The impact of life stage on the unmet personal and or emotional needs of cancer caregivers, as mediated by other unmet needs: An application of the Life Course Perspective.

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

The current study utilizes a life course approach in its exploration of the connection between life stage and psychological well-being, within the context of cancer caregivers. Further the study explores this connection in light of four possible mediating unmet needs factors that is unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs as well as the extent to which these factors differ within each group. The study utilizes data from The Cancer Support Person's Unmet Needs Survey (SPUNS) conducted by Campbell et al. in which a random, stratified sample of 1128 cancer survivors and their immediate caregivers, selected from the Cancercare Manitoba Cancer Registry, were surveyed (2009). The sample for the current study included 789 support persons selected for the study by the survivor for whom they cared. The study revealed that caregivers in midlife exhibited higher levels of unmet needs in work/ financial as well as future concerns life aspects. It is the expectation that the results of this study will enable practitioners to better support and fill the needs of caregivers allowing for improved quality of life and quality of care.

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Chapter 1

Introduction

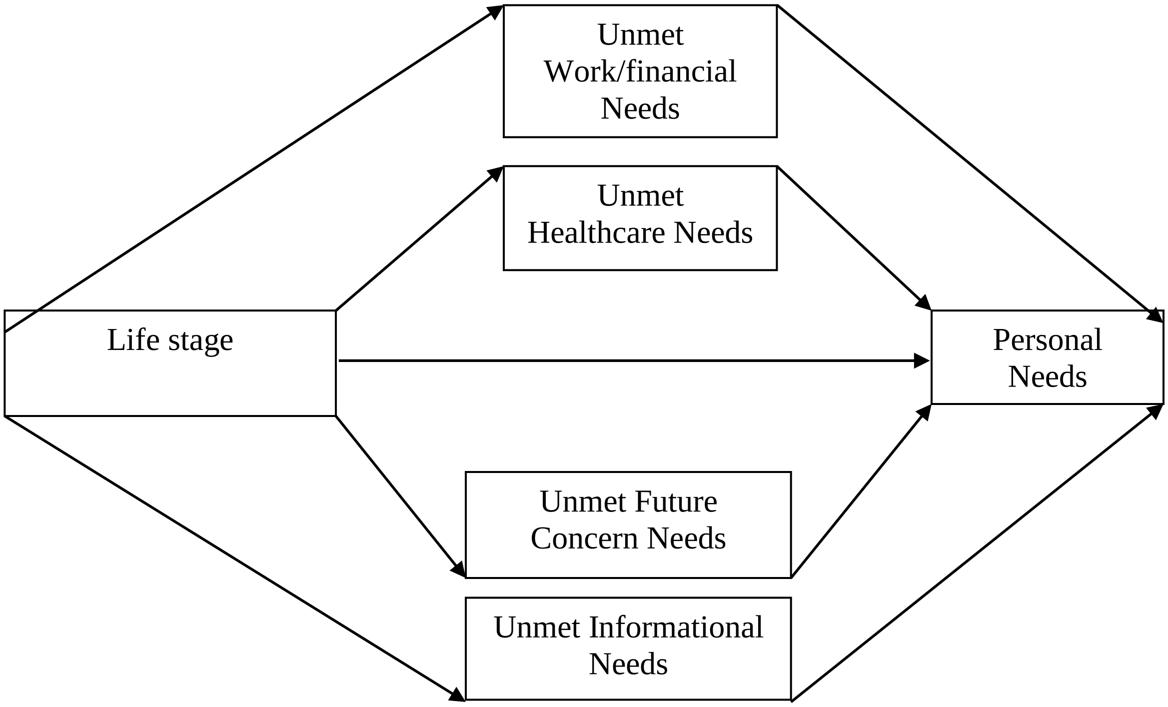
Advances in the medical arena, coupled with the ebbs and flows of population growth over the last several decades, have presented North America with the problems associated with an aging population (Aneshensel et al., 1995). Hodgkison et al. (2007) estimate that the current population is likely to experience a cancer rate of 33% and 25% in males and females respectively, before turning age 75. Added to this prediction is fact that an approximate 1.4 million Americans and 187,000 Canadians receive a new diagnosis of cancer each year, with 2 in 5 Canadians predicted to develop cancer in their lifetime (Given, Given, & Sherwood, 2012; Canadian Cancer Society, 2013). The simultaneous occurrence of these events translate into a rise in individuals requiring extended medical attention and care which will in turn spur an increase in the number of family members involved in cancer caregiving while simultaneously changing the dynamics of the traditional cancer caregiver role (Aneshensel et al., 1995; Lilly, 2011). Nijboer et al. (1998) define a cancer caregiver as the primary care provider to an individual diagnosed with cancer. Nijboer further states that the primary care provider is usually an individual from within the immediate familial network. Studies have shown that relatives of individuals living with cancer are as intensely affected by the events and processes of coping with cancer as the patients themselves (Strawbridge, et al., 1997; Revenson, & Pranikoff, 2005; Adams, Boulton, & Watson, 2009). Studies have also outlined the fact that caring for an individual with a progressive and degenerative illness such as cancer has large implications for caregiver quality of life (Weitzner, McMillan & Jacobson, 1999; Bee, Barnes, & Luker, 2008; Clarke et al., 2013). Further to this Moen, Robison and Dempster-McClain (1995) offer insight into the extent to which the life stage at which caregiving is undertaken affects the caregiver; with caregiving assuming a more normative role in later life as compared to earlier life stages. These factors, coupled with the realities and challenges of an aging population, spell substantial implications in the areas of life stage, cancer caregiving and cancer caregiver needs

(Aneshensel et al., 1995; Kim, et al. 2008; Siegel, Naishadham, & Jemal, 2012). The current study sought to analyze the dynamics involved in caregiver life stage by examining two distinct groups of caregivers, middle aged and older adult caregivers, this in an attempt to assess the degree to which the life stage of each group affects caregiver quality of life, defined for the purposes of the paper as perceived unmet personal needs and unmet emotional needs. The study also sought to ascertain whether any relationship observed between life stage and quality of life is influenced by current work or financial status, access to health care, access to health information, and degree of concerns about the future more specifically the extent to which these mediating factors present the caregiver with the unmet needs.

Study Rationale

The issue of population aging has highlighted the importance of the informal caregiver, thus bringing to the fore the necessity for increased research into the changing dynamics of caregiving (Aneshensel et al., 1995; Lilly, 2011). Some research has been done in the area of life course and caregiver needs with Moen, et al., (1995) elucidating on the life course, role context approach, by examining the relationship between the number of roles taken on by women of various socioeconomic, racial and cultural contexts and the resulting effects. Much of the research that has been done, however, focuses on a particular group of individuals, generally females of retirement age (Moen, et al., 1995; Moen, 1996 ;). There was need for research that focuses on the changing dynamics of caregiving as, while traditionally the caregiving role is assumed in later life, caregiving has over the last few decades become more common during midlife (Igarashi et al., 2013; Wolff & Kasper, 2006; Fingerman et al., 2011). This paper will present the result of comparisons made between both middle aged and older caregivers, assessing any effect the caregiving experience may have on unmet personal and or emotional needs within each group. The researcher concluded that there was also a need for research into whether the effect life course has on unmet personal and emotional needs is mediated by unmet needs in other life areas. The paper will present information on whether unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs affect the relationship between life stage and unmet personal and or emotional needs as well as the extent to which these factors differ within each group (see diagrams 1&2).

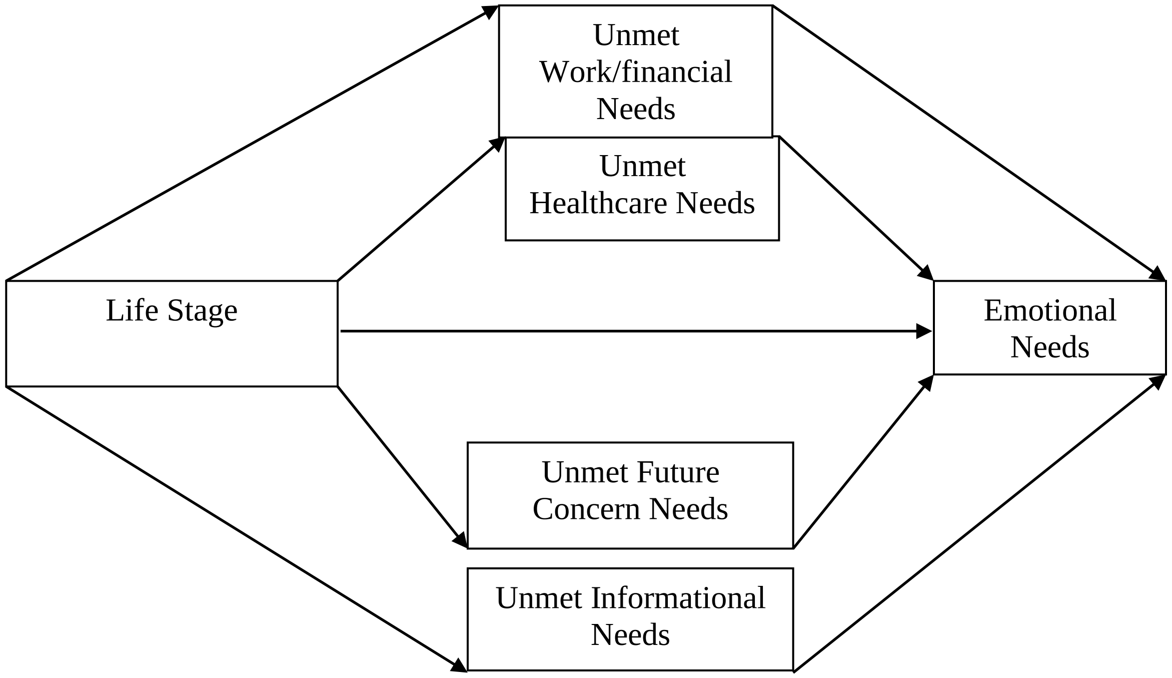
Diagram 1: *The impact of life stage on the unmet personal needs of cancer caregivers, as mediated by other unmet needs.*



Statement of Purpose

According to Moen, et al.'s 1995 research on the Life Course Perspective, caregiving at later stages of life, as opposed to earlier stages, is accepted and even anticipated as a normative and positive aspect of development. The extent to which the needs of caregivers are met also lends substantial influence to the caregiving experience (Strawbridge, et al., 1997). In initiating this study it was the expectation that the association between life stage and unmet personal and or emotional needs would be stronger for those at earlier life stages (40 to 59 years) than it is for those in later life stages (60+ years). Current work or financial status, access to health care, access to health information and degree of concerns about the future as associated with need fulfillment were also tested as mediators of this association (see diagrams 1&2). Data from the Cancer Support Persons' Unmet Needs Survey (SPUNS) done by Campbell et al were used for the purposes of this investigation (2009).

Diagram 2: *The impact of life stage on the unmet emotional needs of cancer caregivers, as mediated by other unmet needs.*



Research Objectives

The current study undertook an exploration of the comparability of the unmet personal and or emotional needs of middle aged versus older cancer caregivers, assessing the extent to which the needs of those within each group are affected by their life stage. The study also assessed whether the presence and level of unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs played a role in mediating the effect of the relationship between the main variables.

This study sought to accomplish the following:

1. Assess the relationship between the life stage of cancer caregivers and their unmet personal and emotional needs, with the expectation that life stage would have a direct effect on unmet personal and or emotional needs.
2. Explore the mediating effect that unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs have on the relationship between life stage and unmet personal and or emotional needs of members within both the middle aged and older adult groups.
3. Examine differences and similarities concerning the relationship between life stage and unmet personal and or emotional needs for each group.

Definitions

The Life Course Perspective: The Life Course Perspective is a multifaceted concept that focuses on specific themes including the interaction of human lives and society, sequencing or timing of life events, social interdependence, and the human capacity (Elder, 1994; Moen, Robison & Dempster-McClain, 1995; Hutchison, 2011). The perspective approaches human development from the point of view that healthy development takes place within specific times, processes, and contexts (Moen, Robison & Dempster-McClain, 1995; Hutchison, 2011). Life stage was assessed in the current study, using participant date of birth (Item 3 of Section 3 in the SPUNS). Study participants were classified into the categories of midlife, those between the ages of 40 and 59 born between 1950 and 1969 and older adult, those who are age 60 and above born on or before 1949 (Campbell, et al., 2009).

Cancer Caregiver: A caregiver is described as a primary care provider or principal support person (Nijboer et al., 1998; Campbell et al., 2009). Further, for the purposes of this paper, a cancer caregiver is defined as one who principally or primarily provides care for an adult cancer survivor who is 19 years and older and is 1 to 5 years post-cancer diagnosis (Nijboer et al., 1998; Campbell et al., 2009; Campbell et al., 2010). The caregiver sample that was used for the purposes of this study was self-selected by the cancer survivor to whom they provide care and this selection process was guided by the following definition for principal support person; "Someone you can count on and who helps you with your needs" (Campbell et al., 2009, p. 3354)

Caregiving: Aneshensel et al elucidates on the caregiving experience by defining it as the provision of unpaid assistance to an individual with physical, developmental or psychological needs and equating it to a career; one that, unlike other careers that are propelled by motivation, is driven by the functional dependency created in caring for another individual (1995). The caregiving experience is one which is punctuated by numerous stages involving various changes and decisions. These stages when applied to the Life Course Perspective are known as transitional changes, defined as "movement from one status to another" (Aneshensel et al, 1995, p. 22). The three main stages of the caregiving experience include: commencement of caregiving responsibilities (role acquisition), performance of caregiving tasks (role enactment) and detachment from the caregiving process (role disengagement). Caregiving then is a dialectical process characterized by a sequence of changing events, likely to present the caregiver with both physical and emotional challenges (Aneshensel et al, 1995; Kurtz, Kurtz, Given, & Given, 2004).

Unmet Needs: Campbell, (2009) defines unmet needs as "a problem or concern for which a person is unable to get the help they need to resolve the problem" (p. 12a). The current study measured the levels of unmet personal and emotional needs of both middle aged and older adult caregivers. Further to this the study assessed unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs, these in the form of mediating variables on the relationship between life stage and personal and emotional unmet needs.

Information Needs Factors: Unmet information needs for the purposes of this study are defined as the inability to access professional written or oral information pertaining to survivor care or management. Campbell et al, define unmet information needs as "unmet needs that relate to finding information" (2009, p. 2). The study utilized the Unmet Information Needs category in the SPUNS as a measure of unmet information need. This category was assessed using data collected from Part A – Unmet Information Needs (Items 1 to 27) in Section 1 of the survey.

Future Concerns Needs Factors: Campbell et al., define unmet future concerns needs as "Unmet needs that relate to knowing about the future" (2009, p. 9). The current study defines unmet future concerns needs as needs that have been created due to a deficiency, inadequacy or inability to address concerns regarding future issues that an individual perceives will develop or persist. Further the study measured unmet future concerns needs by assessing data collected utilizing Part B of Section 1– The Future (items 28 to 31), in the SPUNS (Campbell et al., 2009).

Healthcare Needs Factors: This study defines unmet health care needs as insufficient or lack of access to health care intervention or medical management. Campbell et al, define unmet healthcare needs as "unmet needs that relate to medical care" (2009, p. 14). The study utilized the Unmet Needs for Access and Continuity of Health Care category in the SPUNS as a measure of unmet healthcare needs. This category was assessed using data collected from

Part D – Unmet Needs for Access and Continuity of Health Care (Items 40 to 48) in Section 1 of the survey (Campbell et al., 2009).

Work or Financial Needs Factors: Campbell et al., define work or financial needs as “Unmet needs that relate to your job or finances” (2009, p. 11). The current study defines work or financial needs as needs that create a deficiency in the financial or employment standing of an individual. Further the study utilized the unmet financial needs category in the SPUNS as a measure of unmet work or financial need. This category was assessed using data collected from Part C – Unmet Work and Financial Needs (Items 32 to 39) in Section 1 of the survey (Campbell et al., 2009).

Personal Needs Factors: Unmet personal needs are defined as “unmet needs that relate to you personally” (Campbell et al., 2009, p. 16). The current study defines unmet personal needs as a deficiency in the personal aspects of an individual’s life. Further the study utilized the unmet personal needs category of the SPUNS as a measure of the unmet personal needs that caregivers have by assessing data collected utilizing Part E – Unmet Personal Needs (Items 49 to 62) of Section 1 in the SPUNS (Campbell et al., 2009).

Emotional Needs Factors: Unmet emotional needs are defined as “unmet needs that relate to your feelings” (Campbell et al., 2009, p. 19). The current study defines unmet emotional needs as a deficiency in the emotional or feeling aspects of an individual’s life. Further the study utilized the unmet emotional needs category as a measure of the unmet emotional needs that caregivers have by assessing data collected utilizing Part F – Unmet Emotional Needs (Items 63 to 78) of Section 1 in the SPUNS (Campbell et al., 2009).

The Propel Centre: This study employed the use of surveys developed by the Propel Centre for Population Health Impact (an alliance between the University of Waterloo and the Canadian Cancer Society). The Propel Centre staff, headed by Researcher H. Sharon Campbell, developed psychometric instruments that measure the unmet needs of both cancer survivors and their caregivers. The current study utilized the results of the Propel Centre's data set on cancer caregivers in addressing the research questions.

Research Questions and Hypotheses

The researchers sought ascertain answers to the following questions:

1. What direct relationship does the life stage of cancer caregivers have on their level of unmet personal needs?
2. To what extent is the relationship between the main variables mediated by unmet work or financial, health care, information, and future concern needs?

Having examined the dynamics associated with answering the above questions the current study hypothesized that:

> HYPOTHESIS 1: The acquisition of caregiving responsibilities in middle age (ages 40 to 59) would have a more deleterious effect on caregiver unmet personal and or emotional needs than the acquisition of caregiving responsibilities as an older adult (ages 60 and above).
>
> HYPOTHESIS 2: Additional unmet caregiver needs, more specifically unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs, will serve to affect the association between life stage on levels of unmet personal and or emotional needs; resulting in an increase in the dependent with a greater increase observed in middle age (40 to 59 year old) adult caregivers than in older (60+ year old) adult caregivers.

Literature Review

This review attempts to identify and examine previous research on the association between life stage and the unmet needs of cancer caregivers. The search strategies used involved a use of the JUSTOR, and PubMed databases utilizing Medical Subject Heading (MeSH) terms on a consistent basis between 2011 and 2013 in search of published peer review articles on the subject matter.

Cancer Caregiving and Quality of Life

A key concept in studies on quality of life is that of role enhancement which purports the acquisition of additional roles as being beneficial to well-being in that an accumulation of social identities enhances quality of life. The alternative to this concept is that of role strain which asserts that an increased number of roles translates to an increased number of obligations which causes psychological distress and a decreased quality of life (Moen, et al., 1995). Caregiving is an experience that affects the overall quality of one's life. The outcome of this event may be one that has a negative or positive effect on the caregiver and is dependent on the extent of care duties associated with the experience as well as the approach the caregiver takes to caregiving. The roles associated with caregiving are seen as an enhancement to caregiver quality of life when caregiving is perceived as beneficial. Role strain steps in, on the other hand, when the caregiver focuses on the experience as an additional obligation which negatively affects quality of life (Moen, et al., 1995; Reid & Hardy, 1999).

The caregiver's perception of the caregiving role is, according to Moen, et al., (1995) also heavily influenced by the sequencing or timing of the event and its relation to the caregiver's perceived life sequence (Elder, 1994). This indicates that in order for the caregiving experience to be a positive one it must be understood as normative in its timing in the caregiver's perceived sequence of life events (Moen, et al., 1995).

Another aspect of caregiving that substantially affects the caregiver's quality of life within the caregiving experience is the type and tone of the relationship that the caregiver shared with the patient before the acquisition of caregiving duties. A close and positive relationship between caregiver and survivor prior to acquisition of the caregiving role will naturally engender a more positive caregiving experience. A prior negative, neutral or nonexistent relationship between caregiver and survivor will, on the other hand, tend towards a negative or unsatisfactory care relationship which will substantially affect the possibility of diminished quality of life (Kim et al., 2008).

Finally the toll that the caregiving relationship takes on the caregiver is also of vital importance. The Life Course Perspective stresses the impact of early life experience on later life experience meaning, in the context of caregiving, that what one brings into the caregiving process will affect the outcome of this experience (Elder, 1994; Moen, Robison & Dempster-McClain, 1995). The emotional, physical, social and financial states of the caregiver prior to acquisition of the caregiver role are therefore crucial to the results of the caregiving process. The caregiver's prior resources are important in their effect on the levels of objective and subjective care burden that the caregiver perceives within caregiving process. These variables can leave the caregiver with an increased perception of unmet needs which in turn can have a substantial effect on caregiver quality of life (Nijboer et al., 1999; Nijboer et al. 2001; Pinquart, & Sorenson, 2003).

Caregiver Unmet Needs

Seventy-three point four percent of female caregivers and 80.9% of male caregivers report providing care for over two years with 1 in 5 providing care for a decade or more, and this to multiple individuals (Duxbury, Higgins, & Smart, 2011). The life of a caregiver can be extremely demanding and usually involves maintaining a balance between the various requirements of the survivor's life and the demands of the caregiver's personal life. The life of a cancer caregiver may involve balancing any number of care tasks such as physical care, finance management and or financial support, nutritional support, housekeeping, symptom management, medication management, procedure maintenance, transportation and a host of other duties all above and beyond the managing their own lives and families (Sanson-Fisher et al., 2009; Clarke et al., 2013). This balancing act requires a substantial amount of skill and it is easy for the life of a cancer caregiver to become unbalanced with Moen, Robison and Dempster-McClain (1995) outlining the fact that caregivers often neglect their needs in favor of providing adequate care. This self-neglect that is also common of cancer caregivers often leads to an overall decline in physical and emotional health, coupled with an increase in overall perceived unmet needs leading to a decrease in quality of life (Strawbridge, et al., 1997; Revenson, and Pranikoff, 2005; Adams, Boulton, & Watson, 2009; Sanson-Fisher et al., 2009; Duxbury, Higgins, & Smart, 2011, Clarke et al., 2013).

Research has also uncovered the fact that the needs of caregivers often go ignored by the healthcare team connected with the management of their survivor, with healthcare professionals making the assumption that caregivers have either acquired the knowledge necessary to undertake the caregiving role or are able to undertake the task based on an innate sense for care and caregiving (Kim et al, 2010; Given, Given and Sherwood, 2012, Blindheim et al., 2013).

The Cancer caregiver burden is also further exacerbated by substantial out of pocket and time cost with weekly out of pocket expenses anywhere from $300 to $700 with the time cost associated with caregiving being estimated in the thousands per month (Hanly et al., May 2013; Hanly et al., June 2013).

Much of the research that has been undertaken in the area of caregiver need has focused on the needs of caregivers during treatment of the cancer patient and these studies have highlighted needs in all areas (Given & Given, 1992; Wagner, Bigatti, & Storniolo, 2006; Schumacher et al., 2008) Research has demonstrated, however, that the needs of caregivers actually increase over an extended period of caregiving which indicates that the needs of the caregiver not only persist beyond treatment but become more potent over a protracted period of time (Moen, Robison & Dempster-McClain, 1995; Hodgkinson et al., 2006).

There is still a substantial amount of research that needs to be done on the effects of the caregiving process. While caregivers identify a primarily lack in the area of information needs, caregiver needs range from personal needs in areas where habits have been adjusted or abandoned altogether, to physical needs where care requires physical exertion and is exasperated by caregiver self-neglect of physical needs, to emotional needs derived from the isolation and mental strain associated with caregiving (Campbell et al., 2009; Sherwood et al., 2006; Cipolletta et al., 2013).

Life Course Perspective

The central theoretical focus of this study pivoted on the Life Course Perspective, it is therefore important that a complete synopsis be presented on this fundamental theme. The Life Course Perspective delineates the relationship that exists between human behavior and the passage of time. More specifically it captures the essence of life from birth to death as it is influenced by changes in social integration, age, life transitions and relationships. This Perspective affords us a glimpse into who we are as individuals through an understanding of our total development over time (Elder, 1994; Hutchison, 2011). One major concept of the Life Course Perspective is that of the various cohorts into which individuals transition as they progress along the life trajectory. A cohort is any group of individuals connected by time of birth that experience a similar culture and endure various transitions and changes at a relatively similar age. Members of a cohort will often have to develop coping strategies in order to compensate for particular circumstances associated with that cohort, such as a reduction (when compared to the previous cohort) in the number of children born to members of a cohort that is very large (Hutchison, 2011). A life stage is encompassed within the boundaries of a cohort in that while the members of a cohort will share generational experiences the members of a life stage share a relatively similar age and experience various life transitions at the similar times. Our current study involved two life stages: A middle aged group comprised of those between the ages of 40 and 59, born between the years 1950 and 1969; and an older adult group comprised of those ages 60 and over, born on or before the year 1949. This section of our paper focuses on the four major themes that help to sum up the Life Course Perspective and their relationship to the unmet needs of the two groups of cancer caregivers involved in the current study, the section will also focus on the strengths and limitations of the perspective as it applies to our study.

Life Course Themes:

Interplay of human lives and historical time: This aspect of the Life Course Perspective lays emphasis on the boundaries of the human experience in the context of shared historical time. Shared experiences within a cohort can have the effect of creating a closer bond between members or splintering them into subgroups (Elder, 1994; Li, Cardinal, & Settersten, 2009; Hutchison, 2011). Caregiving when experienced as a societal norm is one which is generally experienced as a cohort. While this event may be one that is shared by a majority of those within a particular cohort, it may have a splintering effect, as caregiving tends to be isolative (Aneshensel et al., 1995). Another aspect of the caregiving experience that is also to be considered is the fact that the face of caregiving has changed in the last few decades. Thus caregiving now more frequently occurs at non normative times in the caregiver's life as is seen in the emergence of the Sandwich Generation also known as the Pivots redefined as middle aged adults who simultaneously serve as the main caregiver for their children (of any age group) and their elderly parents (Igarashi et al., 2013; Fingerman et al., 2011). This situation would serve in splintering a cohort as a mistimed event is one that may not be shared with many other cohort members, thus serving to isolate the members and separating the group. The study posited that a feeling of isolation, a decreased quality of life and a perceived increase in personal and or emotional needs would more acutely affect the middle aged group as traditionally caregiving is perceived as less normative for this group and thus fewer members of the middle age group would have shared the experience with the study participant, allowing for cohort splintering and isolation of the members.

Timing in individual lives: The timing of events is important within a cohort, but it is important on an individual basis as well. Here the perspective outlines the concept of what society defines as normative. Particular events and experiences are expected at a particular time within the life of an individual, and these expectations are generally based on ideas about maturity and readiness in taking on the responsibilities associated with an event (Elder, 1994; Li, Cardinal, & Settersten, 2009; Hutchison, 2011). Caregiving has been found to be normative at a particular stage in the life course (Moen, Robison & Dempster-McClain, 1995). The time or life stage at which caregiving responsibilities are taken on is thus an important aspect of whether or not caregiving has a positive or negative effect on the caregiver (Moen, Robison & Dempster-McClain, 1995). Just as on a group level, a caregiver needs to have a personal perception that the caregiving experience is one that fits with the general life trajectory. The study postulated that members of the middle aged cancer caregiving group would experience a decrease in quality of life with increased perceived unmet personal and or emotional needs due to the perception that caregiving at that stage of life is mistimed and is thus not normative.

Linked or interdependent lives: Here the perspective explores the interconnectedness of the human experience and the extent to which we need others. Again the connections in human lives are sustained or hindered by the circumstances associated with that particular situation. Further, these connections can bring about both positive or negative outcomes and relationships (Elder, 1994; Li, Cardinal, & Settersten, 2009; Hutchison, 2011). The caregiver – survivor dyad is one that is undoubtedly linked, and caregivers do report finding fulfillment in the caregiving experience (Aneshensel et al., 1995). Caregiving however does come with its fair share of challenges and quality of life for cancer caregivers can be substantially influenced if their normal lives are considerably and negatively affected by the issues associated with caregiving (Hagedoorn et al., 2008).

Human agency in making choices: The theme human agency speaks to human autonomy, as they act in sovereignty over their life affairs and the associated choices. This freedom however is contingent upon various life circumstances such as human ability, resources, access, motivation, and circumstantial constraints that serve to propel, or restrain (Elder, 1994; Li, Cardinal, & Settersten, 2009; Hutchison, 2011). The road to becoming a caregiver is often one that the caregiver thinks he or she has taken by choice. This however is generally not the case. The choice of who becomes a caregiver within a group, is made by societal and group expectations, and is highly dependent upon the culture of the group involved. Caregiving responsibilities are usually assigned based on fulfillment of the group's requirements for an individual with the highest propinquity in kinship, proximity, age, and or level of social involvement to their ideal for a caregiver (Aneshensel et al., 1995). The fact that the caregiver was not the one who made the choice to enter into this life sphere is irrelevant. It is however important that the caregiver thinks this process was a choice. An individual who perceives that the caregiver duties have been thrust upon him or her will have a more negative approach within the caregiving experience, versus an individual who assumes that it was a matter of choice. The study assumed that of the two groups being studied the middle age group would have a higher tendency towards assessing the caregiving situation as a duty rather than a choice due again to caregiving within this group being less likely to be seen as normative. As such the study suggested a higher likelihood of the members of this group having a diminished quality of life, with increased perceived personal and or emotional needs.

Strengths and limitations of the Life Course Perspective

The Life Course Perspective is the ideal in examining the current research question as its strengths allow for the examination of the impact of social and historical change on human lives and behavior. Thus in the examination of our two groups we are able to assess the extent of the impact of time and social change on the needs perceptions of our participants. The Life Course Perspective is also ideal for our current study as it focuses on the concept of linked lives and the extent to which our connections to each other affect our life trajectories. The caregiver-survivor dyad is one that exemplifies this concept and the results of this relationship result in substantial changes in life trajectories.

A major limitation of this perspective however is just how broad it really is. The Life Course Perspective focuses on the theme of heterogeneity or diversity, which in light of our current study limits the ability to search for patterns of human behavior among our test subjects. Another weakness of this perspective is its limited ability to link the wider society with the individual and family. This is important in our current study as social support for caregivers is key in working towards needs fulfillment (Hutchison, 2011).

Life Course Perspective and Cancer Caregiving

The life Course Perspective is distinct in its focus on the process of change within particular contexts of an individual's life and how this process extends across the various stages of life (Elder, 1992). The theory has, over the course of its development, brought to the fore questions on the human experience in old age and how this experience is affected by factors within earlier stages of life as influenced by societal change upon these processes (Elder, 1992; Settersten, 2003). The current study sought to focus on the direct relationship between the life stage of an individual and the extent to which that individual experiences unmet personal and or emotional needs leading to an overall decreased quality of life within the context of cancer caregiving. The current study also sought to assess whether this direct relationship is mediated by factors created in the presence of other unmet needs, namely work or financial needs, unmet healthcare needs, unmet information needs and unmet future concern needs. In this section of our paper we will address various aspects of the middle age and older adult groups' experience individually, each in connection with the Life Course Perspective and cancer caregiving.

The Middle-Aged Cancer Caregiver: One of the two groups that were the focus of this study is known as the Sandwich Generation or Pivots, terms used to describe the middle-aged adult who, along with having the responsibilities of formal employment and family obligations, is also a caregiver to one or both parents (Igarashi et al., 2013). Often those of this group find themselves managing the needs of multiple generations, which Rozario, Morrow-Howell, and Hinterlong (2004) have explained, can have a negative effect on various aspects of their lives.

Role Acquisition: Up until the last few decades it was not as common to have members of this life stage involved in older adult caregiving duties. While it is much more common in today's society, with research showing more middle age adults involved in caregiving duties than older adults, this group still does not view the acquisition of caregiving roles as normative due to the idea that caregivers are generally older/retired individuals who are able to devote a lot of time to the role (Aneshensel, et al. 1995; Given & Sherwood, 2006; Wolff & Kasper, 2006). In the case of the middle aged group, life demands and commitments are usually varied and numerous. This group will generally take on the caregiving role in the absence of a more suitable substitute and even in these situations there is also need for an almost specific set of circumstances. These circumstances include a close familial tie to the care recipient, absence of resources to secure professional care, and strong familial expectations (Piercy & Chapman, 2001). It is approximated that 25% of adult children are primary caregivers to a parent and that up to 41% of employed caregivers will cut work hours in order to provide this care. In the current study the above mentioned factors, coupled with the fact that the members of this group extend an average of 6 hours of care per day, brought about the expectation that the study participants within this group would experience a lower quality of life with the acquisition of the caregiving role based on the degree to which its members extend themselves in order to accommodate caregiving responsibilities (Given, Given, & Sherwood, 2012; Igarashi et al. 2013). This expectation was also based on the assumption that the experience is considered to as non-normative at this period of life (1995).

Financial Aspect: The middle age life stage is especially vulnerable to financial distress in the current situation based on the changing dynamics in today's economy. The middle age group today finds itself truly in the middle. This group faces an increased societal demand for higher educational levels, prompting a later entrance into the formal working world and higher levels of debt. It also faces fewer employment opportunities, and a weaker global economy that is still in the throes of a recession. This, coupled with the substantial out-of pocket costs associated with cancer caregiving, and loss of income due to time taken away from work because of caregiving activities can lead to an increased perception of unmet personal and or emotional needs and a decrease in quality of life (Given & Sherwood, 2006; Duxbury, Higgins, & Smart, 2011; Igarashi et al., 2013)

The Older Adult Cancer Caregiver: The second of the two groups in this study is the older adult life stage. This group consists of those ages 60 years and older and are usually the spouses of the survivors. The members of this group have for the most part relinquished most of their formal roles, with many having retired from formal employment, and not being responsible for taking care of young children. Members of this group will often find themselves managing only the needs of their current household with minimal involvement in roles associated with other generations, for example occasionally babysitting the grandchildren. This group experiences caregiving as a normative next step and will likely experience less negative consequences in taking on the caregiving role (Moen, Robison & Dempster-McClain, 1995; Rozario, Morrow-Howell, & Hinterlong, 2004).

Retirement: One major aspect of the life course that specifically affects this group is that of retirement; defined as withdrawal from the workforce in later life (Moen, et al., 1995). While work is thought to give meaning to life, retirement within this group is considered a natural progression into a different phase of work life, as is the acquisitions of additional roles to replace formal employment. It was the expectation of this study that the acquisition of the role of cancer caregiver within this group would result in lower levels of perceived unmet personal and or emotional needs as compared with those of the middle aged group.

One aspect of retirement that may contribute to a lower quality of life and an increased level of unmet needs is the circumstance surrounding retirement. Poor physical health is often associated with reasons behind retirement (1995; Nijboer et al., 1998). A retiree in poor physical health who has retired due to this ill health is less likely to perceive retirement as normative and will experience a lower quality of life. It was the expectation of the study that were the cancer caregiving role to be added to a situation such as this one, it would serve to further decrease quality of life while substantially increasing perception of unmet needs. Conversely Moen, et al. (1995) outline that individuals with increased levels of wellbeing are more prone to prolonging work or taking on compensatory roles after retirement, which suggest that an individual within this age group who retired under what is perceived as conventional circumstances will view cancer caregiving as a natural next step. This set of circumstances speaks to an increase in quality of life and a decrease in perceived unmet personal and or emotional needs.

The concepts of retirement and gender overlap in caregiving as well with Moen, et al. (1995) outlining the extent to which gender shapes the nature of employment one undertakes as well as the length of time for which one stays employed. Women are, more often than not, employed of shorter periods of time than are men, due to life requirements including child rearing and familial obligations. Caregiver role acquisition is therefore again seen as a more normative aspect of the life course for women than men.

Gender: Caregiving is generally perceived as a concept which has more of an application for women due to the traditional view of women as having life trajectories that are more embedded in social and familial connections and support. Female perception of the caregiver role however is also highly dependent upon the individual’s views of traditional female roles with women who have more traditional views of female roles having a more positive experience in the caregiving process (Moen, et al., 1995; Quick & Moen, 1998; Fingerman et al., 2011). An application of this concept to that of cancer caregiving suggests that acquisition of the cancer caregiver role would be more highly perceived as a normative part of the life course to the female members of our study participants, to the extent that these participants do not have a negative perception of traditional female roles. Further to this the study conjectured that female study participants within the older adult group would experience a higher quality of life as well as fewer perceived unmet personal and or emotional needs than those within the middle adult group of our study due to a combination of their decreased number of roles and a more traditional concept of female roles. We conjectured that those within the middle aged group would generally have higher numbers of roles and a less traditional view of female roles (Moen, et al., 1995; Reid & Hardy, 1999).

Men on the other hand, it has been noted, demonstrate an increase in well-being and quality of life with an increase in the number of roles they acquire. This finding suggested that our research should reveal a higher quality of life in males with higher numbers of roles, with the law of diminishing returns stepping in after a certain point and as the number of roles becames overwhelming (Moen, et al., 1995; Kim & Moen, 2002; Rozario, Morrow-Howell, & Hinterlong, 2004). It was however also the expectation that male study participants within the older adult group would experience a higher quality of life as well as fewer perceived unmet personal and or emotional needs than those within the middle adult group of our study due to the concepts of caregiving being non normative at earlier life stages as well as the fact that middle aged men would have higher numbers of roles and would thus experience role strain at a faster rate than our older aged study participants.

Summary

The North American population is on the verge of a substantial age shift that could quite considerably change the entire face of health care and more specifically caregiving. This fact coupled with predictions of increased rates in cancer diagnoses speaks to an increased need for in-home cancer caregivers. A cancer caregiver is defined as the primary carer for an individual diagnosed with cancer and is usually an individual from the immediate familial network. This speaks to the active involvement of partners and family in the care of those living with or recovering from cancer which can result in participation to the detriment of their own needs.

Current studies have indicated that caring for an individual with a progressive and degenerative illness such as cancer can have large implications for caregiver quality of life which in the case of an increased cancer caregiver population will have large implications for population health. It is therefore imperative that the needs of the cancer caregiving population be addressed as a priority. Studies have also indicated that the time at which caregiving role is acquired is imperative in its influence on caregiver quality of life.

This study sought to address the current situation through an analysis of the dynamics involved in the timing of caregiving. The study examined two distinct groups of cancer caregivers, a middle aged and an older adult group, in an attempt to assess the extent to which the timing of caregiver role acquisition affects caregiver unmet personal and or emotional needs within each group. The study also assessed the degree of influence that current work or financial status, access to health care, access to health information and degree of concerns about the future had on the relationship between the two main variables, more specifically the degree to which these mediating factors presented the cancer caregiver with the unmet needs.

Research Methods

This section encompasses a discussion of the procedures beginning with the research method employed in this study. A discussion of the survey, the sample used in the current study, as well as the research sample will ensue. Finally survey items and additional variables will be discussed and expounded upon.

Quantitative Method: In order to examine relationship between life stage and the unmet personal and emotional needs of cancer caregivers a quantitative research method was selected; this to present a complete numerical picture of the resulting data. The researchers chose this method in order to effectively assess the research question while, to the greatest extent possible, guarding against other possible alternative interpretations of the results produced (Punch, 2005). Quantitative research design offers researchers a means through which to objectively test theories by observing the resulting relationship of interacting variables (Creswell, 2009). The current research employed the method of secondary data analysis in observation of this relationship. More specifically the study observed data from the SPUNS collected by Dr. H. S. Campbell and her team at the Propel Centre (Campbell et al., 2009).

Sample: The sample used in this research was selected from the Campbell research (Campbell et al., 2009). The population sampling framework from which Campbell et al. drew their sample is based in the Cancer Registry run by Cancercare Manitoba. Cancercare Manitoba supports a registry comprised of individuals who are 19 years and older and have, in the prior 12 to 60 months, had a confirmed cancer diagnosis. Cancercare Manitoba identified a cross-sectional, stratified random sample of 1600 survivors classified by length of time since diagnosis, the classification time periods being 12 to 24 months, 25 to 36 months, 37 to 48 months, and 49 to 60 months. 1128 survivors were ultimately selected to participate in the study. The 1128 selected participants were sent an initial survey along with an invitation letter to engage their caregivers in a follow-up survey called the Cancer Support Persons' Unmet Needs Survey (SPUNS). The SPUNS demonstrated strong item test-retest reliability with Campbell et al setting a retention criterion of .70 within the 95% confidence interval. Face, content, and construct validity for the SPUNS were also strong as was internal consistency with a Chronbach alpha = .990 for the overall scale. The strength of the survey was demonstrated in over 85 percent of support persons finding the survey clear and easy to understand (Campbell et al., 2009).

Survey Variables and Scales

The SPUNS is a 78 item instrument outlined in three sections each of which collected data on unmet needs in different areas as well as demographic and contextual questions about questionnaire acceptability. The survey collected information on the age group in which the caregiver fell as well as their gender, employment status and educational background. It collected information on the extent of the relationship between survivor and caregiver, whether the survivor lived with the caregiver, and gathered information about the nature of the survivors' cancer status and history. The caregiver was also asked to indicate whether they themselves had ever been diagnosed with any form of cancer and if they had what type of cancer they had been diagnosed with as well as how long ago they had been diagnosed.

The first section asked caregivers to rate their level of unmet need in 6 areas over the past month. Each item was placed on a 5-point Likert-type scale that ranged from 0 to 4 (no unmet need, low unmet need, moderate unmet need, high unmet need, very high unmet need). Section two collected information on health and well-being and employed the use of a 4-point Likert-type scale for the first 21 questions. The scale ranged from 0-3 with the options "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 their health and wellbeing over the past week. The final section collected personal information on the caregiver as well as the person to whom they gave support.

Demographics**:** The demographic variables included in our analysis were, gender, education level, employment status, and nature of relationship. Gender was dimidiated into male (0) and female (1) while education level was coded as secondary school or less, trades, vocational, college or other (0), and university or higher (1). Employment status was coded as does not do paid work (0) and does paid work (1). The nature of the relationship was ascertained by asking the respondents who had given them the survey with possible responses being: 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 other (0) and spouse (1). Age was not included as a demographic variable due to the fact that our control variable, life stage, is age related.

Independent Variable - Life Course: The independent variable used in this study is life course and this variable was dimidiated to represent two life stages; that of midlife represented by those 40 to 59 years and older adult represented by those 60 years and older. The sample for each group was chosen using respondent date of birth in Section 3 in the SPUNS. The mean for which was calculated at α = 0.58 (see tables 2 and 5).

Dependent Variable 1– Unmet Personal Needs: The current study measured levels of unmet personal need from the data using a five point Likert-type scale created from Section 1: About Your Needs, which included 14 questions from Part E – Unmet Personal Needs. Part E included questions such as item number 51 "*Finding time alone, just for myself*" (Campbell, 2009, p. 16). The mean of the 14 questions associated with this variable was calculated (α = 0.62) to create a scale of the perceived unmet personal needs of caregivers and was recoded to produce a measure of 0 or very high unmet need to 4 or no unmet need. The responses were also summed to ascertain the reliability alpha and an alpha score of α = 0.97 was calculated (see tables 2 and 5).

Dependent Variable 2– Unmet Emotional Needs: From the data used, unmet emotional needs was measured using a five point Likert-type scale created from Section 1: About Your Needs, which included 16 questions from Part F – Unmet Emotional Needs. This section included questions such as item number 70 "*Trying to stay positive*" (Campbell, 2009, p. 21). The mean of the 16 questions was calculated (α = 0.54) to create a scale of the perceived unmet emotional needs of caregivers and was recoded to produce a measure of 0 or very high unmet need to 4 or no unmet need. The responses were also summed to ascertain the reliability alpha and a Cronbach alpha of α = 0.97 was calculated (see tables 2 and 5).

Mediating Variables: A variable acts as a mediator when it functions as a conduit through which the independent variable is able to indirectly affect the dependent variable (Preacher & Hayes, 2008). The current study examined level of unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concern needs to assess the possibility of external factors influencing the relationship between life stage and unmet personal and emotional needs.

Unmet Information Needs: Level of unmet information need was measured using a five point Likert-type scale created from Part A, "Unmet Information Needs", of Section 1 in the SPUNS which was comprised of 27 questions. This part of the survey included questions such as item number 2 "*Understanding all the information the person with cancer and I were given*" (Campbell, 2009, p. 2). The mean of the questions associated with this variable was calculated (α = 0.57) to create a scale of the perceived unmet information needs of caregivers and was recoded to produce a measure of 0 or very high unmet need to 4 or no unmet need. The questions summed received a Cronbach alpha score of α = 0.94 (see tables 2 and 5).

Unmet Future Concern Needs: Level of unmet future concern needs were measured using all the items from Part B, "The Future", of Section 1 in the SPUNS which when summed had a Cronbach alpha score of α = 0.96. This section was comprised of 4 questions and included questions such as items number 30 "*Dealing with not knowing what lies in the future*" and 31 "*Dealing with* *worry about the future of the person I support*". The mean of the questions was also calculated (α = 0.97) to create a scale of the perceived unmet future concerns needs of caregivers and was recoded to produce a measure of 0 or very high unmet need to 4 or no unmet need (see tables 2 and 5).

Unmet Work or Financial Needs: Level of unmet work or financial need were measured using a five point Likert-type scale created from Part C, "Unmet Work and Financial Needs", of Section 1 in the SPUNS. The mean of the 8 questions associated with this variable was calculated (α = 0.28) to create a scale of the perceived unmet work or financial needs of caregivers and was recoded to produce a measure of 0 or very high unmet need to 4 or no unmet need (see tables 2 and 5). Part C and when summed had a Cronbach alpha score of α = 0.91 and included questions such as Item number 33 "*Being able to keep working*" (Campbell, 2009, p. 11).

Unmet Healthcare Needs: unmet health care needs were measured using all 9 items from Part D, "Unmet Needs for Access and Continuity of Health Care", of Section 1 in the SPUNS which included questions such as items number 44 "*Getting test results for the person I support quickly enough*" and 46 "*Making sure the family doctor of the person I support could get information from specialists*" (see table 5). The mean of the questions associated with this variable was calculated (α = 0.46) to create a scale of the perceived unmet healthcare needs of caregivers and was recoded to produce a measure of 0 or very high unmet need to 4 or no unmet need. This section when summed had a Cronbach alpha score of α = 0.94 (Campbell, 2009, p. 14).

Data Analysis

The data from the aforementioned variables having been collected were then analyzed using PASW software. In order to gain a clearer understating of the subject matter and associated sample at hand, an initial analysis of the descriptive statistics was conducted. Next two linear regression models were constructed to test the direct effects of each life stage on both unmet personal and emotional needs. The first model tested the effects with the inclusion of demographic characteristics while the second model incorporated the four mediating variables into the model.

The analysis engaged the use of the nonparametric bootstrapped standard error method also known as bootstrapping, an approach which treats the sample as if it is the population by employing the use of random re-sampling of the original sample in evaluating the distribution of a statistic (Bollen & Stein, 1990; Guan, 2003). The study utilized bootstrapping in exploring the extent to which unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concern needs mediated the relationship between life stage and unmet personal and or emotional needs among cancer caregivers. The bootstrapped standard error method enabled the examination of the degree to which these four mediators acted as conduits through which the independent variable was able to have an effect on each of the dependent variables. This method also allowed for a statistical comparison between the four mediators (Bollen & Stein, 1990; Guan, 2003; Preacher & Hayes, 2008,).

Summary

The issue of population aging has highlighted the importance of the informal caregiver, thus bringing to the fore the necessity for increased research into the changing dynamics of caregiving (Aneshensel et al., 1995; Lilly, 2011). Some research has been done in the area of life course and caregiver needs but much of the research that has been done, however, focuses on a particular group of individuals, generally females of retirement age (Moen, Robison & Dempster-McClain 1995; Moen, 1996;). There need to be further research into the changing dynamics of caregiving as, while traditionally the caregiving role is assumed in later life, caregiving has over the last few decades become more common during midlife (Igarashi et al., 2013; Wolff & Kasper, 2006; Fingerman et al., 2011).

This study sought to address the current situation through an analysis of the dynamics involved in the timing of caregiving. The study examined two distinct groups of cancer caregivers, a middle aged and an older adult group, in an attempt to assess the extent to which the timing of caregiver role acquisition affects caregiver unmet personal and or emotional needs within each group. The study also assessed the degree of influence that current work or financial status, access to health care, access to health information and degree of concerns about the future had on the relationship between the two main variables, more specifically the degree to which these mediating factors presented the cancer caregiver with the unmet needs.

Results

The sample for the current study was 66% female while 24% of the sample had attained at least university level education. Almost one half the sample (47%) was formally employed at the time of the study while as it relates to the nature of the relationship, 77% of the sample had a spousal relationship to the cancer survivor.

In the areas of needs fulfillment as it relates to dependent variables, the analysis revealed a mean of 0.62 with a standard deviation of 0.85 in the area of personal unmet needs; while for unmet emotional needs caregivers had a mean of 0.54 and a standard deviation of0.81. In relation to unmet met needs as mediators, caregivers showed mean score of 0.97 and a standard deviation of 1.15 in the area of unmet future concerns needs. Caregivers recorded a mean of 0.28 with a standard deviation of 0.65 in the unmet work or financial needs area. The area of unmet healthcare need caregivers reported a mean score of 0.46 with a standard deviation of 0.78; while unmet information needs saw caregivers reporting a mean score of 0.57, and a standard deviation of 0.81.

Regression analysis was run to determine whether the independent variable is has an effect on the unmet personal and emotional needs of the subjects. Next the study utilized bootstrapping in exploring the effects of unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concern needs on the relationship between life stage and unmet personal and emotional needs among cancer caregivers (see diagrams 3 and 4).

Unmet Personal Needs (Table 3)

In our output from table 2 model 1 we observed that gender, employment status, the nature of the relationship between the dyad, and midlife status all had a significant association with levels of unmet personal needs when assessed without the inclusion of mediating variables.

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

Variable	*M/Percent*	*SD*
Gender (Female)	66%	--
Education (University degree or higher)	24%	--
Employment (Does paid work)	47%	--
Nature of Relationship (Spouse)	77%	--
Life Stage (Midlife)	0.58	0.49
Unmet Work Needs	0.28	0.65
Unmet Health Care Needs	0.46	0.78
Unmet Future Concerns Needs	0.97	1.15
Unmet Information Needs	0.57	0.81
Unmet Personal Needs	0.62	0.85
Unmet Emotional Needs	0.54	0.81

Notes: n = 789

Upon including our four mediating variables as seen in table 2 model 2 we observed two things. Our first observation was that the association between gender and levels of unmet personal needs increased in significance (Model 1: $B = 0.23$, $p < .01$ and Model 2: B = 0.16, $p < .001$). This indicated that the association observed between being female and levels of unmet personal need could be further explained by the presence of other unmet needs. Secondly we observed that all other demographic variables including midlife status lost statistical insignificance indicating that unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concern needs explained and in some instances nullified the association observed between these demographic characteristics and unmet personal needs. Our four mediating variables, however, each showed high levels of significant association with levels of unmet personal needs.

When tested for mediation using the method described by Preacher & Hayes (2008) the data showed a statistically significant direct effect (c) between life stage and unmet personal needs (B = 0.19, p < .01). This direct effect between the independent and dependent variables however losses its statistical significance with the addition of unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs as mediating variables (B = 0.04, p > .05). (See diagram 3).

Table 2: *Un-standardized coefficients for regression models examining associations of demographics, life stage, unmet, work/financial, future concerns, healthcare and information needs with unmet personal needs.*

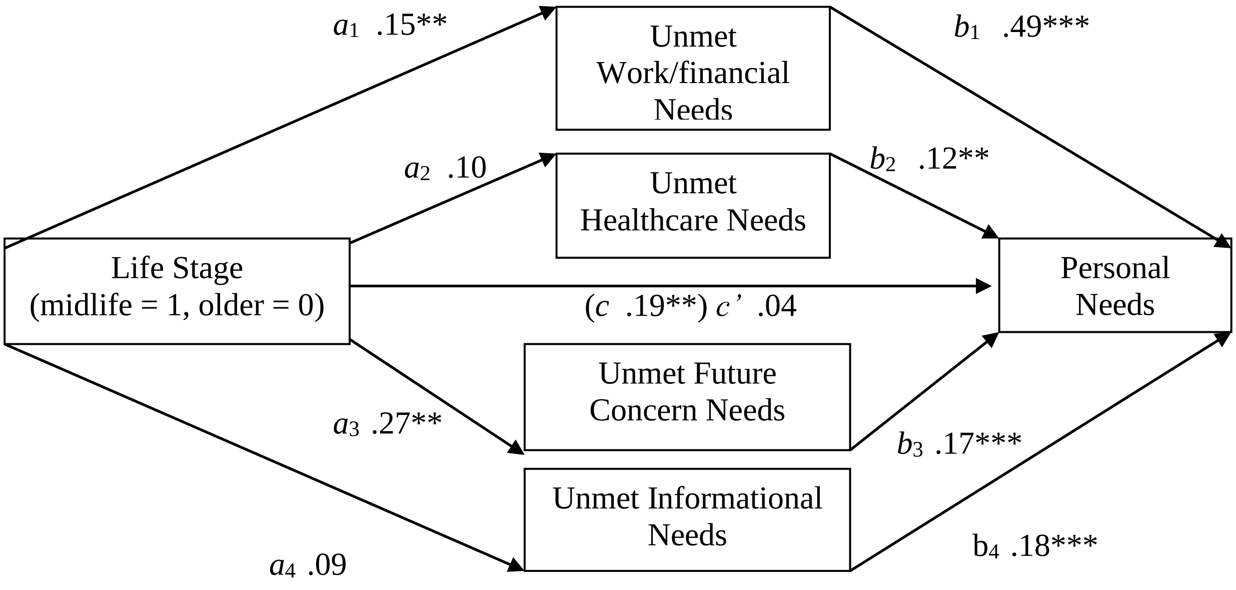
Unmet Personal Needs

Variables	Model 1			Model 2		
	B		SE	B		SE
Constant	.21	*	.11	-.10		.07
Gender (Female)	.23	**	.07	.16	***	.04
Education	-.04		.07	.07		.05
Employment	.19	**	.07	.08		.04
Relationship (Spouse)	.06	*	.08	.09		.05
Life Stage (Midlife)	.19	**	.07	.04		.05
Unmet Work/financial	--		--	.49	***	.04
Unmet Health Care	--		--	.12	**	.04
Unmet Future Concern	--		--	.17	***	.02
Unmet Information	--		--	.18	***	.04
Adjusted R^2	.03			.55		

n = 789; *p* < .05 = *; *p* < .01 = **, p < .001= ***

In diagram 3 the indirect effects (*a1b1* and *a3b3* paths) for the unmet work or financial needs and unmet future concerns needs mediators were statistically significant (work/financial, *point estimate* = 0.07, *SE* = 0.03, *upper confidence interval* = 0.148, *lower confidence interval* = 0.013; future concerns, *point estimate* = 0.05, *SE* = 0.02, *upper confidence interval* = 0.111, *lower confidence interval* = 0.002). When a comparison was made of these two mediators, the difference between unmet work or financial needs and unmet future concerns needs indicated that unmet work or financial needs had a significantly greater mediating value on the association between life stage and unmet personal needs than did unmet future concerns needs.

Diagram 3*: The association between life stage and unmet personal needs as mediated by unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs.*



n = 789; $p < .01$ = **, $p < .001$ = ***

Note: *The value in parentheses is the un-standardized regression coefficient for the association between life stage and unmet personal needs prior to the addition of unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs.*

The *a2* and *a4* paths for the unmet health care needs and unmet information needs mediators in diagram 3 did not show statistical significance while the b2 and b4 paths did (health care, *point estimate* = 0.01, *SE* = 0.01, *upper confidence interval* = 0.054, *lower confidence interval* = -0.007; information, *point estimate* = 0.02, *SE* = 0.01, *upper confidence interval* = 0.063, *lower confidence interval* = 0.019). This indicated that these two variables while having a direct effect on personal needs did not act as true mediators as they were not directly related to the independent variable and thus did not act as conduits through which life stage could have an effect on unmet personal needs.

Unmet Emotional Needs

In our output from table 3 model 1 we observed that gender showed statistical significance (*B* = 0.15, *p* < .05) in its association to unmet emotional needs, also of statistical significance in its association with unmet emotional needs was the life stage variable (*B* = 0.18, *p* < .01). Employment status, the nature of the relationship between the dyad, and midlife status however did not show a significant association with levels of unmet emotional needs when assessed without the inclusion of mediating variables.

Upon including our four mediating variables as seen in table 3 model 2 we observed that while gender was slightly less associated with unmet emotional needs the association between the variables maintained its significance (B = 0.09, *p* < .05). This indicated that the association observed between being female and levels of unmet emotional needs could be further explained by the presence of other unmet needs. Secondly we observed that the midlife status variable became statistically insignificant indicating that unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concern needs affected the association observed between life stage and unmet emotional needs. Our four mediating variables, however, each showed high levels of significant association with levels of unmet emotional needs.

When tested for mediation using the method described by Preacher & Hayes (2008) the data showed a statistically significant direct effect (c) between life stage and unmet emotional needs (B = 0.18, p < .01). This direct effect between the independent and dependent variables however losses its statistical significance with the addition of unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs as mediating variables as outlined in diagram 4 (B = 0.04, p > .05).

Table 3: *Un-standardized coefficients for regression models examining associations of demographics, life stage, unmet, work/financial, future concerns, healthcare and information needs with unmet emotional needs.*

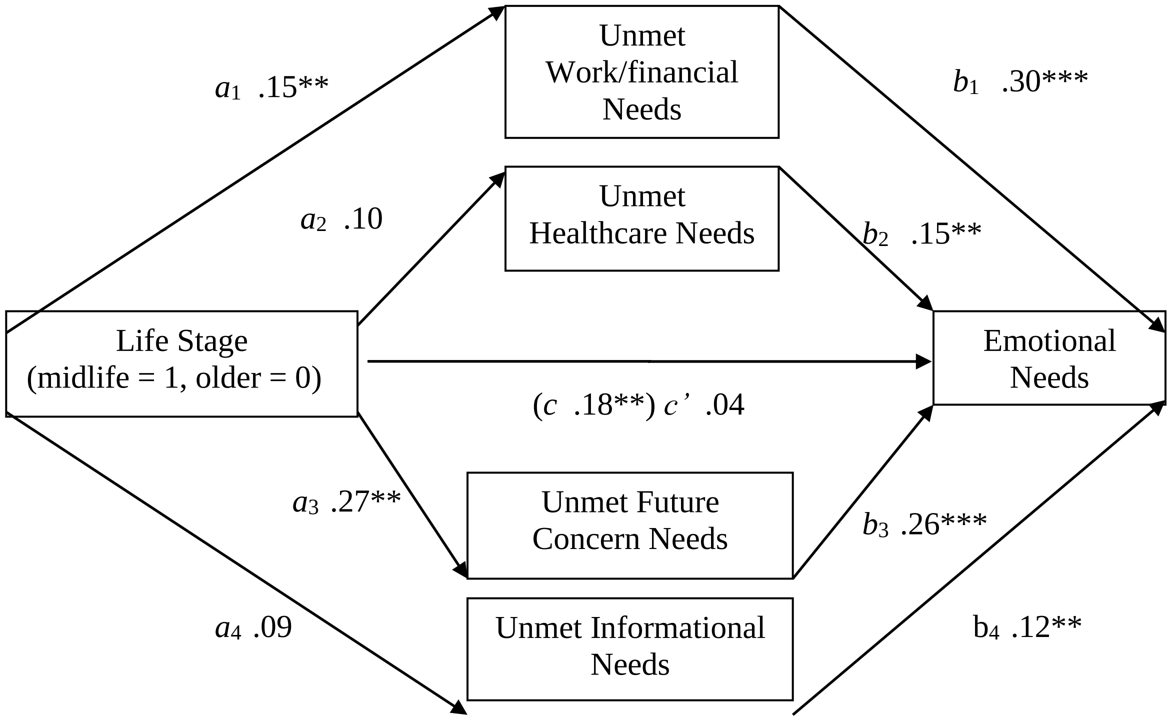
Unmet Emotional Needs

Variables	Model 1		Model 2	
	B	SE	B	SE
Constant	.27	.10	-.07	.07
Gender (Female)	.15 *	.07	.09 *	.04
Education	-.02	.07	.07	.04
Employment	.13	.07	.04	.04
Relationship (Spouse)	.004	.08	.01	.05
Life Stage (Midlife)	.18 **	.07	.04	.04
Unmet Work/financial	--	--	.30 ***	.04
Unmet Health Care	--	--	.15 ***	.04
Unmet Future Concern	--	--	.26 ***	.02
Unmet Information	--	--	.12 **	.03
Adjusted R^2	.03		.55	

n = 789; *p* < .05 = *; *p* < .01 = **, *p* < .001 = ***

In diagram 4 the indirect effects (*a1b1* and *a3b3* paths) for the unmet work or financial needs and unmet future concerns needs mediators were statistically significant (work/financial, *point estimate* = 0.05, *SE* = 0.02, *upper confidence interval* = 0.096, *lower confidence interval* = 0.009; future concerns, *point estimate* = 0.07, *SE* = 0.03, *upper confidence interval* = 0.154, *lower confidence interval* = 0.003). When a comparison was made of these two mediators, the difference between unmet work or financial needs and unmet future concerns needs indicated that unmet future concerns needs had a statistically greater mediating value on the association between life stage and unmet emotional needs than did unmet work or financial needs.

Diagram 4: *The association between life stage and unmet emotional needs as mediated by unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs.*



n = 789; $p < .01$ = **, $p < .001$ = ***

Note: *The value in parentheses is the un-standardized regression coefficient for the association between life stage and unmet emotional needs prior to the addition of unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs.*

The *a2* and *a4* paths for the unmet health care needs and unmet information needs mediators in diagram 4 did not show statistical significance while the b2 and b4 paths did (health care, *point estimate* = 0.02, *SE* = 0.01, *upper confidence interval* = 0.063, *lower confidence interval* = -0.010; information, *point estimate* = 0.01, *SE* = 0.01, *upper confidence interval* = 0.054, *lower confidence interval* = 0.012. This indicated that these two variables while having a direct effect on emotional needs did not act as true mediators as they were not directly related to the independent variable and thus did not act as conduits through which life stage could have an effect on unmet emotional needs.

Summary of Outcomes

In summarizing our findings we have seen that outside of the influence of mediating factors life stage has a statistically significant direct effect on both unmet personal needs and unmet emotional needs as seen in diagrams 3 and 4 above. The addition of mediating variables to association between life stage and unmet personal and emotional needs yielded mixed results. It was observed that all four mediating variables had a direct effect on the dependent variable as again outlined in diagrams 3and 4 above

Further to this, a closer look at diagrams 3 and 4 revealed that while there was a direct effect between the main variables and a direct effect between the mediating variables and the dependent variable the direct effect found between the main variables lost its statistical significance with the application of the four mediating variables. This can be attributed to the fact that of the four mediating variables only two were directly associated with the independent variable.

Discussion

This study was undertaken in an effort to assess the effects of life stage on unmet personal and or emotional needs of cancer caregivers. Further to this the study sought to determine the mediating effect of unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs, assessing the extent to which each mediator had an effect on each outcome variable. This chapter will discuss the results of this study as well as the implications for practitioners and caregivers. Additionally the strengths and limitations of the study will be explored along with an exploration of any areas for future research.

Summary of Results and Previous Research

Demographic Characteristics: It is necessary at this point to take a look at the current situation and trajectory in North American cancer demographics. It is approximated that 1 in 3 men and 1 in 4 women in The United States will have cancer in their lifetime with the Canadian population seeing a rate of 2 in every five individuals (Given, Given, & Sherwood, 2012; Canadian Cancer Society, 2013). It has been further postulated that 1,660,290 Americans and 187,600 Canadians will contract the disease in 2013 (National Cancer Institute, 2013; Canadian Cancer Society, 2013). These statistics signal an increase in cancer demographics which in turn signal an increased need for cancer caregivers and caregiving.

There were 789 subjects involved in this study and of that number 77% were the primary caregivers to a spouse, 65% were female, 23% had a university level education, 47% were employed, and 58% were in midlife. In light of these data there are number of inferences to be drawn:

Caregiving at Midlife – Unmet Personal Needs: As has been outlined in previous research midlife caregivers extend an average of 6 hours of care per day, with up to 41% of employed caregivers cutting hours in order to provide this care (Given, Given & Sherwood, 2012; Igarashi et al. 2013). In relation to our study we see that caregiving in midlife showed statistical significance outside of the presence of our mediating variables in the case of their association to unmet personal needs. This however changed when the four mediating variables were added to the equation.

This finding suggest that while one's life stage contributed to the presence of unmet personal needs this was not the main contributing factor, that in fact the presence of other unmet needs contributed more towards an increase in unmet personal needs. The fact that not all of our mediating variables had a mediating effect between the life stage and unmet personal needs further explains the relationship between the main variables as while unmet work or financial and future concerns needs acted as mediators, unmet healthcare and information needs did not. This paints a clear picture of the presence of role strain in the lives of midlife caregivers. The mediating connection of unmet work or financial and future concerns needs on life stage and personal unmet needs indicates that caregivers in midlife perceive and or experience increased work and or financial demands which leave little time for the fulfillment of personal needs. The results also indicate that these individuals have concerns as to the future which also leads to an increase in perceived unmet needs (Moen, et al., 1995; Kim & Moen, 2002;).

The fact that unmet Work/financial needs had a significantly greater mediating value on the association between life stage and unmet personal needs than did unmet future concerns needs further supports the argument that those of this group are experiencing role strain. The combination of these dynamics in application to our study participants indicates that 58% of our study participants would have undergone role strain while serving as a caregiver signaling a possible increase in unmet met needs based on the degree to which members of this group extend themselves in order to accommodate caregiving responsibilities (Moen, et al., 1995; Rozario, Morrow-Howell, & Hinterlong, 2004).

Caregiving at Midlife – Unmet Emotional Needs In terms of the association between unmet emotional needs and midlife status, these was a statistically significant association between both variables when assessed without the inclusion of mediating variables. The life stage variable however lost significance in its association with between unmet emotional needs when the four mediating variables were added. This again indicated a disconnect between the main variables with the addition of the mediators.

This finding suggest that while one's life stage contributed to the presence of unmet emotional needs this was not the main contributing factor, that in fact the presence of other unmet needs contributed more towards an increase in unmet emotional needs. The fact that not all of our mediating variables had an effect in the association between life stage and unmet emotional needs further explains the relationship between the main variables as while unmet work or financial and future concerns needs acted as mediators, unmet healthcare and information needs did not. This again indicates the presence of role strain in the lives of midlife caregivers. The mediating connection of unmet work or financial and future concerns needs on life stage and emotional unmet needs indicates that caregivers in midlife perceive and or experience increased work and or financial demands which leave little time for the fulfillment of emotional needs. The results also indicate that these individuals have concerns as to the future which also leads to an increase in perceived unmet emotional needs (Moen, et al., 1995; Kim & Moen, 2002;).

The fact that unmet future concerns needs had a significantly greater mediating value on the association between life stage and unmet personal needs than did unmet work or financial needs further supports the argument that those of this group are experiencing role strain as an increase in concerns about the future with lead to an increased in unmet emotional needs. The combination of these dynamics in application to our study participants once again indicates that 58% of our study participants would have undergone role strain while serving as a caregiver signaling a possible increase in unmet met needs based on the degree to which members of this group extend themselves in order to accommodate caregiving responsibilities (Moen, et al., 1995; Rozario, Morrow-Howell, & Hinterlong, 2004).

Caring for a spouse: Our study participants consisted of 58% middle aged individuals and 77% of those who are caring for a spouse. A look at the data would suggest that even in the unlikely event that the other 23% that are not caring for a spouse are those within midlife there is at the least 35% of our study population that is caring for a spouse in midlife. Our results indicate that midlife caregiving is associated with an increase in role which leads to an increased possibility of role strain which will in turn decrease quality of life and increase perception of unmet needs.

The type and tone of the spousal relationship is also of importance. Disease acquisition never waits for a quiet period in one's life where all is well. A cancer diagnosis happens in the middle of life. In relation to a spousal relationship, a diagnosis can come when the relationship is at its best or it may come in the midst of thoughts of separation, an abusive relationship, a request for a divorce, or a loveless marriage that is being held together "for the sake of the children". In situations such as these, caregiving responsibilities take on a negative tone and can become quite burdensome to the caregiver, leading to increased perceptions of unmet needs and a decrease in quality of life (Kim et al., 2008).

Gender: Caregiving is often seen as being more applicable to females due to the traditional view of women as having life trajectories that are more embedded in social and familial connections and support. Female perception of the caregiver role however is also highly dependent upon the individual's views of traditional female roles with women who have more traditional views of female roles having a more positive experience in the caregiving process (Moen, et al., 1995; Quick & Moen, 1998; Fingerman et al., 2011). This is also mitigated by other extenuating possibilities. One interesting finding that was observed in assessing the population demographical statistics associated with this research is that of the effects of gender on both personal and emotional needs.

Bryant, Leaver and Dunn in their 2009 study on British Colombian residents found that gender proved to be a reliable predictor as it relates to having unmet needs in numerous areas. Our study also revealed that gender was significantly associated with unmet needs, and that in its association with unmet emotional needs this significance level remained stable with the addition of mediating variables. Our study further and more interestingly revealed that our gender demographic exhibited an increased significance level in the area of unmet personal needs when mediators were added to the equation indicating that our mediating variables had a greater effect on the unmet personal needs of our female participants. This finding speaks to an increased level of perceived unmet needs among females.

The educational level demographic was found to not be significantly associated with either unmet personal or emotional needs with each outcome actually showing a negative association. This proves to be an interesting outcome as approximately 3 of every four individuals in the sample population had ceased educational pursuits at or before college or trade school. These results indicate that although over ¾ of our sample population had no university level education; yet this did not significantly affect their levels of unmet needs.

Unmet Personal and Emotional Needs

The sample of caregivers in this study reported having high levels of unmet needs with 62 % of the sample reporting a lack in personal needs while 54% of the sample population reported having unmet emotional needs. This dynamic can be explained by a number of contributing factors. Approximately 66% of the population is female which in light of the previous reference to research on gender and unmet need speaks to a substantial portion of those with perceived unmet personal and emotional needs being female (Bryant, Leaver and Dunn, 2009). Further to this 58% of the population is in mid life which raises issues concerning timing of role acquisition, and the possibility of role strain due to overextension/over involvement (Aneshensel, et al. 1995; Given & Sherwood, 2006; Wolff & Kasper, 2006).

More than three quarters of the sample population (77%) reported to be caring for a spouse. This dynamic when assessed in light of the fact that almost 60% of the population is in midlife speaks to a number of midlife caregivers giving care to a spouse which is generally seen as non-normative (Moen et al., 1995).

Two interesting dynamics present themselves in the data set. Studies have shown that caregivers have sited information needs as a primary area of lack and the results shown that 57% of respondents report a need for information (Campbell et al., 2009; Sherwood et al., 2006; Cipolletta et al., 2013). Yet while a lack of information is statistically significant in its effect on personal and emotional needs it is not associated with life stage more specifically midlife status which speaks to a need for information centered around older adult caregivers.

Another interesting finding is that of unmet future concerns needs with almost 70% of the respondents reporting unaddressed concerns about the future. These results could indicate that the future needs variable is a broad one which can encompass all other areas of need. Individuals may have any combination or all of future healthcare concerns, future work or finance concerns, concerns about future personal or emotional needs, and or concerns about not being about to obtain information if there are new developments.

Results as Related to the Study Hypotheses

Our first hypothesis predicted that the acquisition of caregiving responsibilities in middle age (ages 40 to 59) would have a more deleterious effect on caregiver unmet personal and or emotional needs than the acquisition of caregiving responsibilities as an older adult (ages 60 and above). The results of our study have supported this hypothesis with a few interesting outcomes. Over half of our study population (58%) is in mid life a statistic which in and of itself speaks to the changing dynamics of the caregiving experience. At least 35% of this population is caring for a spouse which brings about the issue of reduced household income, having lost a sick spouse's full income, as well as having to cut hours to care for a sick spouse. Added to this finding is the emotional strain associated with spousal caregiving as studies have shown that relatives of individuals living with cancer are as intensely affected by the events and processes of coping with cancer as the patients themselves (Strawbridge, et al., 1997; Revenson, & Pranikoff, 2005; Adams, Boulton, & Watson, 2009). This finding is also significant in light of the fact that caring for an individual with a progressive and degenerative illness such as cancer has large implications for caregiver quality of life (Weitzner, McMillan & Jacobson, 1999; Bee, Barnes, & Luker, 2008; Clarke et al., 2013). The combination of these factors indicate that those in our midlife group would very acutely experience and perceive high levels of unmet personal and or emotional needs

Outside of this, the results of our demographic assessment revealed that being female was strongly associated with having both personal and emotional unmet needs. This finding is interesting in light of studies that have suggested that the female perception of the caregiver role is highly dependent upon the individual’s views of traditional female roles with women who have more traditional views of female roles having a more positive experience in the caregiving process (Moen, Robison & Dempster-McClain, 1995; Quick & Moen, 1998; Fingerman et al., 2011). This suggests that acquisition of the cancer caregiver role would be more highly perceived as a normative part of the life course to the female members of our study participants, to the extent that these participants do not have a negative perception of traditional female roles. The fact that our female study participants have perceive increased levels of unmet needs suggest a nontraditional view of caregiving which is indicative of the majority of those experiencing increased levels of needs being within the middle aged group.

Our second hypothesis stated that additional unmet caregiver needs, more specifically unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concern needs, would serve to increase levels of unmet personal and or emotional needs; with a greater increase observed in middle aged (40 to 59 year old) adult caregivers than in older (60+ year old) adult caregivers.

The interesting thing about our results in relation to this second hypothesis is the fact that while there is a direct association between life stage and unmet personal and emotional needs this direct effect between the independent and dependent variables losses its statistical significance with the addition of unmet work or financial needs, unmet health care needs, unmet information needs and unmet future concerns needs as mediating variables. A closer look at the data reveals that there is a disconnect between the variables as while the mediators are all associated with the dependent only two are also associated with the independent. As such unmet work or financial needs and unmet future concerns needs act as mediators between life stage and unmet personal and emotional needs. An application of this finding to our hypothesis leads to a number of conclusions:

In relation to personal unmet needs the mediation paths between the main variables are unmet work or financial needs ($a1 = 0.15$, $p = < .01$; $b1 = 0.49$, $p = < .001$) and unmet future concerns needs ($a3 = 0.27$, $p = < .01$; $b3 = 0.17$, $p = < .001$). In comparing both mediation paths, unmet work or financial needs had a greater association with personal unmet needs than did unmet future concerns needs. This finding indicates that persons in midlife are experiencing high levels of unmet work or financial needs which in-turn increases their levels of unmet personal needs. One in four caregivers within the sandwich group spends an average of a combined 100 hours per week dedicated to both caregiving responsibilities and formal work requirements. This group also reports that caregiving poses challenges to working effectively with 1 in three reporting a drop in their performance due to a lack of time and energy which can be attributed to caregiving responsibilities (Duxbury, Higgins & Schroeder, 2009). Unmet work or financial needs include needs such as not being supported by one's boss or not having enough resources or time to take care of day to day activities and responsibilities (Campbell et al., 2009). Our findings strongly support the concept of role strain as, the results tell us of a midlife group that has dedicated many hours to both caregiving and work responsibilities, a situation which leads to a physical decline as well as reduced efficiency. This over extension also leads to an increased perception of how little time there is for the fulfillment of personal needs.

The middle aged life stage faces an increased possibility of experiencing unmet work or financial needs due to a number of factors. These including an increased societal demand for higher educational levels, with only 23% of our study participants having attained university level education and assuming that the none of the 43% of our population that is in the older adult age group falls within this category (a situation that is highly unlikely) there is at least 35% of our middle aged group that has never been university educated which indicates lower income levels which, with reduced hours due to caregiving responsibilities and increased caregiving cost, can lead to increased unmet needs and a reduced quality of life.

Those of this group, who have had further education, would experience higher levels of debt, a later entrance into the formal working world, fewer employment opportunities, and a weaker global economy that is still in the throes of a recession. This again coupled with the out-of pocket costs associated with cancer caregiving, and loss of income due to time taken away from work because of caregiving activities can lead to an increased perception of unmet personal and or emotional needs and a decrease in quality of life (Given & Sherwood, 2006; Duxbury, Higgins, & Smart, 2011; Igarashi et al., 2013).

The association between gender and unmet needs was also affected upon inclusion of our four mediating variables. It was observed that the association between being female and levels of unmet needs maintained its significance in its association with unmet emotional needs and actually increased in significance in its association with unmet personal needs. This again suggest a nontraditional view of caregiving which is indicative of the majority of those experiencing increased levels of needs being within the middle aged group. The finding is also consistent with previous research on role strain versus role enhancement which indicates that males have a greater sense of accomplishment and experience role enhancement with the addition of role where as females do not (Moen et al., 1995, Reid & Hardy, 1999). As such it is fitting that the females of our study group would report high levels of unmet needs.

Implications

Implications for Medical Practitioners

Over the years the concept and process of caregiving has changed. Whereas before Medical practitioners would have been more involved in the care of a patient, would have spend more time in the care of a patient, it has increasingly become the onus of familial caregivers with medical practitioners not taking the time to acknowledge the scope of the caregiving responsibility (Kim et al., 2010; Given, Given, and Sherwood, 2012; Blindheim et al., 2012). Caregivers contribute the majority of the hands one time spent in the care process, with practitioners making the assumption that they have been provided with the resources necessary to undertake the task (Kim et al., 2010; Given, Given, and Sherwood, 2012; Blindheim et al., 2012). A majority of caregivers provide care over an extended period of time, a substantial amount of long term carers provide care to multiple individuals and or multiple generations and often practitioners are oblivious or do not take the time to understand the implication of such a situation (Duxbury, Higgins, & Smart, 2011).

Sensitivity training is needed in this area to increase awareness of the current situation. Medical staff also needs to be equipped to support and train caregivers as often caregivers need specialized training in managing survivor needs. Social service personnel should be added as fixture on hospital care staff with the express duty of attending to the needs of caregivers.

Implications for social support systems

At the social support level, intervention strategies should be developed to include both those who have been diagnosed with cancer, and their principal support persons. Studies have suggested that when both parts of the caregiving dyad are supported the care experience is much more positive (Kim et al., 2008). Were caregivers to be much more included in the support process, the expectation is that they would experience less unmet needs as they would have greater access to resources.

Social support is critical in enhancing the caregiving experience and institutional support must also be in place so that resources for formal care are available. Included with this institutional support should be the opportunity for an outlet. Caregivers often report feeling isolated and or alone in their situation and as such are often in need of an outlet through which they are able to express what they are going through (Campbell et al., 2009; Sherwood et al., 2006; Cipolletta et al., 2013). It is important they supports are put in place to enable this process.

A major goal a policy development is the aim to help individuals function at an optimal level. There is an increased need for the development of policies that will allow caregivers to function at an optimal level as the present polices leave much to be desired with caregivers actually reporting an increased level of strain and stress when seeking to access public resources (Duxbury, Higgins, & Smart, 2011).

Caregiving has been associated with feelings of isolation and it is important for caregivers actively seek to remain engaged in social activities and maintain social ties as a withdrawal from social actives can have a negative impact on quality of life. The possibility of maintaining social ties however is greatly diminished if social supports are not in place to encourage this.

Implications for Caregivers

The life of a caregiver is a demanding one and it is very easy to fall into the situation of self neglect, as is often the case with caregivers (Strawbridge, et al., 1997; Duxbury, Higgins, & Smart, 2011, Clarke et al., 2013). If caregivers are to experience an improved quality of life there are a few options. Developing active self management and coping strategies is important in the life of a caregiver. Being organized and informed, knowing when and where to get help will go a long way in alleviating some of the issues associated with caregiving.

Caregivers have a substantial impact on the quality of life of those to whom they provide care. As such, the caregiving experience will be of greater benefit to both parts of the dyad if caregivers actively seek to obtain and strengthen resources that will in turn reduce their levels of unmet need. This will not only improve their quality of life but will allow for a better care experience for all involved.

Strengths and Limitations

Strengths

This study was undertaken to analyze the association of life stage on the personal and emotional unmet needs of cancer caregivers. The study examined two distinct groups of cancer caregivers, a middle aged and an older adult group, in an attempt to assess the extent to which the timing of caregiver role acquisition affects caregiver unmet personal and or emotional needs within each group. The study also assessed the degree of influence that current work or financial status, access to health care, access to health information and degree of concerns about the future had on the relationship between the two main variables, more specifically the degree to which these mediating factors presented the cancer caregiver with the unmet needs. This section will discuss the strengths and limitations of the study, as well as areas for future research.

The design of this study afforded it many strengths and while there were limitations they were far outweighed by the study's strengths which greatly increases confidence in the findings. One strength of the study involved the data collection method. The data for this study was collected using the SPUNS which collected data on unmet needs in different areas as well as demographic and contextual questions about questionnaire acceptability. The survey collected information on the age group in which the caregiver fell as well as their gender, employment status and educational background. It collected information on the extent of the relationship between survivor and caregiver, whether the survivor lived with the caregiver, and gathered information about the nature of the survivors' cancer status and history. The strength of one's data collection tool is telling of the accuracy of the data one collects. The SPUNS demonstrated strong item test-retest reliability with Campbell et al setting a retention criterion of .70 within the 95% confidence interval. Face, content, and construct validity for the SPUNS were also strong as was internal consistency with a Chronbach alpha = .990 for the overall scale.

Another strength of the study was that of being able to assess the caregiving situation form the caregivers' viewpoint as opposed to the imposition of researcher biases. The study sought to measure the perceptions that cancer caregivers have of their unmet needs and not all caregivers perceive the same things as needs or perceive needs in the same way. Therefore, it is important to get input from the caregivers themselves instead of making the assumption that all needs are the same and are perceived as such. The study captures a true picture of the needs perceptions of the study participants.

Thirdly population sample used in this study was large and represents a wide range of caregivers in various stages and phases of the caregiving process. A large population enables a more accurate portrayal of the actual population, facilitates effective statistical analysis and helps in translating data.

Limitations

One of the limitations to conducting this study involved the use of secondary data as the research that can be applied to secondary data is limited to the information that is already in the data set. This limited the amount of information to be gleaned from data and left a few unanswered questions.

Another limitation involved the use of a cross-sectional approach to the cancer caregiver situation. The cancer caregiving experience is a dynamic process that would be better suited to a longitudinal approach.

Finally these results may also not apply to diverse populations or minorities based on the population from which the data was captured.

Future Studies

One interesting outcome from our study was the lack of significance between university status and unmet personal and emotional needs. These results are counterintuitive as one would expect that a lower educational level would lead to a lower income translating to lower quality of life and increased unmet needs. It would be interesting to explore the factors leading these results.

Another interesting dynamic to add would have been a time factor, that is time since diagnosis. Studies have shown that caregiver burden increases over extended periods of time and the inclusion of a time since diagnosis factor would have another level of explanatory value to the equation (Moen et al, 1995; Hodgkinson et al., 2006).

In undertaking this research it was found that the research on males was conspicuously limited. It is therefore necessary to increase the focus on men as caregivers. Also limited in the data pool was the number of articles written on visible and invisible minorities.

There also needs to be further research into the psychological well-being and or quality of life factors of caregivers who have undertaken the role over extended periods. There is also need for research on the quality of life factors of individuals who have undergone chronic stress (as in the case of caregivers) versus those who have undergone episodic stress over extended periods.

It would also be interesting to see the extent to which perceptions about the normativity of caregiver role acquisition in middle age and spousal cancer caregiving at middle age evolve in light of the changing dynamics of caregiving and given the changing population dynamics in relation to cancer diagnosis rates.

Also limited in the data pool is the extent to which caregiving, in the face of an aging population, affects specific countries such as Canada, more specifically in the area of work/finances for example how many Canadians quit, take an extended leave of absence and or retire in order to undertake a care giving role?

Becker and Morissey in their 1988 study on caregivers' reactions to stress suggest that the negative effects of caregiving are only present during the caregiving experience thus there is room for the use of primary data in the exploration of the current topic and due to the cross sectional nature of the current study there is room also for conducting a longitudinal study on the effect of life course on cancer caregiving over a protracted period.

The idea of an extended longitudinal study would be particularly interesting as one would be able to explore the effects of the cancer caregiving experience on the lives of these caregivers after role disengagement, as the middle aged group members move into older adulthood and the older adult group advances to old old age.

Finally it would be interesting to understand more about the way that cancer caregivers cope with transitional disease changes such as disease progression and or recurrence.

Declaration of Conflicting Interests

The author declares no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Appendix

Table 4: *Proposed Variables from the Cancer Support Persons' Unmet Needs Survey*

<table>
<tr><td colspan="3">Independent Variable – Life Stage</td></tr>
<tr><td>Question as found in the survey</td><td>Variable Label</td><td>Response Options</td></tr>
<tr><td>My date of birth is…</td><td>Section 3,
Item 3</td><td>______ ______ _____
Day Month Year</td></tr>
<tr><td colspan="3">Mediating Variable 1– Unmet Information Needs</td></tr>
<tr><td>Question as found in the survey</td><td>Variable Label</td><td>Response Options</td></tr>
<tr><td>Finding information about the signs of cancer to look for and when to be concerned</td><td>NQP1001</td><td>0 = No Unmet Need
1 = Low Unmet Need
2 = Moderate Unmet Need
3 = High Unmet Need
4 = Very High Unmet Need</td></tr>
<tr><td>Understanding all the information the person with cancer and I were given</td><td>NQP1002</td><td>0 = No Unmet Need
1 = Low Unmet Need
2 = Moderate Unmet Need
3 = High Unmet Need
4 = Very High Unmet Need</td></tr>
<tr><td>Finding information about what foods are good for the person I support</td><td>NQP1003</td><td>0 = No Unmet Need
1 = Low Unmet Need
2 = Moderate Unmet Need
3 = High Unmet Need
4 = Very High Unmet Need</td></tr>
<tr><td>Finding information about what activities are good for the person I support</td><td>NQP1004</td><td>0 = No Unmet Need
1 = Low Unmet Need
2 = Moderate Unmet Need
3 = High Unmet Need
4 = Very High Unmet Need</td></tr>
<tr><td>Finding information about what I can do to help the person I support stay healthy</td><td>NQP1005</td><td>0 = No Unmet Need
1 = Low Unmet Need
2 = Moderate Unmet Need
3 = High Unmet Need
4 = Very High Unmet Need</td></tr>
<tr><td>Finding information about how to manage the side effects of treatment at home</td><td>NQP1006</td><td>0 = No Unmet Need
1 = Low Unmet Need
2 = Moderate Unmet Need
3 = High Unmet Need
4 = Very High Unmet Need</td></tr>
</table>

Finding information about cancer and its effects	NQP1007	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about how to manage the illness at home	NQP1008	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about what is included in follow-up care	NQP1009	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about the kind of help available to me and the person I support	NQP1010	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about support groups close to home in our community	NQP1011	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about other medical problems the person I support has developed since having cancer treatment	NQP1012	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about cancer and its impact on sexual relationships	NQP1013	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about what happens after treatment ends	NQP1014	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about what type of financial help is	NQP1015	0 = No Unmet Need 1 = Low Unmet Need

available and how to obtain it		2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about local support programs and counselling services	NQP1016	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Being able to talk openly about my feelings or worries with health care professionals	NQP1017	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about how people from my culture think about cancer and its treatment	NQP1018	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about who I should contact if I have a problem or concern	NQP1019	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about complementary or alternative therapies	NQP1020	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Talking to family and friends about how they are feeling	NQP1021	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about who to contact when the person I support had a medical problem	NQP1022	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding information about the long-term side effects of treatments and medicines	NQP1023	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need

		4 = Very High Unmet Need
Knowing how to make the most of my time with the person I support	NQP1024	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Knowing how to speak openly about cancer with the person I support	NQP1025	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Bonding about things other than cancer with the person I support	NQP1026	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Talking about the changing roles in my family	NQP1027	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Mediating Variable 2– Unmet Future Concern Needs		
Question as found in the survey	Variable Label	Response Options
Dealing with worry about the cancer coming back	NQP1028	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with worry about the cancer getting worse	NQP1029	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with not knowing what lies in the future	NQP1030	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with worrying about the future of the person I support	NQP1031	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need

		3 = High Unmet Need 4 = Very High Unmet Need
Mediating Variable 3– Unmet Work or Financial Needs		
Question as found in the survey	Variable Label	Response Options
Getting my boss to be more supportive and understanding	NQP1032	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Being able to keep working	NQP1033	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Getting time off work when I need it	NQP1034	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Paying non-medical costs (such as travel, special foods)	NQP1035	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Being concerned about how I am going to pay the bills	NQP1036	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with the way co-workers feel about my situation	NQP1037	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with a boss who does not provide me with support	NQP1038	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding and getting financial help	NQP1039	0 = No Unmet Need 1 = Low Unmet Need

		2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Mediating Variable 4– Unmet Healthcare Needs		
Question as found in the survey	Variable Label	Response Options
Having access to a variety of health care services and providers (dieticians, physiotherapists, occupational therapists)	NQP1040	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Getting appointments with health care providers quickly enough	NQP1041	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Making sure the person I support could see the same health care professional at each follow-up visit	NQP1042	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Having enough time with the doctor	NQP1043	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Getting test results for the person I support quickly enough	NQP1044	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Making sure the person I support could see the same cancer specialists at each follow-up visit	NQP1045	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Making sure the family doctor of the person I support could get information from specialists	NQP1046	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding health care	NQP1047	0 = No Unmet Need

professionals who were friendly and could have a laugh with me		1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Making sure the health care providers of the person I support had access to his or her medical files when planning health services	NQP1048	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dependent Variable 1– Unmet Personal Needs		
Question as found in the survey	Variable Label	Response Options
Feeling tired or lacking energy	NQP1049	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Not sleeping well	NQP1050	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding time alone, just for myself	NQP1051	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with feeling stressed	NQP1052	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Knowing how to relax	NQP1053	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with worries about the emotional well-being of your family	NQP1054	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need

Working around the house (cooking, cleaning, home repairs, etc.)	NQP1055	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Doing yard work (cutting grass, snow shoveling, etc.)	NQP1056	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding time to sleep	NQP1057	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding time to eat properly	NQP1058	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding time to do the things that make me happy	NQP1059	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Telling family and friends how my body is feeling	NQP1060	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Telling family and friends how I was feeling emotionally	NQP1061	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding time to see family and friends	NQP1062	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dependent Variable 2– Unmet Emotional Needs		

Question as found in the survey	Variable Label	Response Options
Dealing with feelings of sadness	NQP1063	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Knowing that I am doing the best I can	NQP1064	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with feeling helpless	NQP1065	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with guilty feelings if I enjoy myself without including the person I support	NQP1066	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with feeling like I'm letting the person I support down	NQP1067	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with feeling more vulnerable	NQP1068	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with not being able to 'get away from it all'	NQP1069	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Trying to stay positive	NQP1070	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Thinking about values and	NQP1071	0 = No Unmet Need

what matters most		1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with feeling frustrated about my situation	NQP1072	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Being aware of some of the good things that have happened in my life	NQP1073	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Dealing with depression	NQP1074	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding meaning in this experience	NQP1075	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Finding a sense of hope	NQP1076	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Setting goals	NQP1077	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need
Having to talk about how I am feeling with others	NQP1078	0 = No Unmet Need 1 = Low Unmet Need 2 = Moderate Unmet Need 3 = High Unmet Need 4 = Very High Unmet Need

(Campbell et al., 2009).