiety. In the test for mediation (Preacher & Hayes, 2008) it was found that the total effect ( $c$ ) of meeting leisure needs and anxiety was significant ( $B = -3.41, p < .001$ ) and compared to the total effect, the direct effect

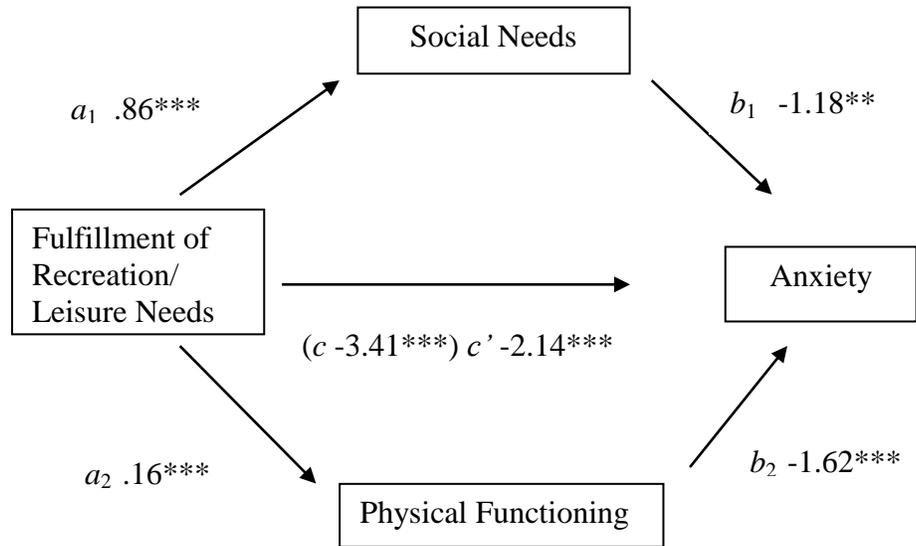
( $c'$ ) of meeting leisure needs and level of anxiety was reduced ( $B = -2.14, p < .001$ ) with the addition of social needs and physical functioning to the model (**Figure 3**).

The indirect effects ( $a_2b_2$  path) for the physical functioning mediator was statistically significant (*point estimate* = -0.26, *SE* = 0.07, *upper confidence interval* = -0.47, *lower confidence interval* = -0.11). The indirect effects ( $a_1b_1$ ) for social needs was not significant, as the confidence intervals crossed zero (*upper confidence interval* = -2.18, *lower confidence interval* = 0.17), indicating that there is a possibility of no effect (*point estimate* = -1.01, *SE* = 0.45). The results revealed that fulfilling social needs is not significant in having an impact on decreasing the caregiver's level of anxiety.

**Table 3.** *Unstandardized coefficients for regression models examining associations of demographics, fulfilling leisure needs, physical functioning, and social support status with anxiety*

<b>ANXIETY</b>								
Variables	Model 1		Model 2		Model 3		Model 4	
	B	SE	B	SE	B	SE	B	SE
Constant	4.40**	1.59	13.72***	1.4	14.32**	1.40	15.15**	1.41
Age	-.03	.02	.01	.02	-.01	.02	-.02	.02
Gender (Female)	1.39**	.48	.64	.41	.57	.39	.51	.39
Education	-.22	.52	-.06	.44	.29	.43	.28	.42
Employment	-.34	.52	-.82	.44	-.46	.43	-.48	.42
Relationship	.17	.77	.42	.65	.12	.63	.09	.62
Relationship	-.25	.71	.08	.60	-.12	.58	-.19	.58
Meeting Leisure	--	--	-3.41***	.20	-3.15**	.20	-2.14**	.36
Physical	--	--	--	--	-1.68**	.23	-1.62**	.23
Social Support	--	--	--	--	--	--	-1.18**	.36
Adjusted R <sup>2</sup>	.01		.30		.35		.36	

*n* = 718; \* *p* < .05; \*\* *p* < .01, \*\*\* *p* < .001



**Figure 3.** Association between fulfillment of leisure needs and anxiety mediated by the fulfillment of social needs and physical functioning

Note: The value in parentheses is the unstandardized regression coefficient for the association between meeting recreation and leisure needs and depression before the addition of social and physical to the model.

$n = 718$ ; \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

### 4.3 Stress (Table 4)

As with depression and anxiety, regression analysis showed that being female was significantly associated with stress. But unlike depression and anxiety, age was also significant. All other control variables were not significant (Table 4, Model 1). Results reveal that meeting leisure needs was associated with lower ratings of stress (Table 4, Model 2). Greater levels of physical functioning were significantly associated with lower levels of anxiety (Table 4, Model 3) as was meeting social needs (Table 4, Model 4). The addition of these mediators to the model reduced the association of fulfilling leisure needs with caregivers' level of stress (Table 4), indicating that physical functioning and social support partially explain the association between meeting leisure needs and level of stress. In the test for mediation (Preacher & Hayes, 2008) it was found that the total effect ( $c$ ) of meeting leisure needs and stress was significant ( $B = -6.15$ ,

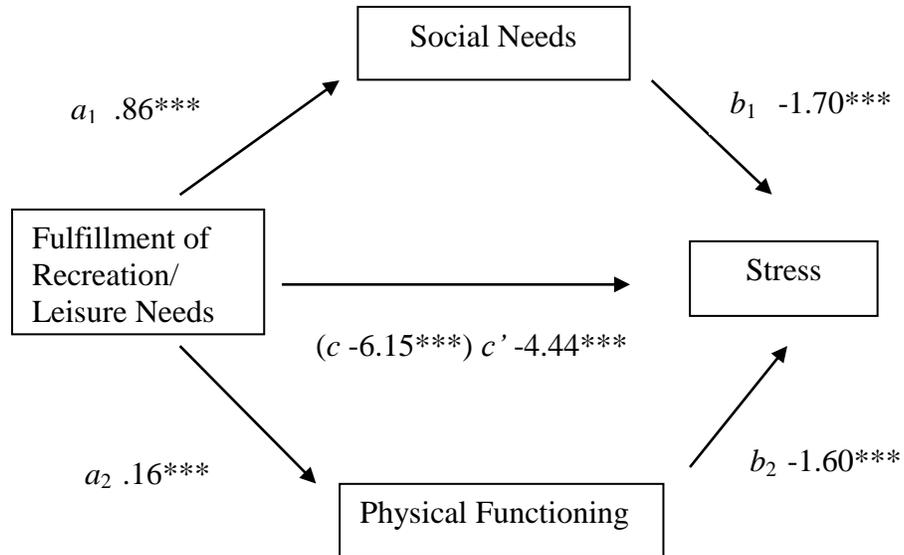
$p < .001$ ) and compared to the total effect, the direct effect ( $c'$ ) of meeting leisure needs and level of stress was reduced ( $B = -4.44, p < .001$ ) with the addition of social needs and physical functioning to the model (**Figure 4**).

As with anxiety, the indirect effects of only one mediator, physical functioning, was significant. The indirect effects ( $a_2b_2$  path) for the physical functioning mediator was statistically significant (*point estimate* = -0.25, *SE* = 0.07, *upper confidence interval* = -0.49, *lower confidence interval* = -0.10). The indirect effects ( $a_1b_1$ ) for social needs was not significant, as the confidence intervals crossed zero (*upper confidence interval* = -3.08, *lower confidence interval* = 0.30), indicating that there is a possibility of no effect (*point estimate* = -1.45, *SE* = 0.63). The results revealed that fulfilling social needs is not significant in having an impact on decreasing the caregiver's level of stress.

**Table 4.** *Unstandardized coefficients for regression models examining associations of demographics, fulfilling leisure needs, physical functioning, and social support status with stress*

<b>STRESS</b>									
Variables	Model 1		Model 2		Model 3		Model 4		
	B	SE	B	SE	B	SE	B	SE	
Constant	11.85 ***	2.34	28.64 ***	1.9	29.24 **	1.86	30.44 ***	1.88	
Age	-.11 **	.03	-.02	.03	-.06 *	.03	-.06 *	.03	
Gender (Female)	1.83 *	.70	.48	.53	.41	.52	.33	.52	
Education	-.27	.77	.00	.58	.36	.57	.35	.56	
Employment	.27	.77	-.59	.58	-.23	.57	-.26	.57	
Relationship (child)	.01	1.14	.45	.85	.15	.84	.11	.83	
Relationship (other)	-1.01	1.05	-.41	.79	-.69	.77	-.67	.77	
Meeting Leisure	--	--	-6.15 ***	.26	-5.89 **	.26	-4.44 ***	.48	
Physical	--	--	--	--	-1.69 **	.31	-1.60 ***	.30	
Social Support	--	--	--	--	--	--	-1.70 ***	.48	
Adjusted R <sup>2</sup>	.03		.46		.48		.49		

*n* = 718; \* *p* < .05; \*\* *p* < .01, \*\*\* *p* < .001



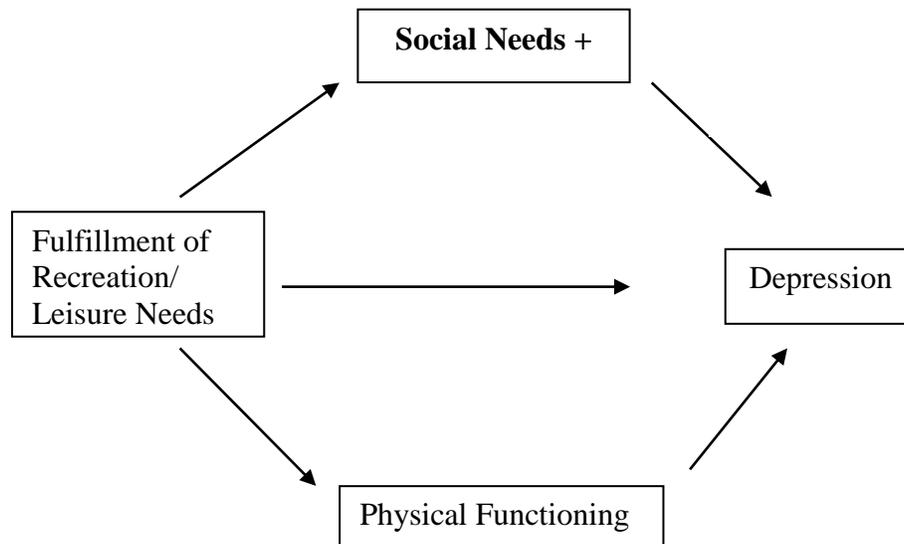
**Figure 4.** Association between fulfillment of leisure needs and anxiety mediated by the fulfillment of social needs and physical functioning

Note: The value in parentheses is the unstandardized regression coefficient for the association between meeting recreation and leisure needs and depression before the addition of social and physical to the model.

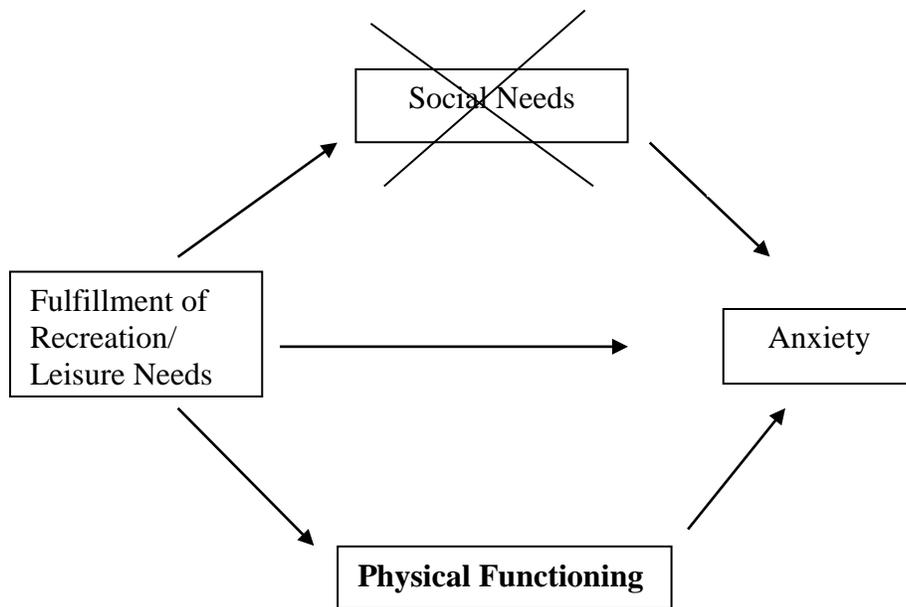
$n = 718$ ; \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

#### 4.4 Summary of Outcomes

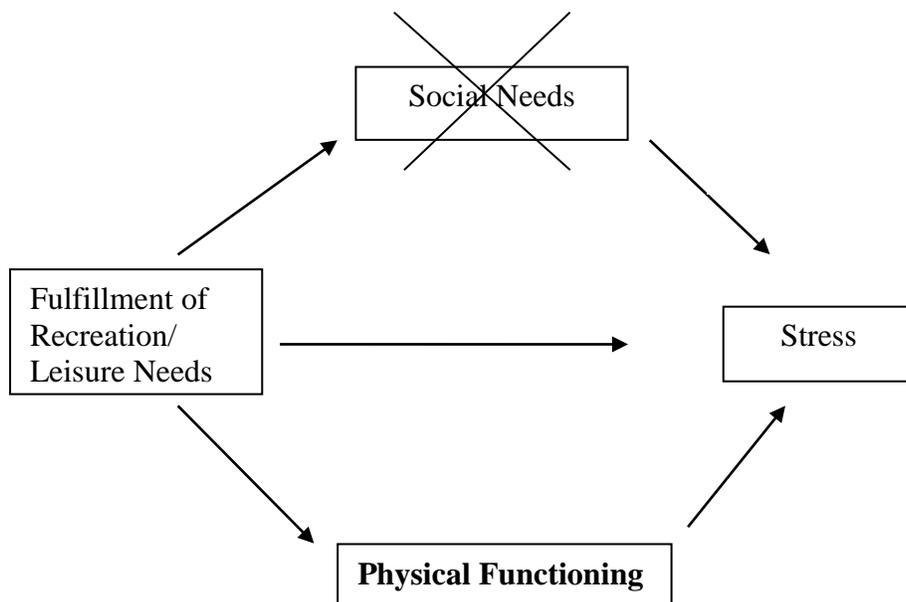
With the dependent variable being depression, both mediators were significant. Fulfilling social needs had a greater impact on reducing depression than did physical functioning (depicted in the following diagram).



When looking at anxiety as the dependent variable, fulfillment of social needs was not a significant mediator. Increased levels of physical functioning did mediate the relationship between fulfillment of recreation/leisure needs and lower levels of caregiver anxiety (depicted in the following diagram).



Fulfillment of social needs was also not a significant mediator in reducing caregiver stress. Physical functioning did mediate the relationship between fulfillment of recreation/leisure needs and stress (depicted in the following diagram).



## **Chapter 5: Discussion**

This study was conducted to determine the effect that fulfilling leisure needs had on mental health for caregivers of cancer survivors. It also investigated the impact of two mediators, social aspects and physical aspects, and determined the impact they had on caregiver's level of depression, anxiety, and stress. This chapter will discuss the findings of the study and it will look at the implications for practitioners and caregivers. Strengths and limitations of the study, as well as areas for future research, will be explored.

### **5.1 Unmet Leisure Needs and Psychological Well-being**

The findings indicate that fulfilling leisure needs does have a positive impact on caregivers' mental health, which agrees with Hypothesis 1. Depression, anxiety, and stress levels were all decreased when caregivers were able to find time alone, able to relax, and participate in activities that made them happy. Fulfilling social needs and having greater levels of physical functioning were associated with lower levels of depression and greater levels of physical functioning were associated with lower levels of anxiety and stress. "Leisure-lack," or having limited leisure time, can diminish one's well-being (Caltabiano, 1994). This corresponds with the findings that there is a correlation between meeting leisure needs and an increase in mental health. Satisfaction of an individual's psychological needs through leisure experiences can have an impact on their physical and mental health, which in turn has an impact on life satisfaction and personal growth.

### **5.2 Demographics**

As past research agrees, females are at a higher risk of depression and other psychiatric disorders (e.g. Rosenfield, 1980; Nolen-Hoeksema, 1987; Breslau, Schultz, & Peterson, 1995). The findings of the current study showed that being female was significant for caregivers in

terms of their levels of depression, anxiety and stress. This reveals that female caregivers are at a great risk for having decreased mental health.

For both depression and anxiety, age was not a significant control variable, denoting that regardless of age, all caregivers' experience the same levels of depression and anxiety.

Examining age in terms of stress, it was found the age is a significant variable, though once fulfillment of leisure needs was added to the model; age no longer had a significant impact on level of stress. Having a university degree, being employed, and relationship status were also not statistically significant.

### **5.3 Outcomes**

The sample of caregivers in this study were found to have lower levels of depression, anxiety, and stress as compared to what past literature has indicated (e.g., Bedini, 2002; Hagedoorn et al., 2008), where some studies found that as many as two-thirds of caregivers have depression and many experience high levels of anxiety and stress. Caregivers also reported that they have "low" unmet leisure needs. A possible explanation of why this sample was doing so well is that they were caregivers of long-term survivors. Some caregiver may be providing care to someone who was diagnosed with cancer 5 years ago. Toseland, Blanchard, and McCallion (1995) explain that periods after initial diagnosis and during terminal care are the most stressful. Therefore, these caregivers may have experienced higher amounts of unmet needs and lower levels of mental health in the initial stages of the cancer diagnosis and treatment. These caregivers may feel more comfortable in their role as the caregiver and may have adapted to the responsibilities equating to less burden and role strain.

### **5.3.1 Depression**

The results showed that 18.6%, or approximately 1 in 5 of the caregivers fell within subclinical levels of depression (as measured by the DASS).

As stated above, fulfilling leisure needs is correlated with depression. That is, when caregivers' have fewer unmet leisure needs, they also have lower levels of depression. The findings show that both mediators, social aspects and physical aspects, had a significant impact on caregiver's level of depression. It was revealed that fulfilling social needs – spending time with family and friends and telling family and friends how I was feeling emotionally – had a greater impact on level of depression than did fulfilling physical functioning. Caltabiano (1994) looked at social activities and it was found that the social aspects of an activity appear to be more important for improving mental health than the activity itself. Therefore, it may not be the actual activity that is important, but as long as there is a social component, participants will get the benefits of a social leisure activity.

These findings agree with Coleman (1993), who found that minimum levels of social leisure contact can provide a sizeable health benefit when compared to having no social leisure contacts at all. Leisure activities can be a great source to meet new people, develop friendships, and gain social support. For example, participating in an activity with others who share a common interest in the activity (e.g., scrapbooking, volleyball, going to concerts) can foster friendships sprouting from shared interest and can also provide the environment for the friendship to continue. Alluding to one's beliefs and perceptions, Iwasaki et al. (2002) describes that perceived social support is a belief and that social companionship is the behaviour. In the current study, caregivers were asked about their perceived social support and results showed that

feeling as though one has social support was an important aspect to caregiver's level of depression and mental health. Perceived social support may also foster social companionship.

Higher levels of physical functioning corresponded to lower levels of depression among caregivers. Even though physical functioning was shown to have a lesser impact on level of depression than social support, it was still a significant mediator in terms of lowering caregiver depression. Therefore, it is clear that increasing physical functioning is also an important factor in decreasing caregivers' level of depression.

### **5.3.2 Anxiety**

Results showed that 11.4% of caregivers were above the normal range of anxiety (as measured by the DASS).

Fulfilling leisure needs also decreased levels of caregiver anxiety. That is, when caregivers were able to meet their leisure needs, they felt less anxious. Looking at the mediating variables, only physical functioning appeared to be a significant mediator in terms of reducing anxiety. Caltabiano (1994) looked at physical leisure activities, specifically outdoor recreation and sport, and found that exercise improves physical health and it is also associated with reduced anxiety and depression. This study did not focus on a particular activity, but it was found that improving physical functioning, which can be achieved through various modalities such as sport or exercise, can effectively reduce caregiver anxiety.

### **5.3.3 Stress**

Fifteen percent of caregivers were found to be above the normal range for stress (as measured by the DASS).

Caregivers also experienced reduced stress when their leisure needs were fulfilled. As with anxiety, only one mediator, physical aspects, was found to be significant. The results

conclude that having a higher level of physical functioning equates to lower levels of stress.

Caltabiano (1994) showed that outdoor recreation can have stress-reducing benefits by elevating mood, as well as the possibility of outdoor physical exercise, which again has been shown to reduce stress.

Leisure is a great tool to help cope with stress and maintain good health. Looking at Iwasaki and Mannell's (2000) *hierarchical dimensions of leisure coping*, it was shown that leisure activities help to cope with stress and improve mood. Leisure palliative coping can give someone renewed energy and better equip them to handle stress when they are able to take a time-out from everyday stressors. Results from this study indicate that it would be beneficial for caregivers to participate in leisure palliative coping through activities that are physical in nature and that help to improve functioning and physical health.

#### **5.3.4 Summary of Mediators**

The findings show that the mediator of physical aspects was significant for each dependent variable – depression, anxiety, and stress (Hypothesis 3). Surprisingly, fulfilling social needs only had a significant effect on caregiver's level of depression and was not a significant mediator for caregiver's level of anxiety or stress (Hypothesis 2 was only met for depression and not anxiety or stress). Therefore, having higher levels of physical functioning proved to be a stronger mediator than fulfilling social needs for reducing caregiver anxiety and stress. In terms of depression, fulfilling social needs was the stronger mediator.

Physical functioning may have played a bigger role in reducing caregiver anxiety than fulfilling social needs because those with anxiety may not be comfortable in social situations, and telling someone about their feelings may in fact increase their anxiety. Another possibility is

that both anxiety and stress have a large physiological component, therefore having a higher level of physical functioning can equate to lower levels of stress and anxiety.

Coleman (1993) explains that the health benefits of leisure become more apparent when someone is experiencing higher levels of life stress. In this study, the average level of stress of caregivers, as measure by the DASS, fell within the normal range, so there is a possibility that if looking only at individuals who experience a high level of stress, fulfilling social needs may have a greater impact on reducing stress levels.

## **5.4 Implications**

### **5.4.1 Implications for Therapeutic Recreation Practitioners**

A major implication for practitioners that arose from this study is to concentrate on the meaning associated with an activity, instead of focusing on the activity itself. This is due to the fact that a leisure experience was measured from an internal viewpoint of the caregiver's perceptions, instead of what specific activities were participated in. To gain the benefits of a leisure experience, one has to be intrinsically motivated and experience choice. This study asked the caregivers if their leisure needs were being met, not what activity they were participating in or for the length of time they were engaged in that activity. Therapeutic recreation specialists should not prescribe activities (for example, telling someone they should run because it will improve physical functioning), but should work with an individual to find activities that provide meaning and enjoyment for them (Sylvester, Voelkl, & Ellis, 2001). Participants need to be interested in the activity in order to gain the maximum benefits. Therapeutic recreation specialists need to "understand leisure experience to maximize the value of those experiences for clients, and to assist clients in acquiring the ability to pursue leisure experiences that enhance their well-being" (Carruthers & Hood, 2007, p. 281). A leisure experience is one that is enjoyable, intrinsically motivating, optimal in nature, engaging, and freely chosen. Relating to

the self-determination theory (Ryan & Deci, 2000), allowing caregivers to freely choose activities and be intrinsically motivated will help to improve their mental health and overall well-being. Allowing the caregivers to have an input on the activities that are most appropriate for them can have many benefits. For example, leisure autonomy can lead to empowerment as well as mood enhancement through activities that are enjoyable (Iwasaki & Mannell, 2000). For caregivers, leisure palliative coping can be very helpful because having a break from caregiving responsibilities can rejuvenate and give caregivers more energy to take on their responsibilities.

Further, therapeutic recreation specialists should work with caregivers to help them increase their well-being - positive emotion, affect and experiences - on a daily basis (Carruthers & Hood, 2007). This can be accomplished by leisure participation that helps caregivers work toward their full potential and to function optimally. Coleman (1993) suggests that in terms of programming, practitioners can offer social activities that are of interest to the participant instead of a specific activity. This could be achieved by working with the caregivers to determine what interests them and what would provide them with meaningful activity. This study asked caregivers if they were able to express to their friends and family how they were feeling emotionally. This study showed that it was very important for caregivers to be able to talk with others about their feelings, and it is important for practitioners to note that social opportunities that allow for emotional expression are valuable. This relates to Iwasaki and Manell's (2000) dimension leisure friendships in the *hierarchical dimensions of leisure stress coping*. Through leisure friendships, one can acquire emotional support and will be better able to cope with stress. It is also important to find activities for caregivers that increase their physical functioning that are not seen as extra work and that can be done within their abilities.

Leisure education is also a practical implication that therapeutic recreation specialists should be aware of. Interventions to reduce the negative impacts of caregiving should focus on prevention programs (i.e. education sessions that explain the possible negative impacts of caregiving and help caregivers find activities that target these areas) (Walker, Pratt, & Eddy, 1995). The findings of this study reveal that leisure activities that are social in nature can help caregivers combat depression, and leisure activities that are physical in nature can help caregivers reduce their depression, anxiety and stress. Bedini and Guinan (1996a) found that many caregivers were unaware of the variety of leisure resources available to them and that it is important to provide leisure education and increase leisure awareness of availability of resources. Leisure practitioners should attempt to increase leisure opportunities, social contacts, and the perceived time the caregivers feel they can devote to leisure pursuits.

Bedini (2002) provides information about what to consider when designing community recreation programs for caregivers and states that practitioners should be proactive in looking for family caregivers, provide care for the care-recipients (parallel recreational activities), and include caregivers in the planning of activities. Including the caregivers in the planning will help to ensure that they are participating in activities that are truly meaningful for them. Allowing caregivers to be self-determined and freely choose their activities will help them to better cope with stress and improve their mental health. Bedini also suggests designing leisure education programs to educate about emotional burden and feelings of constant responsibility that may accompany caregiving. As it has been noted that caregivers experience a loss of social life (Bedini & Guinan, 1996b), it is important for caregivers to be aware of this and actively seek activities where they can maintain social contact. A decrease in social support can lead to depression and other negative health impacts, so caregivers should be educated about social

leisure opportunities. Caregivers should also be educated about the positive effect that physical functioning has on their mental health, as well as opportunities that can improve their health and physical functioning.

Educational interventions can also be provided for care-receivers. If care-receivers better understand the burden and distress experienced by their caregiver, they can work together with their caregiver to increase their mental health. Care-receivers can also be educated about the types of interventions that apply specifically to depression, anxiety, and stress and encourage participation from their caregiver.

Areas of intervention should include not only people who have been diagnosed with cancer, but also their care providers. Kim et al. (2008) also suggests interventions involving both the caregiver and cancer survivor and states that cancer impacts not only the person diagnosed with the disease, but also their family. Couples and families may benefit from interventions that enhance their ability to manage psychological distress, which can improve mental health.

This study has implications not only for recreation professionals, but also for other disciplines. Both occupational therapists, who play a role in improving or maintaining physical and daily living skills, as well as physical therapists, who work to improve physical functioning, can benefit from the knowledge that an increase in physical functioning can mediate the relationship between fulfilling leisure needs and an increase in mental health. Other disciplines can also use the results to note which types of interventions are helpful for caregivers. For example, the family doctor of a caregiver can recommend the caregiver participate in social activities if they are experiencing depression.

### **5.4.2 Implications for Caregivers**

The findings from this study also help to inform caregivers about ways to improve their mental health. It encourages caregivers that finding activities that are meaningful for them is important and shows that not all activities will have the same impact on their mental health. This study explains that caregivers can improve their mental health by finding time to do things that make them happy and fulfill their leisure needs. It also specifically identifies that participation in social activities and activities that can increase physical functioning can improve one's level of depression, and activities that can increase physical functioning can help to reduce caregiver stress and anxiety. Caregivers should work toward finding activities that are social and physical in nature to incorporate into their life and take time for leisure in order to improve, or prevent a decline in, their mental health.

As previously mentioned, caregivers have an impact on the cancer survivors' quality of life (e.g. Cameron, Franche, Cheung, & Stewart, 2002; Given, Given, & Kozachik, 2001; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). Therefore, if caregivers take time for themselves to participate in meaningful leisure activities that will improve their psychological well-being, they will be better suited to provide care and may have a positive impact on the care-recipient and that person's overall well-being.

### **5.5 Strength and Limitations**

Past research has measured leisure objectively and focused on specific leisure activities and the duration of time spent in an activity (i.e. time diary studies; Zuzanek & Mannell, 1983; Scott, 1997), as well as on the outcomes that are produced from these activities (i.e. running, travelling, outdoor-sport; Caltabiano, 1988; Caltabiano, 1994; Iwasaki, Mackay, & Mactavish, 2005). This study is unique because instead of focusing on specific activities, it operationalizes

leisure in terms of unmet leisure needs and this is a major strength to the study. Another highlight of the study is that leisure is surveyed from an internal viewpoint of the caregiver's perceptions as to whether they feel they have time to do things that make them happy, know how to relax, and find time alone just for themselves. Mannell and Kleiber (1997) define leisure as "time free from obligation, the freedom to do whatever one wants to do, or simply as doing something for its own sake" (p. 53). Mannell and Kleiber also explain that leisure can be a certain feeling or experience and that "senses of freedom, relaxation, enjoyment, and even intense concentration have been used to characterize leisure" (p. 53). This study defines leisure subjectively, which defined by Mannell and Kleiber, is that leisure is "associated with certain types of mental states, perceptions, meanings, needs satisfied, and/or experiences" (p. 54). Therefore, since this study measures leisure subjectively, it captures a true leisure experience, which provided the most benefits to health, instead of simply reporting what activities or for how long caregivers participated.

As previously mentioned, leisure coping beliefs are one's beliefs about how leisure can help you cope with stress (Iwasaki & Mannell, 2000). A person's perception of how much time they have for leisure, and the ability to participate in activities that help them relieve stress, is important to help shape their leisure patterns and to participate in freely chosen and enjoyable activities.

This unique way of defining leisure is a strength of this study, as well as a limitation. It can be seen as a limitation because it cannot give practitioners explicit leisure pursuits that caregivers can participate in. However, this is seen as a strength because it is important to have caregivers find activities that are meaningful for them. Individuals find meaning in different pursuits, and it is not necessarily one distinct activity that will produce the same positive benefits

for everyone. Ajzen (1991) explains that when looking at leisure benefits, it is more important “to assess whether people believe that a leisure activity helps them attain their goals than it is to assess progress towards the goal in a more objective manner” (p. 415). This study measured all its components subjectively, which is important because it shows how caregivers feel they are in terms of unmet leisure needs, social needs, and physical functioning and how well they feel fulfilling leisure needs positively impacts their mental health.

Not all caregivers experience the same needs in regard to leisure, or how they pursue leisure (Bedini, 2002). Caregivers can have different leisure interests and can have a different sense of entitlement to leisure, varying in how much they feel they deserve it. Therefore, it is important to get input from the caregivers instead of assuming everyone has the same leisure needs.

Practitioners should be able to provide opportunities for family caregivers to develop strategies to help them best overcome obstacles by finding them meaningful activities.

This study consists of a large sample, which is beneficial for statistical analysis and helps to effectively translate data. This study represents a wide range of survivor cancer types that caregivers are supporting. However, as with any quantitative study, there are limitations to research. Firstly, a quantitative approach may lack underlying meaning of respondent’s answers. Quantitative methods gain numerical descriptions rather than detailed narratives and may miss exactly what the participant is trying to convey. In a survey format, the respondents are restricted in ways they can answer questions and are forced to choose from pre-determined options that may not reflect how they actually feel. This approach does not allow for the same flexibility as a qualitative approach, however, it does enhance the generalizability.

Another limitation to this study is that I am working with secondary data. Secondary data sets are beneficial because there is already a large sample and the data have been collected.

However, it can also add complications because research questions are dependent on the data that has already been collected. I am not able to explore anything further than what is in the data sets. Using secondary data means I did not have control of the questions and could not gear the questions toward my particular research questions. Also, I am not able to collect any further information to back up my hypotheses. The way of measuring leisure in this study was to look at if caregivers were able to meet their needs in terms of finding things that make them happy, finding time to relax, and time alone. A leisure experience includes not only enjoyment and relaxation, but also feeling intrinsically motivated, having choice, commitment, control and challenge (Caldwell & Gilbert 1990). Therefore a limitation would be that the way leisure was measured did not provide a complete picture of all the aspects that make-up a leisure experience.

Another limitation is that the data is cross-sectional rather than longitudinal. Also, there is the possibility of bidirectional and reciprocal association between a number of the constructs examined. Bedini and Gunn (2002) explain that the demands of caregiving responsibilities can lead to depression, which in turn can lead to a decrease in leisure pursuits. This implies that the direction of my mediation model could go the other way. For example, having a higher level of mental health may increase one's ability to fulfill leisure needs, or increase the amount one participates in social and physical leisure activities.

## **5.6 Future Studies**

A recommendation for the Propel Centre would be to develop a survey that specifically looks at unmet leisure needs of caregivers and cancer survivors. This would allow an all-encompassing measurement of leisure and gain a better understanding of what leisure means for caregivers and survivors and the opportunities for them to experience leisure activities.

Qualitative studies delving deeper into the meaning of activities and why caregivers find activities meaningful is another area for future studies.

Future research could include the length of time since the care-recipient was first diagnosed with cancer. A new diagnosis may present with more complications due to the novelty, which may impact both the care-recipient as well as the caregiver. Sanson-Fisher et al. (2000) discovered that time since diagnoses was found to predict some of the patient's physical needs. Patients who had last attended a clinic more than a year ago were less likely to report physical needs than those who were in the clinic in the last month. This can be attributed to familiarity with treatment processes and the phase of active treatment. It would be interesting to examine how time since diagnosis may have an impact on caregivers. Other areas of future research include exploring the influence of a reoccurrence of cancer on the findings and controlling for those whose cancer has come back recently. As well, the type of cancer and its influence could be considered. Another variable that could be controlled for would be the relationship between the caregiver and care-receiver, allowing an in-depth exploration of the level of closeness between them and other aspects, such as if they live together or how close they are emotionally. An additional area to look at would be to investigate the type of disability the care-recipient has and examine the similarities and differences in terms of unmet needs between a caregiver of a cancer survivor versus a caregiver of someone with another disability.

Future studies could also explore the reverse relationship of how increasing mental health impacts fulfillment of leisure needs. Other relationships among the variables in this study could also be explored. For example, if it is possible that increasing physical functioning will lead to an increase in the fulfillment of leisure needs. Also, if there is a relationship between the mediating

variables, such as higher physical functioning equates to fulfilling social needs, or vice-versa, could be explored.

Lastly, pilot projects focusing on leisure education and mental health among caregivers could be implemented and evaluated to determine the efficacy of education sessions. Pilot projects of parallel activities or activities involving both the caregiver and survivor could be developed and run to determine if these interventions are beneficial.

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## Appendix A

**Table 5.** Variables from the The Cancer Support Person’s Unmet Needs Survey

Variable	Variable Label	Question as found in the survey	Response Options
<b>Dependent Variable</b>			
<b>Psychological Well-Being: Depression</b>	HWBWDN01	I found it hard to wind down	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
	HWBPOS03	I couldn’t seem to experience any positive feeling at all	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
	HWBINI05	I found it difficult to work up the initiative to do things	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time

	HWBFWD10	I felt that I had nothing to look forward to	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
	HWBBLU13	I felt down-hearted and blue	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
	HWBENT16	I was unable to become enthusiastic about anything	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
	HWBWOR17	I felt I wasn't worth much as a person	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good

			part of the time 3 = Applied to me very much, or most of the time
	HWBMEA21	I felt that life was meaningless	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
<b>Psychological Well-Being: Anxiety</b>	HWBDRY02	I was aware of dryness of my mouth	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
	HWBBRT04	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
	HWBTRM07	I experienced trembling (eg, in the hands)	0 = Did not apply to me at all

			<p>1 = Applied to me to some degree, or some of the time</p> <p>2 = Applied to me to a considerable degree, or a good part of the time</p> <p>3 = Applied to me very much, or most of the time</p>
	HWBFOO09	I was worried about situations in which I might panic and make a fool of myself	<p>0 = Did not apply to me at all</p> <p>1 = Applied to me to some degree, or some of the time</p> <p>2 = Applied to me to a considerable degree, or a good part of the time</p> <p>3 = Applied to me very much, or most of the time</p>
	HWBPAN15	I felt I was close to panic	<p>0 = Did not apply to me at all</p> <p>1 = Applied to me to some degree, or some of the time</p> <p>2 = Applied to me to a considerable degree, or a good part of the time</p> <p>3 = Applied to me very much, or most of the time</p>
	HWBHRT19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	<p>0 = Did not apply to me at all</p> <p>1 = Applied to me to some degree, or some of the time</p> <p>2 = Applied to me to a considerable degree, or a good part of the time</p>

			3 = Applied to me very much, or most of the time
	HWBSCD20	I felt scared without any good reason	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
<b>Psychological Well-Being: Stress</b>	HWBWDN01	I found it hard to wind down	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
	HWBOVR06	I tended to over-react to situations	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
	HWBNER08	I felt that I was using a lot of nervous energy	0 = Did not apply to me at all 1 = Applied to me to

			<p>some degree, or some of the time</p> <p>2 = Applied to me to a considerable degree, or a good part of the time</p> <p>3 = Applied to me very much, or most of the time</p>
	HWBAGI11	I found myself getting agitated	<p>0 = Did not apply to me at all</p> <p>1 = Applied to me to some degree, or some of the time</p> <p>2 = Applied to me to a considerable degree, or a good part of the time</p> <p>3 = Applied to me very much, or most of the time</p>
	HWBREL12	I found it difficult to relax	<p>0 = Did not apply to me at all</p> <p>1 = Applied to me to some degree, or some of the time</p> <p>2 = Applied to me to a considerable degree, or a good part of the time</p> <p>3 = Applied to me very much, or most of the time</p>
	HWBINT14	I was intolerant of anything that kept me from getting on with what I was doing	<p>0 = Did not apply to me at all</p> <p>1 = Applied to me to some degree, or some of the time</p> <p>2 = Applied to me to a considerable degree, or a good part of the time</p> <p>3 = Applied to me</p>

			very much, or most of the time
	HWBTOU18	I felt that I was rather touchy	0 = Did not apply to me at all 1 = Applied to me to some degree, or some of the time 2 = Applied to me to a considerable degree, or a good part of the time 3 = Applied to me very much, or most of the time
<b>Independent Variable</b>			
<b>Unmet Leisure Needs</b>	NQP1051	Finding time alone, just for myself	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
	NQP1053	Knowing how to relax	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
	NQP1059	Finding time to do things that make me happy	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need

Mediators			
<b>Social Needs</b>	NQP1061	Telling my family and friends how I was feeling emotionally	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
	NQP1062	Finding time to see friends and family	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
<b>Physical Functioning</b>	HWBGEN01	In general would you say your health is...?	1 = Excellent, 2 = Very Good, 3 = Good, 4 = Fair, 5 = Poor
	HWBLM02A/ HWBLM02B	Does <u>your health now limit</u> you in these activities? If so, how much?  a) <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf Climbing <u>several</u> flights of stairs	1 = Yes, limited a lot 2 = Yes, limited a little 3 = No, not limited at all
	HWBWK03A/ HWBWK03B	During the <u>last month</u> , how much time have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u> ?  a) <u>Accomplished less</u> than you would like Were limited in the <u>kind</u> of work or other activities	1 = All of the time 2 = Most of the time 3 = Some of the time 4 = A little of the time 5 = None of the time
<b>Control Variables</b>			

<b>Age</b>	sup_age	Age	18 : 94
<b>Gender</b>	NQP201	I am...	0 = Male, 1 = Female
<b>Education</b>	EDUC	Respondent's Highest Level of Education (derived variable)	0 = Secondary school or less, Trades, vocational, college or other 1 = University or higher
<b>Employment Status</b>	EMPL	Respondent's Employment Status (derived variable)	0 = Does not do paid work 1 = Does paid work
<b>Relationship to survivor</b>	DEMSUR01	Who gave you this survey? <i>(Please check the <b>ONE person</b> that most closely describes this person)</i>	0 = Wife, husband, or partner 1 = Parent(s) And 0 = Wife, husband, or partner 1 = Child(ren) / Grandchild(ren), Brother(s) or sister(s), Other Relative (e.g. aunt, uncle, grandparent, in-law), Friend(s), Housemate, Other <i>(please specify)</i> DEMSUR01OTH