

Care-full: Exploring the Health and Wellness Issues Facing Women Caregivers

by

Holly Marie Heath
B.Sc., University of Northern British Columbia, 2007

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

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Abstract

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Informal caregiving for aging Canadians plays a vital role in the health care system, and scholars have noted the urgency and primacy of studying this important contribution provided by a relatively invisible cadre of volunteers, family members and friends. Despite the recent attention caregiving has received in the scholarly literature, it is dominated by quantitative research. The purpose of this qualitative inquiry was to explore the lived experiences of female caregivers in terms of their perspectives on caregiving and their own personal health and wellness. A sample of seven female caregivers was obtained using a combination of both purposive and snowball sampling. Through semi-structured interviews participants were asked to describe their experiences as a caregiver. A primary theme “one day at a time” emerged from the data. Within this overarching narrative were three sub-themes: “Intensive care”, “Transitions”, and “Support” found to characterize their caregiving realities including both positive and negative aspects. Capturing a rich understanding of the lived experience of female caregivers, intentionally including and honouring their voices, can inform the design and implementation of health promoting policies, programs, and interventions, as well as identify avenues and approaches to future research.

Keywords: caregiver; health and wellness; lived experience; phenomenology

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Chapter 1: Introduction

Evolution of the study

I can still remember the way the waiting room smelled as I sat waiting to hear news of my mother's surgery. It had been hours since the floor sweeper had been by but the sterile smell of the cleaning solution lingered. Where there was once such a flurry of activity rushing around me, I was now alone contemplating every potential outcome. "Surely they would know something by now," I thought to myself, wondering how long an appropriate amount of time was before someone would have some information for me. While my surroundings had stilled, my mind was racing; with each passing hour my thoughts became louder and louder as if competing for attention. Was my mom going to survive this? And if so, what would she be like? How was I going to manage in a world where she didn't exist? Simultaneously I wondered, "what about me?" I continued to sit quietly while I reflected on the past few months and began to take inventory of all that had been lost already. I began working up the courage to find someone, knowing that my whole world could change with the information I was seeking. I walked up and down the abandoned hallways not understanding where everyone had gone but knowing one thing for sure: I was alone. I was scared and I had been forgotten.

As the weeks passed, my mom moved from hospital to hospital and I began to feel at home in the hallways. While everyone circled around me doing their various tasks in almost a blur, it became clear that I was not alone. I was surrounded by other lost souls fading into the background, easily missed, and almost invisible. I could now recognize other caregivers, waiting, searching, lost- they were easy to spot and I began making

friends. We began to share information but most importantly we began to share our stories. Each of us seemed certain our experiences were unique, and knew that no one would understand, yet discovered that our stories resonated in some way with each member of our new club.

Several years later I would find myself taking a course in dysfunctional aging, where the topic of caregiving would present itself. I began to listen to students discuss the many challenges reported by caregivers and present their ideas about what was needed to help them. It became clear that we were a class divided, with caregivers in one corner and those who had yet to experience providing care for someone in the other. It was a constant negotiation between what was needed and what was understood. That is to say, there were some who were certain they knew the interventions needed to help caregivers improve their health, while others tried to point out how their lack of experience and understanding related to caregiving were preventing them from seeing potential challenges.

Research has “primarily focused on the measurable tasks and stresses of caregiving” (Connell, 2003, p.1), in particular when caregiving for those with dementia. In addition, health promoting policies, programs, and interventions that exhibit a much deeper understanding of caregivers’ lived experiences are urgently needed (Connell). Just as my role as a caregiver evolved, it was through listening to others share their stories, identifying some of the challenges within the current literature, and understanding how my own personal experience could be of value that allowed this study to emerge. This thesis is an exploration of the caregiving phenomenon. In this introductory chapter, I present an overview of the caregiving phenomenon and justification for the study,

including the context with which I approached the study given my own background and experience. The chapter closes with the statement of inquiry (research question) and a list of operational assumptions.

Phenomenon of interest

The phenomenon to be explored is the experience of caregiving by adult women and how this experience may affect their personal health and wellness. The caregiving experience is not a new phenomenon (Connell, 2003). Historically, families have always looked after their aging family members. In the past, though, the need to provide prolonged care for family members was quite rare and most commonly a short-lived event as the result of infectious disease or other acute medical complications (Zarit, Reever, & Bach-Peterson, 1980)

The negative health impact experienced by caregivers is a recent phenomenon that has emerged as a result of the shift in demographics, Canada is aging and this shift in demographics is thought to be largely the result of two factors: longer life expectancies and the aging of the baby boom generation. First, the life expectancy of Canadians has been on the rise since the early nineteenth century. Up until 1900, less than five percent of the population was over the age of 65. In 1981, the average life expectancy was seventy-six, compared to eighty-one in 2006. Further, in 2010, 15.3% of Canada's population was over the age of 65, representing 4,386,969 older adults. It is estimated that by 2030 this number will have risen to 24.1% representing a staggering 7,844,309 older adults. In addition to longer life expectancies, the baby boom generation is transitioning into their senior years. At the height of the baby boom, which occurred from 1947 to the early sixties, women were averaging four children each, which helped to reverse the decrease

in fertility rates experienced in the late nineteenth century (Armstrong & Armstrong, 2010). This has resulted in a significant portion of the population entering their senior years in present day.

To date, chronic conditions are the leading cause of death among Canadians and worldwide (Chappell & Hollander, 2013). With longer life expectancies and a larger elderly population there is an increase in the prevalence of those living with chronic health conditions and disability, and thus an increase in the need for support and care. There is concern that this will place unmanageable demands on our health care system. Reports have projected increased health care costs climbing so high that people are left wondering whether or not this increase in older adults could have catastrophic consequences on the Canadian health care system (Armstrong & Armstrong, 2010). Rising health care costs coupled with the impacts of the 'baby bust' only make these concerns more pronounced. That is, after the baby boom phased out in the early 1960's, a combination of more women entering the work force and the introduction of birth control led to a decrease in birth rate, and thus a 'baby bust' period in Canada (Chappell & Hollander, 2013). This relatively small generation of people may be forced to shoulder the massive health care costs for the baby boomers unless there are changes to the health care and community care systems, and/or there are improvements to the fitness and health of older adults who are more likely to rely less on the health care system (Bachman et al., 2015).

As the next chapter details, informal care is often integral to maintaining the health and well being of people who are aging, ill, or disabled. Informal care has been shown to reduce the demands and costs on health care and social systems (Rhee,

Degenholtz, Lo Sasso, & Emanuel, 2009). Most health care and prevention is being provided informally at home and by volunteers in the community who may or may not be trained to do so (Armstrong & Armstrong, 2010). Increasing longevity results in the prolongation of complex health conditions which can place significant demands on informal caregivers. There is increased concern regarding the availability of family members to provide this type of support for several reasons. Women family members, for example wives or daughters, most frequently provide informal care (Wilcox & King, 1999) however; more women are now in the work force and therefore have less time to fulfill this role. In addition there are fewer younger generation family members available to provide care due to lower fertility rates, and greater geographic mobility (Chappell & Hollander, 2013).

Justification for study

Informal caregiving is complex and each person will experience the role of caregiver differently. Researchers have taken an interest in issues related to caregiving as supported by the significant rise in publications over the past two decades. Caregiving has certainly become an area of interest and much research has focused on the demands of the role and the stress these demands place on the caregiver's psychosocial health (Berglund, Lytsy, & Westerling, 2015; Boerner & Mock, 2012; Chiou, Chang, Chen, & Wang, 2009; Tuithof, ten Have, van Dorsselaer, & de Graaf, 2015). While not as robust, there is a body of literature that includes the impact caregiving may have on the caregiver's physical health (Fredman, Lyons, Cauley, Hochberg, & Applebaum, 2015). "What is needed in research is an exploratory study of meaning and significance of the day to day experience of informal caregiving" (Connell, 2003, p.5) and the effects these

experiences have on women caregivers' personal health and wellness in particular given that this role is most often assumed by women.

Often, with such a focus on objective measurement and outcomes, it is easy to forget the caregiver's own personal lived experience. This only results in a continued lack of understanding and ultimately ineffective implementation of health promoting policies, programs, and interventions. In addition, the continued focus in the literature on the negative aspects of caregiving only perpetuates the stereotypical idea of a burnt out caregiver ready to receive caregiving herself. At best, this is not encouraging and at worst, it may create a self-fulfilling prophecy. The health of both the caregiver and care receiver may be interdependent (Pagnini et al., 2010; Rabkin, Wagner, & Del Bene, 2000). That is, the healthier the caregiver, the healthier the care recipient. Many of the decisions fall on the caregiver (Adams, 2006; Dickson, O'Brien, Ward, Allan, & O'Carroll, 2010; Quinn, Clare, Pearce, & van Dijkhuizen, 2008) and it is for this reason that caregivers need to feel empowered to take control of their situations. As long as policies, programs, and interventions are developed and implemented with little to no understanding of the lived experience of the caregiver, this is not possible. In fact it could be setting them up for failure.

Context

My interest in the experience of informal caregiving and the impact it has on the health of the caregiver arose from both my personal and professional experience. My mother was diagnosed with Multiple Sclerosis when I was born and I have been helping her in some way or another my whole life. It wasn't until about eight years ago that her health took a significant turn for the worst, requiring much more care than before. We

were left alone to navigate the system and define our new normal, and this took a toll on my health. I had always taken great pride in my health; I participated in various sports both as an athlete and as a coach and worked as a personal trainer and nutrition consultant. What once was a very important part of my life was lost when my mom became very ill. I was no longer interested in activities I had previously enjoyed, I had gained a significant amount of weight, and I became less social.

Professionally, I began to work at a number of hospitals providing additional care to those in need. It was through this experience interacting with other caregivers, social workers, and nursing staff that I began to see that what I was experiencing was not unusual. I would listen to others talk about how someone had really “aged” since caring for their loved one, or a caregiver would ask me what I was eating and then open up about their struggle to prepare healthy food for themselves after a long day of care. Most of all, they would tell me about what they used to be like before they took on the role of caregiver. They used to be friendly, easygoing, and active. They used to read, cook, draw, and hike. They never anticipated the extent to which their lives and health would change and they felt powerless to do anything about it.

My initial response was to think of a way to educate caregivers about physical activity and nutrition- to offer suggestions about creative ways to sneak in activity and tips on how to prepare healthy food on the go. I then thought about how I, as a caregiver, would receive this information and it was not well. A number of people around me had expressed concern about my health and offered practical suggestions as to how I could improve it. This advice left me feeling ashamed, angry, and most of all like no one understood what I was going through. I found myself questioning: What role does a

caregiver's knowledge of health and wellness play in their ability to maintain their health throughout this experience? How does the experience of caregiving impact their health and wellness? If it isn't a lack of knowledge, what is standing in the way of caregivers improving their current health? Is anyone doing anything that might work well for the rest of us? I certainly had more questions than answers. My personal and professional knowledge and experience provided a history of caregiving on which I was able to draw from. On the other hand, it made it imperative to be aware of any bias that might hinder impartial analysis of the data.

Thus the objective of this study is to give a voice to the lived day-to-day experiences of female informal caregivers. The study focuses on how these everyday experiences may be taken for granted and have an impact on the caregiver's personal health and wellness. Through qualitative thematic analysis located within the philosophy of phenomenological exploration, this study seeks to provide a better understanding of the lived experience of female informal caregivers so that this information may be used to better shape future policy, programs, and/or interventions, ultimately improving the quality of life for both the care provider and the care recipient.

Phenomenology

Phenomenology is derived from the Greek 'phainomenon' meaning 'to show itself'. While first and foremost a philosophy, phenomenology is also concerned with approach and method. This can be challenging as it requires the researcher to first understand a complex philosophy before they are able to decide how this philosophy may be used in practice as a phenomenological study (Sparkes & Smith, 2014). As stated by

Merleau Ponty (1962), the philosophy of phenomenology is to view the world in such a way as to capture ‘the lived experience’ (Merleau Ponty as cited in Connell, 2003).

The main objective of phenomenological research is to explore, in detail, how participants make sense of their personal and social worlds. To this day there have been at least eighteen different schools of phenomenology identified, each with similarities and differences when compared to the others (Sparkes & Smith, 2014). However, despite their differences, one thing phenomenologists can all agree upon is their “rejection of scientific realism and the accompanying view that the empirical sciences have a privileged position in identifying and explaining features of a mind dependent world” (Sparkes & Smith, 2014, p. 37). It is then the intention of phenomenological research to better understand the meaning of an experience often taken for granted as commonplace (Morse, 1994). In an attempt to accurately portray the meaning of an experience, the researcher engages in a process of phenomenological reduction or epoché. Sparkes and Smith describe this process as the suspension of everyday, taken for granted assumptions about a phenomenon. At the very least, it should involve the identification of assumptions, followed by setting them aside in order to suspend or bracket the natural attitude. As described by Munhall (1994), ‘unknowing’ may, in fact, be a more accurate term to describe the process of setting aside assumptions. In her words, “bracketing... [is] the position of standing before an experience with an attitude of unknowing, even if and especially if one has lived the experience personally in order to allow multiple different possibilities to emerge” (Munhall as cited by Connell, 2003, p.9). However, one’s personal experience and beliefs form the foundation from which one can proceed with unknowing.

Area of inquiry

The purpose of this study was to gain a better understanding of how the experience of females providing informal caregiving for care recipients living at home and in care facilities could affect the caregiver's own personal health and wellness.

Assumptions

1. Qualitative thematic analysis is an effective method for understanding how the experience of females providing informal caregiving for care recipients living at home and in care facilities could affect the caregiver's own personal health and wellness.
2. Participants are interested in sharing their perspectives, beliefs, and experiences relating to caregiving.
3. Participants will provide honest responses during the interview process.

Operational definitions

Health as defined by the World Health Organization is no longer simply "the absence of disease or infirmity" but encompasses "complete physical, mental and social well-being" (World Health Organization, 2016). *Wellness* on the other hand is more of a dynamic, "conscious, self directed and evolving process of achieving full potential" (National Wellness Institute, 2016).

An *informal caregiver* can be a family member, friend, or member of the community who provides "regular and sustained" assistance to someone who requires support. The work informal however, is not intended to suggest that the care provided is casual but rather it is meant to provide a distinction between "the unpaid care provided by

family, friends or neighbours from care provided by formal agencies or institutions”

(Australian Institute of Health and Welfare, 2016).

Chapter 2: Review of the Literature

Canada is experiencing a shift in demographics as a result of the retirement of the baby boom generation and the increase in life expectancy. Like many other countries, the proportion of seniors in Canada's population is growing and consequently the care needs of this segment of the population are increasing. There is much concern about the burden this shift will place on an already over-taxed formal health care system. As such, informal support systems are becoming increasingly important, as recognized by the significant increase in literature related to informal caregiving over the past two decades related to informal caregiving. While this type of support can vary in nature, it generally includes unpaid care provided voluntarily to an elderly, ill, or disabled person.

When most of us think of health care, we immediately conjure up images of doctors and nurses in hospitals and care homes. However, much of health care support- including assistance with activities of daily living such as bathing, toileting, eating, and leaving the home for errands and/or appointments- is actually being provided informally. Family, friends, and neighbors are playing a vital role in providing this type of assistance despite often having competing demands on their time and energy (Connell, 2003). As described in the ensuing pages, while most informal caregivers gain personal satisfaction through the role they provide, it can be unpredictable and demanding. For these reasons it is important that we examine the impact of caregiving and the costs associated with caregiving on the caregiver's own personal health and well-being and the sustainability of informal caregiving.

In this chapter, the literature on caregiving is extensively reviewed, beginning with a discussion of the diversity of caregiving experiences. Also in this first section, I

note the urgency and primacy of caregiving research identified by scholars, which has led to a profusion of caregiving research, in turn informing several new support programs. The Caregiver Identity Theory is also presented to describe the direction for the development and implementation of support services for caregivers. The following sections discuss the role of caregiving in health care, its positive and negative outcomes, how it has been explored through phenomenological research, and limitations within the current literature.

Caregiving and health care

Canada's health care system has been a source of great pride for many Canadians. Saskatchewan introduced the first provincial hospital insurance program in Canada in 1947, and since that time, Canadians have become accustomed to publicly funded healthcare. Canadians today, who were alive before the initiation of publicly funded health care, may not have experienced the alternative (i.e. full cost for services, restricted health care providers or treatments, and segregation based on income), not needing it in their early years. Armstrong and Armstrong (2010) would argue that the only sustainable health care system is a fully public one and base this on the notion of the individual right to care and the collective responsibility for that care. However, with the continually rising cost of Medicare, the current publically funded health care system may be under threat. With many Canadians unfamiliar with a non-publicly funded system, some researchers fear that Canadians might not know how good they have it until it is too late (Armstrong & Armstrong, 2010).

Over the years, a number of recommendations have been made in order to deal with rising healthcare costs. These include: reducing public services; increasing taxes;

introducing individual co-payments; reducing the quality of health care; and developing a two-tiered privately funded system. Despite this gloomy picture of the impending health care crisis, Chappell and Hollander (2013) argue that while the number of older adults is increasing, this should be cause for attention, not alarm. Reports from many national and private sector organizations neglect to consider increasing value for money, which Chappell and Hollander (2013) say can, and has been achieved through the development of integrated models of care delivery. Options that warrant further exploration include expanding information and care delivery technology, focusing on quality and value, and health promotion.

Historically, a great deal of money has been spent on the health care system with little return on investment. One common criticism is that the focus of health care has been on illness rather than health: in order for the system to be more effective, the priority should be on health promotion instead of treatment and cure (Armstrong & Armstrong, 2010). Further, although some policy makers claim that previous health care reforms have been based on consumer preferences, a number of policy documents show disagreement. For instance, while reforms have targeted the formal health care system, reports show that Canadians would prefer to be cared for at home and in the community rather than through the formal health care system (Armstrong & Armstrong, 2010). Canadians have demanded more say in how their health care system operates; however, despite promises to reform, challenges continue with respect to quality, access, and choice.

As the number of people requiring care and support increases, the main issue is sustainability. It has been reported that informal caregivers provide approximately 80%

of the care required by those with chronic health (Lum, 2011) issues saving Canadians anywhere from \$25-\$26 billion (Hollander, Liu, & Chappell, 2009). In order to combat these issues, the nature of health care is changing. There has also been a shift in emphasis from institutionalized care to home care, which may suggest that more people are relying on help from informal support networks provided by family, friends, and the community than in the past.

Who cares?

Most health care and prevention is being provided informally by women at home and by volunteers in the community (Lee & Porteous, 2002; Singer, Biegel, & Ethridge, 2010) who may or may not be trained to do so (Gitlin, Marx, Stanley, & Hodgson, 2015). According to the 2012 General Social Survey nearly half (46%) of Canadians above the age of fifteen, an estimated 13 million, reported providing care, in some form, to a family member or friend who was aging, ill, or disabled. It was also not uncommon for informal caregivers to be providing care to more than one person at a time. While the median number of hours providing care for both men and women were similar (3 to 4 hours per week) women were more likely than men to spend 20 or more hours per week providing care (17% versus 11%). In addition, men were more likely to spend less than one hour per week caregiving (29% versus 23%). The author suggests that this increase in caregiving intensity among women may be related to the tasks in which they perform. Women were more likely to provide assistance with personal care needs, which require a more regular or set schedule. Other tasks more commonly performed by women on an ongoing basis were assistance with medical treatments, housework, and preparing meals. Men, on the other hand, were more likely to provide assistance with tasks that could be

done periodically and around the caregivers schedule such as house maintenance and outdoor work (Statistics Canada, 2012).

According to Statistics Canada (2012), parents were the more frequently cared for population. For example, approximately half (48%) of caregivers reported providing care to a parent or parent-in-law within the last year. It was reported that adult children were four times more likely to provide care to a parent than to a parent-in-law and two and a half times more likely to care for their mother as apposed to their father. It was noted that this was likely the result of women outliving their spouses and requiring assistance from their children to help with age related issues. This is not to say that caregiving is limited to family members as the second most common category of care-recipients was comprised of close friends, colleagues, and neighbors (16%). Other care recipients included: grandparents (13%), siblings and extended family members (10%), and spouses (8%).

Reflecting the fact that the majority of caregivers in Canada were caring for parents it is not surprising that the largest groups of caregivers are reported to be between the ages of 45-54 years (24%) and 55-64 years (20%). While senior caregivers were the smallest of the groups it is particularly important to understand that they are also the most likely to be providing the most hours of care. For instance, it was reported that 23% of senior caregivers were providing in excess of twenty hours per week of care. This was attributed to the fact that most senior caregivers are providing care to a spouse, which typically requires a greater level of commitment. Therefore, despite being the least common group of care providers, given their advanced age the responsibility of caregiving may have a more pronounced impact on their lives.

As the prevalence of caregiving is known to be higher among women it is important to better understand some of the unique challenges experienced by this population. One such challenge is the fact that many women do not identify as being a caregiver as soon as men or at all. This is particularly true for women who have traditionally performed many of the domestic tasks such as cooking and cleaning. These women may not see increased levels in domestic care responsibilities as being part of the caregiving role, while men readily see this as care work (Arber & Ginn, 1995; Dwyer & Seccombe, 1991; Yee & Schulz, 2000). Throughout the literature it has been reported that women experience more health problems (Denton & Walters, 1999), lower levels of social resources (Pinquart & Sorensen, 2006), and greater use of health care (Koopmans & Lamers, 2007) supporting the need for further exploration into the health consequences experienced by women who are providing informal care.

Informal caregiving and health

Informal care is often integral to maintaining the health and well-being of people who are aging, ill, or disabled. Informal care has been shown to reduce the demands and costs on health care and social systems (Armstrong & Armstrong, 2010). In addition to the many benefits that go along with an increase in life expectancy there is also the down side, which is the prolongation of complex health conditions. Unfortunately, this can place significant demands on informal caregivers. There is increased concern regarding the availability of family members to provide this type of support, because of lower fertility rates, and greater geographic mobility. Further having more women in the work force significantly influences the availability of family support given that women most frequently provide informal care.

Informal caregivers provide an essential service for society and the ones they care for; however, they do so at a cost to their own personal health and well-being. Caregiving can be stressful and when there is an imbalance between the care demands and the types of support available (e.g., financial resources, social support, and respite), the caregiver may experience greater levels of stress and burden (Wang et al., 2011). This is most commonly referred to in the literature as caregiver burden or burnout and can have serious health consequences.

Caregiver burden is a multifaceted phenomenon with numerous objective and subjective inter-related component (Emlet, 1996). While each caregiver will experience their role differently, it has generally been found that informal caregivers experience more stress and emotional difficulties, such as depression and anxiety, than their non-caregiving peers (Andrew, Kilkenny, Naylor, Purvis, & Cadilhac, 2015; Berglund et al., 2015; Denno et al., 2013). Further, informal caregiving may result in sacrifices to their financial well-being (Andrew et al., 2015) and physical health (Fredman et al., 2015). There is also some evidence that the chronic stress experienced by caregivers can have adverse effects on their psychosocial health.

Psychosocial consequences

Several studies have examined the psychosocial factors associated with informal caregiving (Chiou et al., 2009; El Masry, Mullan, & Hackett, 2013; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; McPherson, Wilson, Chyurlia, & Leclerc, 2011). While stress, depression, and insomnia have been cited most frequently, caregivers may also experience feelings of social isolation, anxiety, and a reduced quality of life (McPherson et al., 2011). When one decides to take on the role of a caregiver they often

find themselves relinquishing leisure time activities and relationships with friends and family, all of which can contribute to poor psychosocial health.

Depression

The World Health Organization recognizes depression as the leading cause of disability and estimates that, by the year 2021, it will be the second most burdensome mental health disease worldwide. A number of studies found that caregivers had higher rates of stress and depression than their non-caregiving peers (Denno et al., 2013; Pinquart & Sorensen, 2003). Depression has been identified as one of the most concerning potential adverse consequences for caregivers because of the high prevalence and connection to poor quality of life (Chio et al., 2010). Further, it acts as a risk factor for other adverse health outcomes such as functional decline and early mortality (Barrow & Harrison, 2005; Canuscio et al., 2002).

Informal caregivers may be at an increased risk of depression if they are affected by a variety of other medical, social, and economic factors. The most frequently found to be at risk are those in poor health and/or functional status (Hsiao & Chiou, 2011), those who have fewer financial resources, women and spousal caregivers, and those who spend more hours caregiving (Lou, Kwan, Leung, & Chi, 2011). It should also be noted that there are important ethnic differences in the prevalence of depression experienced by caregivers; the lowest rates are reported by caregivers of black patients and the highest by those providing care for Hispanic patients (Sorensen & Pinquart, 2005). Also, there is strong evidence that difficult patient behaviours, particularly angry or aggressive behaviours, can increase the risk of depression in the caregiver. Behavioural disturbances

and a decrease in the patient's ability to carry out activities of daily living have both been found to be independently associated with caregiver depression (Pagnini et al., 2010). It is important to examine not only the prevalence of depression in both caregivers and care recipients, but also the relationship between the care provider and recipient as it relates to depression. It has been found that even when health, social and psychological resources are taken into account, the emotional stress of a caregiver can have a significant direct and positive association on the care recipients level of depression (Ejem, Drentea, & Clay, 2015).

Anxiety

Like depression, anxiety has been found to be higher among caregivers when compared to a non-caregiving population. Although anxiety and depression are often grouped together, the predictors of depression may not be the same as those of anxiety, so it is important to consider anxiety as a separate outcome measure. For instance, although it has been reported that most depressed caregivers are also anxious, it is not necessarily the case that caregivers with anxiety also suffer from depression.

Not only is it common for caregivers to report anxiety levels in the clinical range, many are reporting levels even higher than those receiving care. Despite some evidence that anxiety disorders may be more prevalent in caregivers than depression, this comparison has not been examined as extensively. Cooper, Balamurali, and Livingston (2007) examined the prevalence and covariates of anxiety in caregivers of dementia patients and found that nearly one quarter of these caregivers exhibited symptoms of anxiety, classified as clinically significant. Further, although burden and physical health

covariates were similar to those of caregiver depression, coping styles were more likely to be associated with anxiety than with depression.

Fatigue and sleep disturbance

Fatigue and sleep disturbances are reported frequently among caregivers and include inadequate sleep at night, decreased daytime enthusiasm, poor sleep quality, and the use of sleep medication. While not given much attention throughout the literature, fatigue and sleep disturbance are important to consider as they have been identified as major factors in deciding whether or not to institutionalize the care recipient (Creese, Bedard, Brazil, & Chambers, 2008). Nighttime awakenings appear to be the most disruptive on the caregiver and occur for a variety of reasons depending on the health of the care receiver. For example, people with dementia often experience insomnia (Wilcox & King, 1999), while nocturnal cramps, pain, and impaired motor function tend to be more specific to those with Parkinson's disease (Happe & Berger, 2002). Other care receiver variables that may affect the caregiver's sleep include depression and level of functional impairment (Creese et al., 2008).

Caregivers of dementia patients report more sleep disturbances than their non-caregiving peers. Wilcox and King (1999) suggest a number of factors that may contribute to more frequent sleep disturbances in caregivers of dementia patients. First, caregivers report higher levels of stress and depression, both of which are associated with sleep disturbances. Second, people with dementia may experience nocturnal awakenings, one of the factors reported to be the most disruptive to caregivers. In addition, the caregiver's own personal needs, which may not be timed with the care receivers, make them likely to be awakened more frequently. Lastly, there could be interactions between

these factors. For example once awake, a caregiver may have difficulty returning to sleep as the result of negative thoughts and feelings.

Creese (2008) also concluded that caregivers who were woken frequently could be at risk of falling into an unhealthy sleep routine. Over time, continual sleep disturbance could lead to daytime fatigue, stress and depression, all of which have been known to contribute to further sleep disturbance. Caregivers may attempt to compensate for the disturbed sleep by taking short naps throughout the day, drinking caffeinated beverages to stay awake, and/or drinking alcohol to help fall asleep, resulting in a self-perpetuating cycle of sleep disturbance.

Spousal caregivers may represent a particularly vulnerable population. They appear to be more adversely affected both mentally and physically than other caregivers, which may place them at greater risk for sleep problems. Creese (2008) examined the sleep characteristics in spousal caregivers who lived with the care receiver. Sixty-three percent of the caregivers reported sleep disturbances from nocturnal disruptions, which was associated with poorer mental health and a greater number of depressive symptoms. Although previous studies have suggested that these sleep disturbances may be the result of the caregiver sharing a bed with their spouse (Wilcox & King, 1999). The study by Creese (2008) however, did not support this finding, as they reported no difference between spouses sharing a room or those in separate spaces. The authors indicate that the nocturnal disruptions reported by the caregivers included such tasks as the care recipient needing to use the washroom, wandering, or requests for assistance, all of which would require the caregiver to respond whether they were in the same bed or not.

Other studies have examined sleep disturbances in caregivers of patients with diseases other than dementia and found similar results. Carter and Chang (2000) examined fifty-one caregivers of cancer patients and found that ninety-five percent reported severe sleep problems. In a study looking at caregivers of Parkinson's patients, not only were sleep disturbances and depressive symptoms reported frequently, it was discovered that the frequency of caregiving was related to self-perceived poor sleep (Happe & Berger, 2002). Disturbances in sleep are contributing to both physical and psychological burdens to caregivers. A number of studies have shown a correlation between disturbed sleep and higher levels of depressive symptoms (Creese et al., 2008; Happe & Berger, 2002; Wilcox & King, 1999). Caregivers experiencing poor sleep are also at risk for and have been linked to lowered quality of life, decreased cognitive functioning, and increased risk of the morbidity and mortality associated with depression and cardiovascular disease. Furthermore, as mentioned previously, disturbances in caregivers' sleep have been shown to be a major contributing factor when deciding to place the patient in an institution.

Physical health

Although not as well documented as psychosocial effects, providing care for someone has been linked to poor physical health (Berglund et al., 2015; Fredman et al., 2015). There is mounting evidence supporting the notion that the chronic stress experienced by many caregivers is responsible for the adverse effects on physical health being reported (Monin et al., 2010). When compared to their non-caregiving peers, caregivers are experiencing higher rates of physical distress including, but not limited to: metabolic syndrome, decreased immune function, stroke, and coronary heart disease

(Fredman, Doros, Cauley, Hillier, & Hochberg, 2010; Von Kanel et al., 2008). Research indicates that the physical demands, prolonged distress, and predisposition to adverse health may collectively be placing informal caregivers at greater risk for physical health problems and mortality (Berglund et al., 2015; Buyck et al., 2013; Monin et al., 2010)

Caregivers consistently have higher levels of self-reported stress and stress related biomarkers than that of their non-caregiving peers (Fredman et al., 2010). This chronic level of stress may lead to stress induced metabolic syndrome, thought to contribute to the association between chronic stress and adverse physical health seen in caregivers. Workers in high stress occupations have a higher prevalence of metabolic syndrome and the stress experienced by informal caregivers has been found to be comparable (Fredman et al., 2010). Both show neuroendocrine and inflammatory markers associated with chronic stress and linked to metabolic syndrome. This is of concern as metabolic syndrome is a risk factor for functional decline and mortality.

Furthermore, there is considerable evidence of the adverse effects of chronic stress on cardiovascular health, especially for women (Torimoto-Sasai, Igarashi, Wada, Ogata, & Yamamoto-Mitani, 2015). Chronic stress, experienced by caregivers, is thought to trigger psychological distress and it is not uncommon for this to result in poor health behaviours and disengagement from self-care. Similarly, when low personal and social resources accompany chronic stress, the result may also lead to poor health behaviours, which can result in cardiometabolic abnormalities, and ultimately coronary heart disease (Fredman et al., 2010).

Most of the research looking at the relationship between caregiving and coronary heart disease has been conducted on elderly individuals, primarily female spousal

caregivers, with short-term follow-ups. As a result, conclusions cannot be made regarding the long-term impact caregiving may have on cardiovascular disease in non-elderly populations (Buyck et al., 2013). More recently, Buyck (2013) presented the results from research done on a large sample (5,468 men and 2,457 women aged 39-63 years) of middle-aged men and women who were followed for almost two decades. While no clear evidence emerged in support of caregivers being at greater risk for coronary heart disease, caregivers in poor health at the start of the study were at an increased risk when compared to non-caregivers in good health. An increased risk of coronary heart disease was not found in caregivers who were in good health. These results were made independently of a variety of characteristics including age, sex, ethnicity, marital status, socioeconomic position, health behaviours, and chronic diseases and risk factors. It is important to highlight that this study did show an increase in the risk of coronary heart disease among middle-aged caregivers who reported poor health.

Caregiver gains

Less attention has been devoted to the positive aspects of caregiving compared to the overwhelming amount of literature on caregiver strain and burden. However, not all caregivers experience these negative aspects and research has been able to show that the role of caregiver can be associated with numerous benefits (Cohen, Colantonio, & Vernich, 2002). Some examples of the positive experiences reported by caregivers include satisfaction and personal growth, joyful moments, and enhanced relationships with the care recipient.

Throughout the literature a variety of terms have been used to describe the positive experiences associated with caregiving including: caregiver gains, rewards,

uplifts, and satisfaction with the caregiver role. For consistency, the term caregiver gains will be used. While strain or burden has been defined as “the extent to which the caregiving role is judged to infringe upon an individual’s life space and be oppressive” (Montgomery & Borgatta, 1989, p. 204), gain is defined as “the extent to which the caregiving role is appraised to enhance an individual’s life space and be enriching” (Kramer, 1997, p. 219). Thus, caregiver gains can include any positive affective or practical return that is experienced by the caregiver as a direct result of their care-providing role.

Another conceptual model used within the caregiving literature is the Transactional Model of Stress and Coping, which suggests that stress occurs when there is a perceived discrepancy between the demands of caregiving and the caregivers’ ability to respond to those demands (Grant, Ramcharan, McGrath, Nolan, & Keady, 1998). This conceptual model assumes that the onset and progression of chronic illness and functional decline is stressful for both the caregiver and care recipient, allowing the experience to be examined using traditional stress/health models. Recently, a new conceptual framework was proposed, suggesting that positive gains emerge through a variety of enrichment events experienced by the caregiver throughout his or her daily routine (Carbonneau, Caron, & Desrosiers, 2010). The argument made is that the caregiver’s ability (self-efficacy) to replicate these events will determine the level of positive gains.

One common concern among the literature examining caregiver gains is that there tends to be a greater focus on the absence of negative effects such as depression and anxiety as opposed to the presence of positive gains. Rapp and Chao (2000) however tell us that a positive appraisal by the caregiver of their role can affect well-being by

buffering the stresses associated with caregiving and that they are independent of negative appraisals. This has been supported by a longitudinal study examining benefit finding in a sample of 502 people with Multiple Sclerosis. Although the study was not conducted on a sample of caregivers it does show support for the need to further examine the use of benefit finding as a tool in promoting the health and well-being of caregivers as it was reported to play an important role in sustaining positive psychological states (Pakenham, 2005).

Cohen, Colantonio, and Vernich (2002) documented positive aspects reported by a sample of caregivers from the Canadian Study of Health and Aging. The authors found that, of the 289 caregivers included in their study, 73% were able to identify one positive aspect of caregiving and an additional 6.9% were able to identify more than one. Among the positive aspects identified were that the caregiving role: provided companionship (21.8%), was fulfilling/rewarding (12.8%), was enjoyable (10.4%), fulfilled a duty/obligation (7.3%), provided quality of life (5.9%), was meaningful/important (5.5%), and allowed the provider to make decisions (1%). In addition to the positive aspects identified, participants were asked on a seven-point scale to rate their overall feelings of caring which resulted in 30.4% giving the happiest rating and 72.7% within the top three ratings. These findings are supported by a more recent qualitative study by Parveen, Morrison, and Robinson (2011) where they found that caregivers not only discussed the burdens associated with caregiving but wished to discuss what they had gained as well. Positive gains in caregiving are an important area to examine as research supports the idea that these gains tend to be negatively correlated with chronic stress and overall well-being. Specifically, positive feelings about caregiving have been found to

show a significant inverse relationship with depression, burden, and perceived poor health (Cohen et al., 2002).

Research has primarily focused on caregiver gains as a buffer against negative consequences, but some researchers have identified factors that could improve the positive gains experienced by caregivers. Some examples include social support, advanced age, female gender, spousal relationship, and religious beliefs. A meta-analysis by Pinquart and Sorensen (2003) showed that even perceived gains in caregiving were positively associated with the subjective well-being of the caregivers. Langner (1995) demonstrated that when caregivers focused more on the meaning of their experiences rather than the stress, they were able to rediscover a sense of self, and felt greater satisfaction and self-worth.

To summarize, caregivers who report more positive views about their role are less likely to experience the negative consequences associated with caregiving. As people experience both positive and negative emotions, simply focusing on the negative aspects of caregiving in research skews perceptions of the caregiving experience, limiting the ability to enhance the theory of caregiver adaptation, as well as support programs and policies.

Exploring the experience of caregiving through qualitative research

A review of the quantitative literature on caregiving has brought to light a number of potential health consequences caregivers may face while also recognizing some positive aspects associated with the role. To date caregiving research has been abundant with data and information assembled using statistical analysis. However, the theoretical, causal, and explanatory mechanisms, which lie behind such associations, requires greater

attention (Funk et al., 2010). This traditional natural science approach has paid particular attention to the stresses and tasks associated with caregiving (Abel, 1990). Connell (2003) however, explains that while quantitative research may provide an objective understanding of the intense labor involved in caregiving it does not offer insight into the meaning of the subjective human experience of caregiving. Qualitative research, on the other hand, can make important contributions to understanding in this regard by describing the complex nature of the caregiving experience, assisting in the development of “empirically based conceptual and theoretical frameworks for research and practice” (Funk et al., p. 595)

In a review of qualitative literature on home-based family caregiving at the end of life, Funk and colleagues (2010) reviewed a total of 105 articles published from 1998 to 2008. They observed that most researchers used a convenience sample of volunteers and clarified that while non-random sampling is appropriate for qualitative research, ideally samples would be selected using purposive sampling techniques, guided by principles of theoretical saturation. It was also reported that interviews and focus groups were the predominant method of data collection (89%). In addition to the methodological observations a number a key findings were presented. Family caregivers reported experiencing intense, often negative, and sometimes conflicting emotions and stress. They often felt unprepared which resulted in feelings of uncertainty and anxiousness. Caregivers also reported additional stressors, such as declines in physical health, social isolation, lifestyle changes and disruptions, time pressures, and negative impacts on finances and employment.

Furthermore, it was reported that qualitative research on caregiving was placing a

great deal of attention on the use of and need for both formal and informal support networks. Despite a variety of findings in the area of support, the authors suggest that these results may highlight the complex nature of providing support to caregivers. Particular attention should be given to support for the caregivers themselves as it was shown that caregivers find it particularly difficult to ask for help when it is related to their own personal needs. Moreover, considerable attention has been paid to the acquisition of the caregiver role as well as to the motivation behind maintaining it. Mixed findings were reported which may suggest a complex combination of voluntary and obligatory motivations that could also include caregiver capacity and a lack of available resources (Funk et al., 2010). Lastly, most caregivers reported their experiences to include positive and rewarding aspects. This is consistent with a growing body of qualitative research, which suggests a shift in focus from primarily negative to a more balanced appraisal of the caregiving experience.

The majority of informal care being provided is being done so by family members. Erlingsson, Magnusson, and Hanson (2012) in a survey of the qualitative literature on family caregivers' health, reported that caregivers' beliefs, experiences of reciprocity, or non support, in combination with their quality of interpersonal relationships and feelings of responsibility and guilt, have a profound effect on their health. After carefully examining thirty-one articles using both qualitative analysis and three themes were derived: "sliding sideways into caregiving", "caregiving in reciprocity", and "caregiving in disintegration". Based on these three themes a conceptual model was developed. This review recognized previous methods used to explain the relationship between health and caregiving however offers additional knowledge on the

important role the family caregivers' beliefs about caregiving and their experiences with reciprocity are in better understanding caregiver's health.

Lastly, as adult children are increasingly becoming caregivers to their ageing parents. Bastawrous, Gignac, Kapral, and Cameron (2015) conducted a review of the literature examining factors in 55 studies that contribute to adult children caregivers' well-being. Within these results, only four studies employed a qualitative methodology and the authors refrained from distinguishing the quantitative from the qualitative results in their review.

Within the literature surrounding caregiving, methodologies are evolving; there is a renewed interest in postmodern epistemology to better understand the context of human life in research. A growing number of researchers are recognizing human narrative as valid knowledge, which is being reflected in the literature by the increasing number of studies using ethnographic, phenomenological, case history, and life narrative methodologies (Connell, 2003). Phenomenology has been used to explore the lived experiences of young people providing care to a dependent relative (Bolas, Wersch, & Flynn, 2007), spousal caregiving (Coombs, 2007; Dickson et al., 2010), the transition to caregiving (Adams, 2006), and those providing care to a specific population such as people with cancer or dementia (McIlfatrick, Sullivan, & McKenna, 2006; Quinn et al., 2008).

Interventions

When researchers first began examining the effects of interventions targeting caregivers they often had to rely solely on the clinical impressions of the group leaders or satisfaction surveys from small, select samples of caregivers revealing varied but mostly

promising results. Once interventions utilized more standardized measures, changes in emotional distress became less clear. A surge of publications in the early nineties were thought to be in response to an essay by Callahan (1989) arguing that “respite care had no impact on caregiver distress, further study is pointless, and that a national respite policy would be empirically unfounded” (as cited by Knight, 1993, p. 240).

Knight, Lutzky, and Macofsky-Urban (1993) published a meta-analysis that found “a moderately strong effect for individual psychosocial interventions and for respite care programs that deliver more respite to the treatment group than to the control group” (p. 243). Although this publication contrasted Callahan’s (1989) results, it did not completely invalidate them.

In contrast to Knight and colleagues (1993) who divided caregiver outcomes into one of two categories (caregiver burden and dysphoria), Sorensen and Pinquart (2002) suggest that a number of outcome criteria need to be examined. In their meta-analysis examining the effectiveness of interventions for family caregivers of older adults, caregiver outcomes were placed into the following categories: subjective well-being, uplifts of caregiving, ability/knowledge, and symptoms of care receivers. Studies were then collected and compiled into the following categories: psychoeducational interventions (38), supportive interventions (7), respite/adult day care (13), psychotherapy (10), interventions to improve care receiver competence (6), and multicomponent interventions (12) allowing them to be analyzed separately. Consistent with Knight and colleagues (1993) Sorensen et al. found that interventions with caregivers had, on average, a small to moderate positive effect (0.14 to 0.41 standard deviation units) for all six of the outcome variables.

Unfortunately, the overall quality of studies is consistently disappointing. In a systematic review by Thompson et al. (2007) the authors identified a number of practices that make it very difficult to make conclusions regarding the strength of reported results. For example, only randomized studies were included in the review; however, 41 of the 44 studies did not clearly outline the method of randomization and concealment of allocation to experimental groups was rare. In addition, sample size calculations were not well reported, with only two of the studies providing an adequate a priori power calculation. While most of the studies reported attrition, it was not always done by group allocation. Often authors simply included an overall percentage of participants, ranging from 0-55%, and more than two thirds of the studies did not use intention to treat analysis.

Northouse, Katapodi, Song, Zhang, and Mood (2010) conducted a meta-analysis looking at the efficacy of interventions for family caregivers of people with cancer. The authors evaluated 29 random controlled trials and classified them into three types: 1. Psychoeducational, defined as protocols whose primary focus was to “provide information regarding symptom management and other physical aspects of patient care as well as to direct some attention to the emotional and psychosocial needs of patients, caregivers, and/or marital or family relationships”; 2. Skills Training, defined as protocols that focused primarily on the “development of coping, communication, and problem-solving skills, with some focus on behaviour change”; and 3. Therapeutic Counseling, which focused on “the development of a therapeutic relationship to address concerns related to cancer or caregiving”. When examining the content of each intervention it was found that most included some combination of material relating to providing care for the patient, providing self-care, and maintaining family and spousal

relationships. The authors suggest that this consistency among the content being delivered shows that there is some consensus as to the importance of these components and the need for them to be included in interventions offered to caregivers. However, it should be noted that many of the interventions included in this analysis were designed with the primary purpose of addressing patient care. The inclusion of content related to the caregiver's self-care was often not a primary focus and, in many cases, more of an afterthought in patient focused interventions. Despite this oversight, it is promising to see that the majority of the interventions included in this analysis were delivered to both the patient and their family/caregivers, providing support that researchers are aware of the impact disease has on both the patient and their care provider.

The literature shows agreement about the value of programs and interventions designed to assist caregivers however; program providers have identified two important issues related to the effective delivery of services. The first issue is surrounding the level of information given to service providers so that they may effectively make decisions about how best to allocate and deliver services. The second issue relates to the underutilization of these services as reported by the service providers. They have consistently shown evidence that caregivers are not using the support services despite being good candidates, which begs the question why? (Montgomery & Kosloski, 2013) Montgomery and Kosloski (2013) suggest this may be due to a variety of reasons including: a lack of perceived need by the caregiver, inappropriate targeting of services to caregivers needs, and barriers created by service providers in the manner in which services are delivered. A main objective of the caregiver identity theory is to "provide an understanding of the reasons for non-use of services and to articulate the circumstances

under which services will be maximally useful for caregivers” (Montgomery & Kosloski, 2013, p. 134).

Caregiver identity theory

The Caregiver Identity Theory is built around three fundamental principles, each of which was developed and supported by the literature, 1) The role of caregiver is acquired in a systematic way, 2) Caregiving is a dynamic process that changes over time, and 3) As caregivers experience a change in their role they also will experience a change in their identity. This theory is further broken down into the following components, each described below: Acquisition of the caregiver role, Caregiving as a dynamic process, Avenues of identity change, The identity maintenance process, Change in the care context as pressure toward identity change, and Phases of the caregiving career and identity change.

Acquisition of the caregiver role

In order to understand the outcomes of caregiving and the varied experiences of these outcomes Montgomery and Kosloski (2013) explain that you must first have an understanding of how the role of caregiver is acquired and the demands that acquiring the role places on the caregiver. Based on the large number of women providing care it can be concluded that there is a systematic cultural rule involved in the decision making process when figuring out who should be responsible for providing care. In Cantor’s (1979) ‘Hierarchical Compensatory Theory of Social Supports’ it states that the role of providing care is taken up by a spouse first, then children, followed by more distant family members, friends, and neighbors, and lastly by more formal care. Despite this hierarchy it should be noted that there is still a great deal of variability among caregivers

as to the influence these expectations will have on their attitudes and behaviours. As a result Montgomery and Kosloski (2013) explain that “there are considerable differences among caregivers in their perceived duty to provide care in the first place, in their expectations regarding appropriate care tasks, and ultimately, in their level of commitment to the caregiving role” (p. 135).

Caregiving as a dynamic process

Montgomery and Kosloski (2013) identify that caregiving as a process of change has only recently been acknowledged as a valuable avenue for examination. They elaborate further by explaining that this shift in the study of caregiving is promising. Their concern is that if this piece of the puzzle is left out of the discussion on caregiving there could be serious implications related to the conduction of studies and the selection of effective interventions. Chronic illness often progresses slowly and as a result a change in role identity will often follow the same pattern. That is, as the care recipient’s health declines and the caregiver is often faced with increasing demands, the caregiver begins to move away from their initial role relationship, for example wife or daughter, towards the role of a caregiver. As the caregiver moves further away from their original role identity there begins to be a discrepancy between their previous and new role identities. Montgomery and Kosloski (2013) attribute this “incongruence between the caregiving tasks and the meaning attached to these tasks that causes caregiver distress and prompts actions to restore congruence, in whatever way possible to relieve this distress” (p.136).

Avenues of identity change

Caregiver Identity Theory states that when a caregiver experiences distress it is due to a disruption in an identity maintenance process and uses the Piagetian notions of

‘assimilation’ and ‘accommodation’ (Piaget, 1971, as cited by Montgomery & Kosloski, 2013) to better understand this change in identity. Assimilation refers to the ability a person has to integrate their activities into an already existing role structure. For example, early on in the caregiver role a wife may be able to incorporate a few caregiving activities into her existing role of wife and not experience any distress. In contrast, if these activities increase to a level outside of her role identity of wife she may need to do more accommodating at which time distress may be experienced. Montgomery and Kosloski (2013) explain further that caregiving is characterized by the ongoing shift between periods of identity stability and identity change that reflect the notions of assimilation and accommodation. As stated previously if a person is able to assimilate their activities into an existing role identity little or no distress may be experienced. However, as the discrepancy increases so too will the psychological distress, which results in the caregiver being motivated to find any way possible to relieve this distress:

Knowledge of the iterative process of change where caregivers alternate between periods of maintaining an existing identity and periods of restoring congruence through identity change is essential for understanding both the source of caregiving distress and for identifying strategies that will be effective for relieving this distress (Montgomery & Kosloski, 2013, p. 138).

The identity maintenance process for caregivers

The caregiver identity maintenance process is grounded in identity theory (Montgomery & Kosloski, 2013) which views identity as a homeostatic control system (Stryker & Burke, 2000). The objective of this maintenance process is to preserve identity stability. Montgomery and Kosloski (2013) define identity as “a set of meanings

applied to the self in a social role or situation that define an individual's conception of self" (p.139). They go on to explain that a person will use their own personal set of meanings as a reference point with which they will use to govern their behaviour as it relates to a particular social role or situation. In the case of caregivers this situation is the caregiving context defined by "the care needs of the care recipient, the living arrangement, and the array of informal and formal resources available to support the caregiver" (Montgomery & Kosloski, 2013, p.139). The theory suggests temporal processes including the person's identity standard, behaviour, and self-appraisal. The identity maintenance process is first established by the creation of an identity standard which is a set of norms associated with a person's particular role identity and related to a role partner. What this means is that in the case of a caregiver they will have an established identity standard associated with the person whom they are caring for. This identity standard will influence how they define what a "good" caregiver is and what they do (behaviour). For example it may influence the use or non-use of more formal care supports. As the caregiver continues to interact with the care recipient and take on more activities related to their role as a caregiver, a self-appraisal process will take place. If a caregiver's self-appraisal is congruent with their identity standards then their identity will be maintained. If however, there is incongruence between their behaviour and their identity standard the caregiver will experience distress. These larger discrepancies between the caregiver's self-appraisal and identity standard are what create the pressure towards identity change (Montgomery & Kosloski, 2013).

Change in the care context as pressure toward identity change

Large discrepancies between the caregiver's behaviour and identity standard are often the result of external forces such as a change in the caregiving context, most notably a change in the physical or cognitive abilities of the care recipient, a change in the living arrangement, or a change in support resources (Montgomery & Kosloski, 2013). A change in context, such as a decline in the care recipient's health, may require the caregiver to engage in behaviours' incongruent with their identity standard, and/or experience role conflicts. Montgomery and Kosloski (2013) state that role conflict is "essentially a negative connection between two identities such that an increase in the congruence of an actor's self-appraisal with one identity standard decreases the congruence of the actor's self-appraisal with a second identity standard" (p.141). In order to understand what is being described here it is important to note that a person has many different identities, which together make up a person's sense of self. Caregivers, for example may also be wives, mothers, daughters, friends, or employees. Each person may place a different level of value on each of his or her roles and as pressure is placed on one particular role, for example the caregiver identity, it may result in another identity needing to change or fall off completely.

Phases of the caregiving career and identity change

In order to better understand caregiving as an identity change process Montgomery and Kosloski (2013) provide us with five phases of a caregiver's career which are closely linked to changes in the care recipients needs for support: (1) Role onset, this phase is characterized by the caregiver providing the recipient with assistance that is not typically within their usual role; (2) Self-identification as a caregiver, (3) Caregiving career begins and the caregiver struggles with maintaining their initial role

identity, (4) caregiver continues in their new identity, (5) Caregiver is relieved of the primary care responsibility, most often as a result of institutionalization of the care recipient. It should be noted however, that while initially research identified institutionalization as the end of the caregiver's career more recent literature tells us that this is not the case (Gaugler et al., 2003). Montgomery and Kosloski (2013) further explain that these phases are not a continuous process nor are they unidirectional. They also indicate that what caregivers do have in common while moving in and out of these phases is that the period where caregiver's transition between phases is associated with a significant amount of stress.

Study purpose

There is an overwhelming amount of literature reporting the adverse health effects associated with caregiving. Furthermore, there is a focus in present political agendas to alleviate the burden Canada's aging population is having on the health care system by promoting opportunities for people who are aging, ill or disabled to remain at home. It is not surprising then, as a result of this motivation, that caregiving has become a major topic of interest within the literature. However, caregiver's perspectives, beliefs, and experiences providing care are not well understood. This is especially true when looking at how these experiences relate to the health of the caregiver. Further, beyond simply listening to the caregiver's experiences, researchers in the field of health promotion emphasize the need for participant involvement throughout the entire program development and implementation process to ensure the highest levels of success and acceptance.

Therefore the purposes of this study were threefold: 1) to give a voice to female informal caregivers; 2) to better understand the meaning of the caregivers lived experience as it relates to their personal health and wellness; and 3) to make this information accessible to support service providers to be able to better tailor programs, policies, and interventions to the needs of this population. The following chapter outlines the methodology used to address these purposes.

Chapter 3: Methods

The purpose of this study was to understand the phenomenon of caregiving from the perspective of female caregivers, including how the experience of caregiving could affect the caregiver's own personal health and wellness. Qualitative thematic analysis (Braun & Clarke, 2014) was used to locate the study within the philosophy of phenomenology to explore the everyday, often taken for granted, lived experiences of adult women caregivers. I sought to bring forward and provide interpretation to the meaning of the caregiving experience without drawing on a prior theory. This chapter begins with a discussion of the philosophy of phenomenology and qualitative research and its relevance to this inquiry. It continues with a description of the participant recruitment process, data collection and analytical techniques as intended through the phenomenological paradigm.

Rationale

The phenomenological research method aims to better understand the unique experiences of each individual. The manner in which we come to understand these experiences involves not so much a mental or intellectual process, but rather a way of being or a way of behaving in our existence (Grondin, 2003; as cited in Holroyd). Because phenomenology includes an examination of the lived experience and the meaning people place on these experiences, it is a valuable research method in health promotion.

Although qualitative research is not new, it was quite common during the 1920s and 1930s in larger scientific disciplines like psychology. Some disciplines, however, have been slower to accept it as a legitimate method. Qualitative research methods are

very popular within the medical profession and disciplines related to physical activity and health promotion have been using it for over twenty years. One of the strengths of qualitative research lies in the fact that it is extremely humanistic. Researchers are interested in how people perceive their experiences, what they believe about issues, and how their interactions with others influence these attitudes and values (Pitney & Parker, 2009). For these reasons a phenomenological premise lends itself well to the field of health promotion and thematic analysis is an appropriate method to explore the perspectives, experiences, and realities of women caregivers, particularly given the dearth of these data within the caregiver literature. The details of the research process are then described including securing ethical approval, participants and the recruitment strategy, and data collection and analysis procedures. The chapter closes with a discussion of my role as researcher in the inquiry and the steps taken to ensure trustworthiness.

Outcome

The result of a phenomenological oriented study is to “uncover the meaning and essences in the experience being studied and to provide rich, in depth, descriptive and interpretive information that promotes greater understanding of a particular phenomenon” (Connell, 2003, p.43). As Gubrium and Holstein (1997; as cited in Connell) explain, “we must have a good clear picture of the qualities of the world before we can attempt to explain it, let alone predict or modify it” (p.43). It is therefore the intention of this study to encourage future research related to health promotion and caregiving and to think differently, ask different questions, or implement different policies, programs, or interventions based on a deeper understanding of the lived day-to-day experiences of women caregivers.

Ethics

Ethical approval for this study was obtained through the Human Research Ethics Board at the University of Victoria. Participants were made aware of the provisions taken to ensure their anonymity. All descriptors (e.g., participant name, place of employment) were removed from the transcripts in order to maintain the confidentiality and anonymity of the participants. Any paper documents were stored in a secure location at the University of Victoria while all electronic documents were stored on a password-protected computer. Participants were sent a transcript of their interview to review for accuracy, and to add comments they felt clarified or expanded upon their answers, as well as delete information they may have felt revealed their identity.

Participants

A combination of purposeful criterion and snowball sampling was used to recruit participants. The goal of purposeful sampling is to select information rich cases to be studied in order to better understand the research questions. Qualitative inquiry will often focus on smaller samples selected purposefully that allow for a richer understanding of a particular phenomenon (Patton, 2002). Rather than engage a larger sample to respond to pre-determined questions through surveys or structured interviews, I sought information-rich cases to include in the study with the intention of capturing rich insight related to the purpose of the research: understanding the needs, concerns, and experiences of a small number of carefully selected women caregivers.

Initially participants were targeted primarily on two factors: their personal interest in the study's purpose and their willingness to participate. Once these two factors had

been established they were invited to participate provided they met the inclusion criteria. Participants met inclusion criteria if they were women providing one or more of the following types of care: eldercare to a parent, care for a spouse or partner, and/or care to another adult family member or friend. Further, participants needed to be over the age of 18, living in Victoria, BC, and able to understand English well enough to participate in the study.

Although initially recruitment targeted members of the Family Caregivers' Network Society, a lack of response from the society and a set timeline for data collection required other strategies to be implemented. Participant recruitment was done through the use of a letter of invitation (Appendix A) that I would provide to potential participants. After receiving their letter of invitation, three caregivers contacted me, either by phone or email and stated that they wished to be included in the study. I then followed up with them in the same manner in which I was contacted and provided them with a consent form and list of interview questions. The letter of invitation, consent form, and interview questions provided details of the study's purpose, what information I was looking to gain, and how their information would be used.

Snowball sampling was also used to recruit additional information-rich cases based on referrals (Patton, 2002). After speaking with the initial three participants, I asked them to pass on my contact information to any other caregivers they felt would be a good fit for the study. Through snowball sampling, an additional four participants were included for a total of seven. One of the three initial participants provided me with four other potential candidates by forwarding my letter of invitation to them via email along with a friendly introduction. The other two initial interviews were conducted on

caregivers from within my immediate personal network. I was contacted by three of the four referred participants within a two-day period, and while all of them met the inclusion criteria, only two of them were willing to participate. The first interviewee from this initial referral also provided me with two additional referrals, both of whom contacted me later that same day. Both new referrals met the inclusion criteria and wished to participate. One of these participants needed to reschedule several times due to a heavy workload and competing care demands. I confirmed with her that I did not want to impose; however, she was keen to participate and so I simply waited for a time that allowed her to do so. Participants were not obligated to participate in the study. They were asked to volunteer and informed that if for any reason they no longer wished to participate, they were free to do so without consequence. Because data analysis took place concurrently with interviews, recruitment continued until a point of saturation was reached. It was determined that saturation had been reached when no new information emerged from the interviews. Once all data were collected, participants were sent a thank you card and small token of appreciation (a fitness pass).

Data collection

Once contact was made with participants, an interview was scheduled. Participants were given the option of being interviewed over the phone or in person at a location and time that was convenient for them. All participants preferred to be interviewed in person and locations included: the participant's home (4), their place of employment (1), a local coffee shop (1), and my living room (1). Each location was selected with a number of factors to consider. For example, my home was offered to a neighbor who wished to participate while remaining both close to and separate from the

person she was caring for, thus allowing her to be available if needed but able to speak freely about her experiences. Another example included a participant's back deck where we sat out under the sun and spoke casually about what her life was like while she could unwind from a long day at work. It should be noted that when participants invited me into their homes, they were warm and inviting, offering tea and goodies. They were also well prepared. Each participant had thoughtfully looked over the interview questions ahead of time and many had made notes to ensure they wouldn't forget anything. I recognized that it was a privilege to be invited into my participants' worldview and as such I was appreciative and prepared.

After a general introduction I went through the consent form with each participant, providing them with an opportunity to ask questions. Once consent was obtained the interview began. Interviews were scheduled to run approximately sixty minutes and I took care to be respectful of this timeframe. Participants were made aware of the time when approaching the one-hour mark in the event they had subsequent commitments. In the cases where interviews ran overtime the participants were willing to stay, as they were eager to share their experiences.

Interview method

Interviews are one of the most common methods used in qualitative research (Hancock & Algozzine, 2006) and are valued for their ability to obtain rich and personalized information. A semi-structured life world interview was chosen as these interviews are focused on understanding themes that emerge from the lived and everyday experiences of the participants as articulated from their own perspectives (Kvale & Brinkmann, 2009). There are three main approaches to collecting data using an open-

ended interview method, including: the informal conversational interview, the general interview guide approach, and the standardized open-ended interview. While not as exploratory and spontaneous as an informal conversational interview, the general interview guide approach still allows the researcher some flexibility without the level of structure of the standardized interview.

Kvale and Brinkmann (2009) describe a semi-structured life world interview by stating: “It comes close to an everyday conversation, but as a professional interview it has a purpose and involves a specific approach and technique; it is semi-structured—it is neither an open everyday conversation nor a closed questionnaire” (p.27). In keeping with this view, a general interview guide (Appendix B) and semi-structured approach was selected. Patton (2002) emphasizes two key components that contribute to a researcher’s competency with interviewing. The first is a genuine interest in, and care for, the perspectives of other people; the second is a commitment to disciplined and rigorous inquiry built on a foundation of skill and technique. A general interview guide approach was appropriate as it ensured that I was prepared and focused on the topic of inquiry while maintaining the ability to “explore, probe, and ask questions that [would] elucidate and illuminate that particular subject” (Patton, 2002, p. 343). For example, if a question was asked about current health promoting behaviours and the participant spoke mostly about a lack of resources, I was able to follow up with other questions related to resources, regardless of where those questions fell in the interview line up. As I was concerned with acquiring information on specific topic areas, I felt that the informal conversational interview did not provide enough structure to ensure that each participant would be asked about each topic. In contrast, the rigidity of the standardized open-ended

interview was not flexible enough to allow for probing and a more natural conversational style of interviewing that I thought was appropriate for the purpose of the study and my sample of research participants.

An interview guide was developed using a combination of Patton's six types of questions: experience and behaviour, opinions and values, feeling, knowledge, background/demographic, and sensory (Patton, 2002). While the previous categories helped to ensure that a comprehensive understanding of the topic area was obtained, it was the types of interview questions outlined by Kvale and Brinkmann (2009) that really allowed for a greater depth of understanding. These types of questions included: introductory, follow-up, probing, specifying, direct, indirect, structuring, silence, and interpreting (p. 136). To best "capture how those being interviewed view their world, to learn their terminology and judgements, and to capture the complexities of their individual perceptions and experiences" (Patton, 2002, p. 348), I was committed to constructing all types of open-ended questions from each of the six categories. Open-ended questions were used as they allow for better comparability of responses, enhanced completeness of data, minimized interviewer bias, and better organization (Hancock & Algozzine, 2006).

After completing the interview guide, I conducted a pilot interview. This was done to ensure that the questions were clear, produced the desired information, and were able to be answered in the allotted amount of time. The pilot test was conducted on an acquaintance that had previous experience with the topic of inquiry. They were provided with the interview questions ahead of time and given an opportunity to comment on anything they felt was not clear or could be improved. As I was new to conducting life

world interviews, additional questions were asked about my personal interview style, speaking voice, and the overall experience. The feedback I received was mostly positive, though it was brought to my attention that I occasionally speak too quickly. I was mindful of this feedback during the subsequent interviews.

Each interview was digitally recorded and the researcher took field notes. Field notes included information such as body language or any other information that may have been missed on the recording. The one exception to this was an interview where the participant would stop talking any time that I made a note. In this case, I made the decision to stop taking notes as it was impeding the natural flow of information from the participant. This made my post-interview reflection even more important.

The time immediately after an interview is “critical to the rigor and validity of qualitative inquiry” (Patton, 2002, p. 383). For this reason, following each interview, I set aside a specific amount of time for reflection. This time allowed for more detailed observations to be noted as well as an opportunity to confirm that the interview was recorder properly. In addition to being the beginning of analysis, the post-interview time acted as “quality control to guarantee that the data obtained [would] be useful, reliable, and authentic” (Patton, 2002, p. 384).

Data analysis

Interviews were transcribed as soon after the interview as possible. Transcription is the first step in data analysis, and while often viewed as a straightforward technical task, its complexities can be taken for granted. The process of transcription is a selective one whereby “certain phenomena or features of talk and interaction are transcribed (Davidson, 2009, p. 38). Even with an understanding of the importance of recording all

information and interactions that occurred within the interview, some selectivity was needed during the transcription process. Selectivity will always be a part of analyzing qualitative research, especially the process of transcription, it has been recommended that selectivity should be looked at as a theoretical necessity rather than a problem to overcome (Duranti, 2006). Following this advice, I continuously made judgments about the level of detail to be included as well as the elimination of data altogether, making this interpretation and representation of data into the written form the first step of analysis. Transcripts were reviewed several times throughout both data collection and analysis. This was done to prevent any data from being overlooked, prevent me from becoming overly focused on any one particular piece of data, and to maintain a familiarity with the material as a whole.

As this study was informed by the principles of phenomenology, the analytical and interpretive process was guided by Van Manen (1984; 1990) (Table 1).

Table 1

Methodological outline for doing phenomenology

| |
|---|
| A. Turning to the Nature of Lived Experience |
| Orienting to the phenomenon |
| Formulating the phenomenological question |
| Explicating assumptions and preunderstandings |
| B. Existential Investigation |
| Exploring the phenomenon: generating “data” |
| Using personal experience as a starting-point |
| Tracing etymological sources |
| Searching idiomatic phrases |

Obtaining experiential descriptions from subjects

Locating experiential descriptions in literature, art, etc.

Consulting phenomenological literature

C. Phenomenological Reflection

6. Conducting thematic analysis

6.1.1 Uncovering thematic aspects in lifeworld descriptions

6.1.2 Isolating thematic statements

6.1.3 Composing linguistic transformations

6.2 Gleaning thematic descriptions from artistic sources

7. Determining essential themes

D. Phenomenological Writing

8. Attending to the speaking of language

9. Varying the examples

10. Writing

11. Rewriting: (A) to (D), etc.

Adapted from *Practicing Phenomenological Writing* (1984, p.42)

Turning to the nature of lived experience

Orienting to the phenomenon

Merleau-Ponty tells us that phenomenology is the study of essences. However, van Manen (1984) assures us that the word essence should not be taken to mean not something of mystery but rather as a linguistic construction, or more simply put, the description of a phenomenon. The key to good description lies in its ability to transport the researcher into the lived experience being examined in such a way that they become aware of the nature and significance of this experience in a new way (M. van Manen, 1984). Van Manen equates this process to that of an artistic endeavour, explaining that it

is “a creative attempt to somehow capture a certain phenomenon of life in a linguistic description that is both holistic and analytical, evocative and precise, unique and universal, powerful and eloquent” (p.43). When it comes down to it, orienting oneself to the phenomenon is, in large part, a matter of figuring out what it is that is truly of interest. My experience as both a formal and informal caregiver was where my interest in the area of caregiving developed; however, it was through journaling and personal reflection that the real research inquiry began to emerge.

Formulating the research inquiry

Once an interest is established, the researcher begins to question. This is where I began asking myself what the lived experience of caregiving is really like. A phenomenological orientation to research requires that the researcher not be separate from the question but rather that we ‘live’ or ‘become’ this question (van Manen, 1984). Once a question has been established (in this case, what is the lived experience of women caregivers and how does this experience affect their personal health and wellness?), the researcher must bring the reader into an experience, recreating it in such a way that they begin to question themselves, eventually disclosing the inquiry to them. It was through my own personal experience, as related in chapter one, where I attempted to bring the reader into my own lived experience to provide an understanding of how this research study emerged.

Explicating assumptions and preunderstandings

Holroyd (2007) explains that in order to begin to understand a phenomenon, the researcher must first reflect on their own pre-understandings in order to both determine their legitimacy and contain their influence on new understanding. Journaling and

reflection were also used in this step in my own research as a tool to guide me to a place of openness, where new thoughts, ideas, and understandings about caregiving could take place.

To begin the process of transformation current ways of knowing, there must be a willingness on the part of health professionals – in research and practice – to merge their own history and culture with the history and culture of an unfamiliar other. One’s ability to experience and understand the encounter with the other will be directed by the initial fusion of the familiar – your own lifeworld – with the unfamiliar – the individual other’s lifeworld. From here, it is possible to begin to challenge the taken for granted attitudes and beliefs that are part of each individual’s context and history (McManus Holroyd, 2007, p. 5).

Existential investigation

Exploring the phenomenon: generating data

Van Manen (1984) was careful to explain that the term ‘generating data’ may not be the most appropriate as it has a tendency to suggest that this may be a separate stage or that it may be gathered by someone other than the primary researcher. Unlike experimental or survey type research, the data cannot be collected and then given to the researcher to later interpret. van Manen recommends that it may be more appropriate to think of this stage as the “educational development of the researcher”(p.50) that comes about in two ways. First, they need to have real life experiences “of being experienced, of standing in the middle of life, of having a sense of practical wisdom that comes from working and living with those...in whose lives they have pedagogical interest. All understanding is ultimately self-understanding”. He elaborates on this idea by explaining

how difficult it would be for someone with little life experience, related to the inquiry, to conduct this type of research. Second, they must know “the value of having read widely and deeply and of having an insatiable interest in the ways in which sensitive artists are providing us vicariously with expressive examples of fundamental truth experiences” (p. 51). My life experience as a caregiver, both personally and professionally, in combination with a strong desire to better understand the area of inquiry contributed greatly not only to my ability to conduct this study, but also to present one in the area of caregiving. The process of gathering data is further broken down into four practices provided to assist the researcher in accessing the least tainted experiences possible. They are as follows: using personal experience as a starting point, tracing etymological sources, searching idiomatic phrases, and obtaining experiential descriptions from subjects.

Using personal experience as a starting-point

Personal experiences are just that- personal- meaning that they are only accessible to the person they belong to. However, despite this, a person’s personal experience may also be the possible experience of others. It is important to be able to provide rich description of your personal experience in such a way that that reader is transported without offering ‘causal explanations’ or ‘interpretive generalizations’ (van Manen, 1984). In order for the reader to better understand the experiences, I included rich description of these experiences within chapter one.

Tracing etymological sources

One potential concern with gathering data in a phenomenological study is that as language has evolved over time, the words we associate with a particular phenomenon may have lost some of their original meaning. For example, van Manen (1984) presents

us with the word care, which is quite appropriate for the purpose of this study. He explains how the word care is being overused, especially as it relates to the fields of social work, medicine, education, and counseling. The terms Medicare, daycare, and health care are given as examples where the original definition of 'care', may have been lost. Due to the subjective nature of caregiving, I have reviewed and included my understanding of informal caregiving for the purpose of having inclusion criteria and have also asked my participants to define what health and wellness meant to them.

Searching idiomatic phrases

Just as words have evolved, so have idiomatic phrases, which are born out of lived experiences (van Manen, 1984). As detailed in the next chapter, a number of participants used the phrase "it's like running a marathon" which required me to probe a bit more in order to better interpret and understand what it was they were trying to convey. Were they referring to how exhausting it may be, how long it may take, how overwhelming it may seem, how much preparation and skill would be needed to complete it successfully, or the fact that it may be rewarding? Each participant provided a different interpretation of their use of the phrase, and interpretations included all of the above statements.

Obtaining experiential description from others

One of the key concepts in phenomenology is that the relationship between the researcher and participants is as partners, both working towards a better understanding of a particular lived experience. Several options have been presented by van Manen as means by which to obtain experiential descriptions from participants, and these include: protocol writing, interviewing, observing, lay literature, art, and phenomenological

literature. For the purpose of this study the method of interviewing was selected as described in further detail earlier in this chapter.

As a guide to assist with the reflective process in research van Manen (1990) offers four existentials: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality). The first, lived space is felt space. Van Manen (1990) describes lived space as “the world or landscape in which human beings move and find themselves at home” (p.102). Lived body refers to the process of revealing and hiding parts of ourselves by what we choose to share through our physical body or presence. Lived time is more subjective or as the person experiences the time not how long it actually was. For example this could be how a person experiences a particularly boring lecture as very long or it could be in how someone reflects on the past or looks to the future. Lastly, lived other addresses how we relate to others in the space that we share with them. These four existentials can be differentiated but not separated they are what van Manen (1990) refers to as our lifeworld or our lived world.

Locating experiential description in literature, art, etc.

Qualitative researchers have the privilege of turning to a variety of sources as a resource for a particular experience. This unlimited potential for understanding allows the researcher to seek additional insight from novels, art, movies, poems, and songs, just to name a few, as they push forward towards a greater understanding of that which is their phenomenon of inquiry. Take heartache, for example - a great connector of human experience. Imagine the feeling you get when you listen to a particularly insightful song

on the subject. You cannot help but feel what the artist is going through as it resonates deep within you, potentially offering further insight into a shared experience.

With respect to this study, being a caregiver myself I became fascinated by the way others experienced caregiving. One particular blog really resonated with me and I began to sit and read about the experiences of Canadian singer and songwriter Jann Arden looking after two aging parents. Throughout this study I sat at my computer and lived through her, the experiences of caring for *two* aging parents. The scientific caregiving ‘knowledge’ I had gathered through my reading of the exclusive scholarly literature reverberated throughout her own musings blogged throughout the virtual world. The following excerpt, I believe, contains a number of the fundamental themes of caregiving.

There are days when I feel like I am the worst person in the world. I sit in a chair and feel like everything I do and everything I say is mean spirited and selfish.

This is the weight that slithers my way on occasion, when it comes to the care of my mom and dad. Both of their memories are all over the place and I find myself getting more and more impatient-more snippy-more grumpy more frustrated. My mom said to me the other day “You always seem mad at me Jann...” I died a little inside after she let that sentence fall out of her mouth. I told her I wasn’t mad at all, that I was just somehow caught off guard with this new version of them.

“This is new to me too”, she said, “And I can’t do a darn thing about it. I am practically drinking that coconut oil you bought us...” That really made me laugh.

I told her that I hoped she was kidding.

I loathe watching them misplace every single thing; keys and purses and credit

cards and hats and coats and money and electric bills and coffee mugs and glasses and the TV remote...ALL of it, goes missing. There are elves in the house, “movers” my mom calls them, that take little things and put them just out of reach, just out of plain sight. “The movers move things” she said. “Either that- or your dad and I are going crazy. At least we’re doing it together.” They are indeed doing it together. They NEVER get mad at each other. My dad will answer the same question from my mom a hundred times and not even flinch. After about the 4th time mom asks me something, I seem to lash out like a whip and I feel completely ashamed. I called her the other day and told her how sorry I was and she said “About what?” It gave me a lump in my throat the size of a toaster. “About me being so short with you.”

“Well, you’re doing the best you can, you always do and we appreciate everything you do...” I can feel my heart pump the blood to the end of my fingers. I can feel it fill my cheeks and pulse in my running shoes that are tied too tight again.

My mom is so kind. It baffles me most days how my dad’s drinking and carrying on back in the day didn’t make her coarse and bitter and unmerciful. No matter how much he yelled, or how drunk he got, or how often he stormed around like 4 year old, my mom just kept right on being herself- empathic, good natured, generous, funny and thoughtful. And here I am, turning into some kind of memory referee, blowing my whistle and crying fowl, every time either of them repeat themselves or get mixed up. After much reflection, I have realized how scared I am. I am scared of them forgetting themselves into oblivion and taking

me with them. I am scared of all the changes, how their lives seem to be stolen day to day, their pasts thrown into a blender and set to STUN. I am just scared. The funny part of all of it, is that they aren't the least bit concerned. They on the contrary, are not scared at all. They are happy. They are so good humored and light hearted, positive and faithful and easy going. I am the only one freaking out. I need to tear a page out of their book and just calm the hell down. So what they put the remote in the fridge? So what the car keys are in with the dog food? Mom said, "We find things eventually Jann, it's not the end of the world." Indeed, it is not.

Consulting phenomenological literature

Just as literature and art are useful resources for a phenomenologist, so too are other phenomenological research studies. Where literature and art may provide additional insight into an experience outside the scope of one's own understanding, phenomenological research may contain material that has already looked at and interpreted the phenomenon one is interested in (van Manen, 1984). "Selected phenomenological materials enable us to reflect more deeply on the way we tend to make interpretive sense of lived experiences and, thus, to transcend the limits of our interpretive sensibilities" (van Manen, 1984, p. 58). For example, Connell (2003) wrote about the experiences of adult caregiving daughters and their elderly mothers while others looked at the caregiving experience as it related to specific issues (McIlfatrick et al., 2006) or disease processes (Dickson et al., 2010).

Reflection - Conducting thematic analysis

“Phenomenological themes are the structures of experience” (van Manen, 1984, p. 59), and when analyzed it is these structures that together make up the experience. Three approaches are presented by van Manen to assist the researcher in the identification of themes: 1) a ‘wholistic’ approach, 2) a selective or high-lighting approach, and 3) a detailed or line by line approach. I engaged in the wholistic approach first where I completed reflective reading and re-reading of the transcripts, listened to the recordings and began to identify sentences or sections that stood out to me. Next, after I had a sense of the main ideas presented in each interview, I used open coding to identify key phrases, highlight commonalities, and make connections between the participant’s comments. Once all interviews had been coded I then reviewed each code to identify patterns and themes throughout the data using a constant comparative method of data analysis. At this point the participants’ responses began to come together resulting initially in three themes, each consisting of between two and five categories.

Lastly, by exploring patterns and relationships among codes allowed me to group conceptually similar ideas. A theme table was created to summarize the initial findings. Throughout this process themes, sub-themes, categories, and sub-categories were constantly re-examined which resulted in one overarching theme.

Determining essential themes

In an attempt to provide a more complete phenomenological description, themes must be developed on which to cultivate this description. To accomplish this, the researcher must continuously be asking, “Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning?” (van Manen, 1984,p. 107). These

questions were kept in the forefront of my mind, while working and reworking my potential list of themes, until I finally reached a point where I felt the remaining theme, was essential to the understanding of how women experienced caregiving and how this experience affected their own personal health and wellness.

Writing

Attending to the speaking of language

When engaging in the writing process van Manen (1984) emphasizes the importance of being “sensitive to the subtle undertones of language” (p. 64). For example I deliberately presented quotations, with minimal editing, in order to stay true to the linguistic style of the participants.

Varying the examples

In order for the reader to understand the lived experience, the author must include a variety of examples. By varying the examples the reader can then become fully immersed in the phenomenon. This is done through the selection of exemplary descriptions used to bring to light the true essence of the themes.

Writing

As participants’ experiences are examined and translated into themes, through the art of writing, the phenomenologist is able to gain a better understanding of the phenomenon itself.

Rewriting: (A) to (D), etc.

Despite the practical need to describe phenomenological methodology as a number of steps, van Manen (1984) suggests that the process is more a “carefully cultivated thoughtfulness than a technique” (p. 67). That is to say, the phenomenological

approach allows the author to represent his or her own unique perspectives and experiences and incorporate these in the analysis of qualitative data.

Data Quality

Within the field of sport, exercise, and health the most common approach to determining the quality of qualitative research is based on the work of Lincoln and Guba (1985) and Guba and Lincoln (1989). In place of the criteria used to judge quality in quantitative research (objectivity, reliability, generalizability, validity) they proposed the following parallel criteria: credibility, transferability, dependability, and confirmability. In combination these make up the trustworthiness criteria used to determine the quality of qualitative research (Sparkes & Smith, 2014).

Qualitative researchers use numerous methods for ensuring trustworthiness; Creswell (1998) suggests that researchers use at least two strategies per study. Following this recommendation, I used a variety of criteria presented by Lincoln and Guba (1985). Peer debriefing and member checks were used to establish credibility; thick description was used to present the widest range of information and support transferability; and lastly an audit trail and reflective journaling were used to ensure confirmability.

I engaged in peer debriefing with my supervisor whose formal training and experience in qualitative research ensured that the study was conducted rigorously and appropriately. This was accomplished by reviewing and advising on the literature review, data collection procedures, data-management processes, transcripts and field notes, data analysis procedures, and subsequent findings.

The process of member checking ensured that I was able to accurately interpret each participant's responses contributing to the study's credibility. Participants were

provided with a copy of their transcript as well as a condensed version of the results. Participants were encouraged to look over the findings and ensure that they accurately represented the experiences and perceptions that they had intended. I utilized interpretive verification where participants received an explanation of the study's emergent themes along with the supporting quotes. The participants were then able to share any thoughts on the plausibility of the findings. Participants were asked to ensure that the transcripts were accurate and given the opportunity to respond with any additional information or comments on the findings.

Thick description was used throughout the study to support transferability. Lincoln and Guba (1985) tell us that it is “not the naturalist’s task to provide an index of transferability; it is his or her responsibility to provide the data base that makes transferability judgments possible on the part of the potential appliers” (p. 316). Purposive sampling was one way in which the research ensured that the widest range in information possible was included.

In qualitative research an audit trail is essentially a very thorough collection of all documents pertaining to the research study. As the design of a study may change or emerge through the iterative process of data collection the researcher is often faced with the need to make decisions, which could ultimately alter the course of the study. An audit trail was used to ensure confirmability and this was done by recording, in detail, any information that contributed to how decisions were made about the research process. Through the process of keeping an audit trail I was able to retroactively assess the conduct of the study and have the documentation to address issues related to the rigor of the research. Finally, reflexive journaling was used by the researcher as a tool for

bracketing. A reflexive journal is much like a diary where the researcher can reflect on the self, which is particularly important in a phenomenological research study. This was done by the researcher as a means of identifying their own personal experiences related to the phenomenon of caregiving in order to be able to ensure that the participants voice, not their own, was present throughout the study.

Chapter 4 - Findings

The following chapter is organized into two sections describing: the participants and the resultant themes that emerged from the data.

Description of participants

Participant one - Gloria

Gloria has been providing support to her husband after he was diagnosed with bowel cancer in 2014. She explained that first he had to have a portion of his bowel removed before he was able to receive chemotherapy. When asked to describe her role as a caregiver she described providing both physical and emotional support. As a result of the chemotherapy her husband was experiencing a great deal of fatigue, which meant that many of the previously shared household duties were not falling on her to complete. In addition to the increase in manual labor she elaborated on the psychological impact that cancer had on her husband and felt as though it was up to her to remain positive and upbeat. Gloria is a social worker and reported that the combination of her inside knowledge of the health care system along with her character created a real challenge for her. She said:

I don't want him to inconvenience anyone else...because everyone has got to get a fair kick at the can...[T]hat knowledge of the healthcare system or telling him what may or may not be possible is a disadvantage. People would see it as an advantage, I don't.

Gloria was still working full time and felt strongly that more support from employers was greatly needed. She suggested more flexible work hours to accommodate her caregiving responsibilities and felt that “focusing on bringing health into the

workplace [was] the only way...to try and stop some of those health care dollars from getting away from us". When looking at areas in need of more support and resources Gloria identified mental health as the number one priority:

Mental health to me is the most important. I think that mental health is very instrumental in how people focus on their physical health... So for me it is a mental health thing, it has nothing to do with physical health, to be honest.

Gloria was aware of many resources available to her, no doubt as a result of her occupation however; she reported no longer being able to rely on her husband for support as her desire to protect him prevented her from being completely honest. Friends were where she felt as though she could speak openly and receive candid advice.

Participant two - Janet

Janet provides care for her husband and while he has been a paraplegic for almost forty years she feels as though her role as a caregiver really began in the last five years. She explains that in addition to the physical limitation of being in a wheelchair some other challenges her husband experienced were chronic infection, pain, and fatigue. Janet described her husband's health as declining and was aware that this would continue to place greater demands on her as a caregiver but didn't want to think too far ahead as it could be quite depressing to think about.

As there was no real pattern or predictability to her husband's care needs this could create a number of challenges related to employment, planning, and leisure pursuits. Janet had previously worked full-time as an accountant until about five years ago when she felt as though she was no longer able to balance both her career and caregiving responsibilities. This resulted in her making the decision to start her own business,

working from home on a part-time basis. This was a difficult decision for her to make and required the support of a counselor, who she referred to as her ‘angel’.

Janet really understood the value in taking care of herself. She referred to herself as the “queen of self-care” and identified a number of activities she was doing in order to be healthy enough to take care of her husband for a long time. One example was the use of a personal trainer. As her husband would at times require assistance getting himself back into his chair, after falling out, she recognized that she would need to be as physically fit as possible in order to be able to assist.

Incorporating formal support into their lives was something that Janet and her husband had been negotiating. She described her husband as being very supportive and encouraging of her need to take care of herself however when it came to seeking help they were often not on the same page. She was concerned that without formal support in place she may not be able to participate in some of the activities such as long hiking trips that she had previously enjoyed.

Participant 3 - Rosa

Rosa was the one participant who did not identify herself as being a caregiver. Her situation was also unique to the others in that her husband was involved in a serious accident that resulted in a spinal cord injury requiring him to be cared for in a residential care facility. Despite the accident having taken place five years prior to the interview it was clear that she was still experiencing very raw emotions as she found it difficult to speak without crying. Although she was not sure whether or not she was a caregiver she described in detail the many tasks she performed:

My role mostly is visiting him and making sure he is taken out a lot because I don't want him to feel as though he just lives in a facility. He has lots of physiotherapy there but I take him out on the weekends and I am always there to feed him his supper because he can't feed himself. Also, special clothes I bring home to do laundry.

Prior to her husband's accident she was employed full-time as a legal assistant. She explained that after the accident many decision surrounding her employment were being made for her which she found to be particularly distressing and hurtful. Rosa explained that work provided her both financial security and a change of scenery:

Part of it was financial, at the very beginning I needed to have something that I actually had control over. You know the usual stuff that I new how to do and I could go somewhere and there were people there because everything else in my life was not going very well.

Rosa struggled a lot with guilt while being away from her husband, which made it a challenge for her to take a break. She had just accepted that this was the way their life was now and called it their "new normal".

Participant 4 - Kathy

Kathy is providing care for her elderly parents with help from her siblings. She describes her role as follows:

I care for both of them pretty evenly. I'm not full time, I'm not living with them but I'm really contemplating that I'm going to be doing that. That's sort of my goal.

Her father was diagnosed with Parkinson's about a year ago and her mother was diagnosed with cervical cancer around the same time. Kathy has been sharing the caregiving role with her five siblings and reported that they were a huge support to her:

I'm really lucky...I have five siblings, not like nowadays where there are only maybe one or two. I have a lot of support for my siblings... One sister does the laundry, one sister does the plants and bird feeders, you know, that kind of stuff. She also reported using some formal support in the way of housekeeping and yard work.

Although the interview focused on her current caregiving role as it related to her parent's she also shared that this was not a new role for her and that she felt as though caregiving was what she was meant to do:

I was thinking...of why you're on this earth and I think that's really what my reason is, to look after people because I have been doing that since I [was] seven years old, basically. When my baby brother was born my Mom just went "Here Kathy, look after him". Then my husband, when we first got married...was diagnosed with Hodgkin's disease, so I looked after him for ten years while he was sick. We had two little kids and then he died when they were little. It's just been part of my life... So I just go "that's what I'm doing". I'm not feeling like "why me" or that I'm stuck doing this I just figure...I've just accepted it.

Despite having so much experience providing care for others she did not anticipate that her retirement would involve so much responsibility and reported that she had very little time to herself.

Participant 5 - Dorothy

Dorothy has been caring for her husband with Multiple Sclerosis for the past twenty years. She cares for him fully four days a week and has formal care come into their home to assist for a couple of hours three days a week. They have renovated their home to accommodate his care needs, which included the implementation of an overhead lift. While Dorothy and her husband are still married she reported that she no longer identifies as a wife, only a caregiver. She does not feel as though her husband appreciates the care she provides or the sacrifices she has made. She described her husband as being controlling and noted that while the caregiving tasks were not difficult his personality was the real challenge. Despite her perceived lack of understanding from her husband she took great pride in the job she was doing and reported that just knowing she was responsible for his improved quality of life was what kept her motivated to continue.

Dorothy found great pleasure in spending time with friends and family and was one of the participants who reported using respite care in order to travel. She described herself as being healthy:

I think that I look after myself as far as eating healthy. I'm not on any medication and that's something at my age. In the winter months I will take vitamin C and D but that is about the extent of what I do.

However, she did report being concerned about the stress of caregiving and the impact this may have on both her mental and physical health later on. Dorothy wished that she were able to leave the house more often but explained that the effort required to plan and participate in recreational activities was often a barrier for her.

Participant 6 - Eva

Eva is providing care to both her parents who have each been diagnosed with cancer. In addition to the cancer diagnosis her mom has also been diagnosed with dementia. Eva and her two siblings have established a rotational system of care that has each of them providing care for one week at a time. Eva's parents do not live close by and she explains how it can be difficult to balance working full-time and caring for her parents:

I find the fatigue factor really challenging because I'm doing...an eighty hour work week in order to take a week off to take care of them and so then compacting my own work in order to take care of them. I am two years off of sixty so I'm no longer a spring chicken...I find it does take a lot of energy.

At the time of the interview she had completed six rotations and was beginning to question how much longer she would be able to continue.

Eva was concerned about the toll her role as a caregiver was taking on her health and mentioned that she had noticed a change in her personality. Where once she would have described herself as being very patient she was finding it more difficult to manage her emotions. She also shared that her commitment to caring for her parents was having a real impact on her own family as she still had two young adults who needed her support and a husband who she described as having been 'put on a shelf'. Regardless of the many sacrifices identified it was clear that Eva wanted to care for her parents and appreciated the opportunity to reciprocate the love and affection she had received from them. She said:

The most rewarding [aspect of caregiving] is that I genuinely feel as though I am demonstrating my love in action and knowing that they likely will only have two more years to live I feel really positive about that. That I'm able to give of myself in a constructive way. I know that when they do pass away I'll have piece of mind for that.

Eva is self-employed as a psychologist and has a great appreciation for mental health however, when asked to describe what health and wellness meant to her she provided a very holistic definition, which was reflected in the very balanced approach she took to caring for herself.

Participant 7 - Marie

Marie began caring for her husband approximately sixteen years ago, ever since he was first diagnosed with dementia. They have been married for 59 years. She reported that she first became concerned about him when he would ask the same questions over and over again. She explained further:

He has no short-term memory and he has no ability to map in his head... he could get lost unless I am in view. So it means that somebody, usually me, has to be in view...[H]e's ok around the house...but he can't go anywhere on his own.

Marie's entire lifestyle is based on the needs of her husband and she described how this lack of freedom had significantly impacted her relationships with friends and family. Additionally she noted that she had stopped participating in many of the recreational activities she once enjoyed. She described their world as being very small and shared that people, including her own children, did not understand what she was going through.

While she does not have any formal supports in place within their home, her husband does go to the lodge for a couple of hours twice a week. She is reluctant to use formal supports for a variety reasons but has attended a support group and a number of talks on caregiving within her community. While Marie has a background in physical and occupational therapy she still found both of these resources to be helpful, as other caregivers have been her primary source of support and information.

Resultant theme from qualitative data

One Day at a Time is the overarching, primary theme, which captures the participants' narrative of their experiences of caregiving. Each participant described in detail the tasks associated with their role as a caregiver, how they were trying to make it all work despite the numerous other commitments in their life. They described a feeling of "being stretched to capacity" and often stated that they were not sure how long they could continue with the current status quo. They were not able to look too far ahead or make plans as they were taking things one day at a time. Although there are distinctions made between three sub themes and a number of categories and sub-categories, these reflect nuanced patterns within the data, each contributing to the core phenomenon of "One day at a time".

Table 2

One Day at a Time Sub-Themes, Categories and Sub-categories

| Sub-theme | Category | Sub-category | Description | Exemplary Quote |
|----------------|------------------|-----------------|---|--|
| Intensive Care | | | Participants noted many challenges associated with the role of caregiving. However, despite the challenges each participant felt as though what they did mattered and they found that to be gratifying. | |
| | | It's a marathon | Caregiving was described as being constant and relentless. It was often compared to that of running a marathon | I think all of us thought we could do it for six months but we all feel like metaphorically we are running this marathon that we don't know when the end is. So it's taking a toll on all of us. [Eva] |
| | It takes stamina | Self-care | Participants reported that the act of caregiving requires stamina and emphasized the importance of self-care in order to be able to sustain their role long-term. | Be prepared that when you take on a caregiving role that you have to have the stamina for a potential marathon. So if you don't take care of yourself you are not going to have the stamina for that. [Janet] |

Table 2 continued

One Day at a Time Sub-Themes, Categories and Sub-categories

| Sub-theme | Category | Sub-category | Description | Exemplary Quote |
|-----------|-------------------|----------------------|---|---|
| | It takes planning | | | I've always tried to have some kind of plan in my head. Hopefully you don't have to use it but it should help you make decisions more quickly or more easily if it ever got called into action. [Marie] |
| | | One step ahead | Caregiving requires a great deal of planning and participants reported the need to always be thinking ahead in order to prevent problems from arising. | |
| | | It's a moving target | Participants reported that with a sudden shift in the care recipient's health their role could change at any moment, which could make planning ahead challenging. | It's really hard to plan anything because you just never know what's coming up the pike. [Kathy] |

Table 3 continued

One Day at a Time Sub-Themes, Categories and Sub-categories

| Sub-theme | Category | Sub-category | Description | Exemplary Quote |
|-----------|----------------|------------------------|---|--|
| | | I didn't plan on this! | Despite the best of intentions caregivers explained how not everything could be anticipated. | I did not anticipate both my parents getting cancer, my mother getting dementia, my mother was very astute. I just did not anticipate that us siblings would be providing this type of demanding care [Eva] |
| | It's rewarding | | Although many challenges were reported caregivers were eager to express the positive and rewarding aspects of their role. | The most rewarding is if I can keep him happy and calm for a day then I've done my job well for the day, I think. You can't always avoid upsets throughout the day it's just physically impossible...but you know if he goes to bed calm then I feel I've achieved something for the day. I feel like it's worth doing [Marie] |

Table 3 continued

One Day at a Time Sub-Themes, Categories and Sub-categories

| Sub-theme | Category | Sub-category | Description | Exemplary Quote |
|-------------|------------------------|--------------|--|---|
| Transitions | Role/ identity | | Transitional periods were identified as challenging, often causing the caregiver distress. Participants identified the acquisition of the caregiver role and a change in identity as a difficult transition. | I also have a counselor who is like my angel. She's just a huge resource to me...there were times, especially in that transition when I was going from the wife to the caregiver... That was a huge transition for me! [Janet] |
| | Health and wellness | | Changes in both physical and emotional health were reported and identified as causing distress. | Well, I think it probably hasn't shown up health wise yet but it probably will is me being so reactive to whatever is being said or done or having to account for everything. [Dorothy] |

Table 3 continued

One Day at a Time Sub-Themes, Categories and Sub-categories

| Sub-theme | Category | Sub-category | Description | Exemplary Quote |
|-----------|--------------------|--------------|--|---|
| Support | | | Due to the level of commitment often associated with providing care it is not surprising that many caregivers reported the use of both formal and informal support networks. | |
| | It takes a village | Friends | Often caregivers reported using friends as a sources of emotional support | My friends...female friends. Friendships are very important... friendships are huge, my support network is huge. [Gloria] |
| | | Family | Family was reported by caregivers to be a resource that could have both benefits and challenges. | We're probably going to have to ask the family to give us some support, even if it's just emotional support. You know and I talk to them about it and it's like they don't even believe me because I'm saying one thing and then they look at him and he seems fine. So that's been a bit of a frustration for me. [Janet] |

Table 3 continued

One Day at a Time Sub-Themes, Categories and Sub-categories

| Sub-theme | Category | Sub-category | Description | Exemplary Quote |
|-----------|----------|------------------|--|--|
| | | Other caregivers | Participants reported that their greatest resource for information related to caregiving came from other caregivers. | There's some point to be spent with other caregivers. I don't want my whole life to be spent with other caregivers, that's for sure but there is some point to going to one group or opportunity to hear about what other people are doing because you can learn a lot and invariably you all come up with some stories that have everyone in the room just howling. Laughing is something we don't do nearly enough so it's good. [Marie] |
| | | Formal support | Caregiving often requires the use of formal support such as respite, day programs, and home health care. | He doesn't need my company he needs company. It doesn't have to be me and so you could enrich his life with more social contacts...but I don't know how to do it. Mutually beneficial like the day program he is in now, it's also respite for me. [Marie] |

Table 3 continued

One Day at a Time Sub-Themes, Categories and Sub-categories

| Sub-theme | Category | Sub-category | Description | Exemplary Quote |
|-----------|--------------------|---------------------------|--|--|
| | Rethinking respite | One size does not fit all | Traditional respite options were reported as being valuable however participants noted a number of challenges related to their use. | You know their looking after a large amount of people so there would be areas obviously where things are missed. Just knowing from when he is in respite it's not the way that he is used to having it done. He also knows it's short term, in the long term I don't think he would be able to cope with that. [Dorothy] |
| | | It's the little things | As caregiving was reported to be constant often requiring the caregiver to be available 24 hours a day, 7 days a week, participants reported more creative ways in which they were able to find some relief. | I try to schedule time alone. And that's a recharge for me and I usually try to schedule that time in the mornings so even if I am going to a public place I usually have an iPod on and I am very much just kind of in thought [Eva] |

Sub theme 1: Intensive care

In this first sub-theme, caregivers spoke about the amount of effort required to care for someone. They described long days, endless tasks, and feeling fatigued, likening it to a marathon. They explained how in order to be successful you needed to have stamina, but that often this was a real challenge for them. Planning was a skill that helped them deal with the unending chores as detailed in the sub-categories of ‘One step ahead,’ ‘It’s a moving target,’ and ‘I didn’t plan on this!’ However, despite such challenges, they were proud of what they were doing to improve the quality of life for a loved one, and while there was concern about the sustainability of their role, many found it to be quite rewarding.

Category: It’s a marathon

When caregivers were asked what their roles included, they were quick to respond with a never-ending list of day-to-day duties they needed to provide, ranging from nursing to chauffeuring and everything in between. Some were comfortable with the variety of tasks being asked of them, while others found the learning curve to be quite steep. Whatever the range of duties included, one thing that was reported consistently was that the responsibilities were relentless and ongoing:

He was first diagnosed in ’92 and I think I have been caregiving for him for at least 20 years... [It] starts in the middle of the night. When I actually get up in the morning, the first thing I do is get his legs repositioned to stop his spasms. Then I get on with putting the sling on him and toileting him, and then I sponge bathe him in bed, empty his night bag and so forth. Then I get him dressed and into his chair and then it’s off into the kitchen to get his medication and then back into the

washroom so that he can get washed thoroughly, his face and hands and what not. Then take him back out and finish dressing him, the upper part, then take off his sling and bring him into the kitchen for his breakfast ... [T]here are a thousand and one interruptions then. You know he either needs something to be done with the computer or his legs need to be adjusted or so forth or so on. [Dorothy]

Some caregivers lived with the person they were caring for, while others needed to travel and make arrangements in order to be available to help. Sometimes this required participants to work extra hours one week or evenings and weekends in order to make up the time:

I double up my work in the time period before. Then when I am there I prep all their meals. I take them to their chemo/radiation appointments. Both of my parents have cancer and I take them to pain specialists and nutrition specialists and that is a two-hour round commute from their hometown to Kelowna. While I am there I take them for their lab blood tests and on the domestic side, to live in their home, I do all the laundry, the light housekeeping, and I grocery shop for them. I also liaise with professionals over the phone for upcoming events. I make sure that I calendar them and make sure that I note appointments that I am not there for, for the next caregiver that will be taking a round. At this point it's my other two siblings and myself. [Eva]

While the level of care fluctuated from day to day, caregivers reported that they were always on call, with little to no time to themselves and no end in sight:

There's lots to do (laughter). I mean, it sounds terrible, it's not terrible, it's not hard, it's not anything, it's just constant. [Dorothy]

Each participant reported extreme fatigue and feelings of being stretched to capacity as they described their struggle to find a balance between work, family, leisure time, and their role as a caregiver:

You know it's not really too bad but then my daughter says "you know, I never see you." 'Cause you know I'm busy too. I am trying to play tennis, golf, and trying to have a bit of a social life. Yeah, it's just I never sit down basically...yeah...no down time. [Kathy]

Participants frequently mentioned a lack of freedom to engage in their own activities as a result of needing to be available all day, every day:

There's no point in him going to an appointment or anything like that, a doctor or dentist on his own or even just leaving him in there because his memory is a problem and I need to be there for the ears. I've thought of myself for years as his day timer and his day timer has to always be with him. Right now he's out but he's in the care of someone else or I wouldn't be free because I'm with him 24/7. [Marie]

In addition to the numerous tasks identified, caregivers struggled with the idea that their caregiving roles would likely continue for a long time. Just as day-to-day responsibilities seemed to have no end, the long-term outlook for the caregiving role was similarly overwhelming. This hectic schedule was reported to be very strenuous, and many participants questioned how long they would be able to maintain it:

Well...I really don't think it's sustainable on a long-term basis so I know that I will have to adjust it at some point. [Eva]

Most caregivers struggled more with the amount of work than with the difficulty of it; however, a few mentioned that they needed to learn new skills in order to provide the care required. Others reported that they were being pushed out of their comfort zones and weren't sure how much longer they would be able to perform the tasks needed to maintain the current level of care they were providing:

I know at some point there will be a boundary that I will come to where I'll say we're calling an ambulance you know or we're calling the fire department and it's not because you're sick it just means that I cannot do this anymore without risking injury to myself... The last time he fell, which was a couple weeks ago was our worst... because he is just so much weaker. You know it used to be that he would push, and I would pull and it was like I hardly even notice I was lifting because we were working together. Now I am lifting two hundred pounds of dead weight and it's totally different. So we're getting very close to the point where I won't be able to do it anymore. Very close! [Janet]

Considering the massive commitment associated with caregiving, participants noted that it was difficult for them to think about the longevity of their situation. For some, like Rosa, the role happened quickly while for others it was a slow, gradual, process that developed over time. Either way the idea of not knowing how long it could go on for was often overwhelming and depressing:

Finally the last challenge is there's no end in sight... Like he's 61 now, he's still a young man. This could go on for another twenty years and it's not ever going to get better- that we know for a fact. If anything, it's going to get worse and worse and worse and worse. But will it kill him? I don't know. Could I be in this role for

another 15, 20 years? Yes. And I'm 62 and I'm thinking oh my God, that's a long haul. [Janet]

Category: It takes stamina

Most caregivers talked about the sustainability of their role as caregiver. They expressed concern about the many demands of the role and the fact that they were aging. While skill was not something many of them were worried about acquiring they did explain that the role needed stamina and it was for this reason that they felt self-care was so important. Motivation for health promoting activities were different for each participant however, all participants agreed that self-care was crucial to the sustainability of their role as caregiver. In reference to her self-care one participant stated,

I need to do this for myself because I don't want to burnout, I want to be here for [my husband] long-term and in order to do that I have to take some breaks. [Janet]

When participants were describing their reasons for incorporating activities or practices with the objective of improving their health it was not for this reason alone that they were motivated to continue with them. Many were concerned about injuring themselves:

My concern was that I was going to hurt myself. Yeah, like really hurt myself much sooner in the process and hurt myself badly. Hurt my back in particularly and then end up with chronic back issues...I was very concerned about hurting myself...and also not being able to help him. You know and then we would have had to escalate the other kinds of support. [Janet]

For some self-care was a priority and they made the time to make sure it happened

I have to say, I call myself the ‘Queen of self-care’ because it’s all I can do is self-care. I have no control over anyone else but I do, to a certain extent, have control over myself. I really focus on self-care. [Janet]

For Dorothy, there were challenges with even the most basic self-care tasks:

You just don’t take quite so much time for yourself...I make sure that [my husband] is washed and his teeth are looked after properly...but when it goes to me, it’s just I quickly give a brush or sometimes it’s even just a water rinse to get into bed...because at that time I’m tired you know, so I don’t do the proper things for myself.

For others, self-care meant focusing on their mental health through techniques such as square breathing and meditation, while some focused more on their physical health in order to meet the more physical demands of their caregiving role, and a few were attempting to do it all.

Square breathing, where you breathe to slow your heart rate down. Little things like that are so pivotal in making people get into synch with themselves and their bodies when it comes to caregiving. [Gloria]

It is paramount to give yourself pillars of wellbeing while you’re going through the process of caregiving. That it is really important to take time for physical exercise. If you have a spiritual inclination that you take time for that as well, which is my case. So to take time for meditation and yoga. That you take time for your own intellectual pursuits and for me what I can do, time limited, is reading.

[Eva]

When I met at the beginning with the personal trainer...I said 'well I am a caregiver and I'm doing a lot of lifting and my husbands a big man and I need to be strong, period!' I needed to be strong and so we really focused on that and that is what I continue to do to this day. [Janet]

Eva summed self-care up nicely when she said:

It's really important to set boundaries and it's really important to make your yes be a yes and your no be a no, and also to realize that even though you love your parents or whomever it is that you be care providing for that you parallel the love and compassion for yourself, as well as the love and care and compassion for those that you're giving to, and that the metaphor for a person who historically wrote that you keep your ores in balance.

Category: It takes planning

Planning was something that came up frequently with participants. They shared how important it was to make sure everything was well planned out in order to prevent problems from occurring. The need to be 'one step ahead' was a common pattern; however, due to the very unpredictable nature of caregiving, participants also described a plethora of challenges associated with the planning process that I have grouped into sub-categories of 'it's a moving target,' and 'I didn't plan on this.'

Sub-category: One step ahead

Many caregivers reported that activities, which were once easy to do, were now much more complicated. They required a greater level of planning, taking more time and energy, neither of which caregivers felt they had in great supply. They frequently

reported trying to stay one step ahead in order to prevent being in a situation that was not good for either them or their loved ones.

We still go up to Chemainus to the theatre but we used to just go and pop into a restaurant afterwards. But now I've got everything all planned before we go. We can't take anything for granted when we go anywhere because it's not like I can take G out of the van and do all that and then find out that he can't get in or the restaurant's full because then you have to go through the process again. It's not so simple. [Rosa]

Caregivers described not only planning for the immediate future but also looking further ahead. This required making plans for what could happen later on and making them early enough that the care receiver could be included in the decision making process:

I decided that the right person to talk it over with was him as he was the one who knew me the best. So I told him what was going on in my head and so he helped me make a ... together we made a plan as to what I should do if I was ever on my own. And so I've always tried to have some kind of plan in my head. Hopefully you don't have to use it but it should help you make decisions more quickly or more easily if it ever got called into action. [Marie]

For some, this could be a really difficult thing to do:

When I let my frustrations get to me... I call it 'awfulizing', worrying about the future, what's it going to be like. 'Cause you know another part of this is that he, especially when he's sick, he starts talking about end of life. You know "I can't go through this, it's too hard". And you know we now have a package of material from W to sort of walk us through all the end of life stuff we need to do- he needs

to do really... But, you know, it's not very happy stuff ... I really have to ... like talk about negative influences. When I let that get to me that is then I know I am going to have to seek out support from my physician and my counselor. [Janet]

The concern shared among participants was that if they didn't have a plan they might both end up in care. While this was a concern, participants also reported that they knew that not everything could be planned for, and that sometimes you just had to let things happen. "Somebody would have to then be looking after me too. I guess somebody would have to come to town and sort it out...and good luck!" (laughter). [Marie]

Sub-category: It's a moving target

A common challenge among all of the caregivers, related to planning, was that they never knew what was going to happen from one day to the next:

One of the things is the unpredictability...He can be fine and then in two hours later he is flat on his back with a raging fever and an infection. They come on like that [snaps fingers]...And then it's like I have to drop everything, cancel everything, cancel plans, put my clients on hold. You know, so that's hard!

[Janet]

I guess the challenging thing is when issues happen like my mom getting diagnosed with cancer, And then, just last week, she wouldn't get out of bed for four days....Then the next day she's up and about doing stuff but there's always that worry that something is going to happen and that's challenging. The phone rings and you're going, 'Ahhhh, what could happen to them'? Just not knowing from day to day. [Kathy]

Some caregivers described a large fluctuation in the amount of care they needed to provide on a day-to-day basis. They expressed concern over not knowing when they would be needed and always feeling as though they were on call as the situation could change at any time:

Some days I don't really have to be a caregiver at all. Some days caregiving is all I do and I have to drop everything. So there's no real pattern or predictability... [T]hat's one of the real challenges I face. It can be a real all or nothing. [Janet]

Similarly, another participant reported:

I have to be there all the time. I can't make my plans say with my friends to go do something and friendships you know have lessened, that's another thing. I have one very, very close friend that I feel I also need to be there for her because she is older and she doesn't drive but I enjoy her company... [I]f I have to say well I can't do this today because I have to go to QA or so forth um...that's frustrating. [Dorothy]

The unpredictable nature of caregiving had some participants surrendering, essentially giving up on the idea that planning was even possible:

I just basically...ahhh (sigh) I just don't plan anything and that's basically what my sister says. It's really hard to plan anything because you just never know what's coming up the pike. You know we're pretty good at scheduling their appointments and we try to work them around things but you know it's just hard to do things. [Kathy]

Sub-category: I didn't plan on this!

When caregivers were asked if this was how they anticipated their life going without exception they all reported no. For some, the role of caregiver happened very quickly and took them by surprise. For others, it was a more gradual process that a few described as sneaking up on them. Some knew that they would at some point be providing care for their partner but didn't really understand what that meant until they were in the throes of it:

I guess maybe somewhere in the recesses of my mind there was always like, you know... he was a paraplegic when I met him, so I kind of knew there might be a time I guess. Um...but...I mean, you know, he had a very healthy life for many, many years. Probably until about five years ago, so I mean he was just...he wheeled marathons, we had two kids together, he had a full career as a chartered accountant so um...a very full successful life... You know like I said it's been deterioration over time but it has definitely been a change. If you look at my life now versus say five or seven years ago for instance it's very different. [Maya]

For others, it came as a bit of a surprise due to the very slow progression of illness. While they may have anticipated some of the more practical aspects, such as the use of mobility aids, they were not prepared for many of the other challenges that would come along with the disease:

[B]ecause his was such a slow progressing, I thought okay, maybe we will have to deal with a cane and we could deal with that. When it progressed to a walker I thought okay, we can deal with a walker and the occasional manual wheelchair if we went longer distances or if we went somewhere where he just couldn't keep up

with things. I didn't realize that was just the bodily part of him. I didn't realize that there was a mental thing and then the frustration, too, I guess of not being able to retain information. Not to be able to carry on with the daily routines he had. So that was hard on him as well. I didn't envision all those changes. To some degree, small changes but not to this degree, the dramatic changes. [Dorothy]

Others were similarly surprised at the level of care they were required to provide. For some, this was due to having not had experiences with other family members needing as much help:

Well, I guess the vision is that both my paternal and maternal grandparents lived long lives. They literally lived healthfully, went into hospital, and died. I did not anticipate both my parents getting cancer, my mother getting dementia. My mother was very astute. I just did not anticipate that us siblings would be providing this type of demanding care. [Eva]

When participants were asked to describe how they anticipated their retirement years, they all described lifestyles with much more flexibility and fun:

You know, coffee every morning, long walks on the beach. Golfing everyday. Playing tennis all the time, just being able to go out with my girlfriends once in a while. I think last year I went out for lunch maybe once with my girlfriends...Having the flexibility, like every day is my oyster. Going on trips. That's the thing, see my sister and I thought "wait until we retire we are going to go on all these trips". [We] can't go on any trips, we can't go together, we can't leave my parents. So now we're thinking about planning trips with our parents and taking them with us (laughter). [Kathy]

While each participant noted that they imagined their lives very differently, Rosa also recognized that there were times that she didn't think it would work out as well as it had. When she was first faced with her husband's accident, she didn't know how she was ever going to get through it or how they would manage to survive. She explained how she wished she had a crystal ball that showed her the future so that she could see that while both her and her husband would have to create a 'new normal', they would get through it.

Category: It's rewarding

What kept caregivers going was that, without exception, they all found providing care to be a rewarding experience. It was clear that they felt like what they did mattered, and that without their service, their loved one's quality of life would be greatly impacted for the worse. For some, this was empowering:

The rewarding part is being able to give of myself in a way that is so important and necessary to someone I love. Like being able to support and help my husband in a very practical and tangible way. I think it would almost be harder if I felt helpless, if I felt like I couldn't do anything and I was just watching them suffering and struggling. So the fact that I am able to help him and bring him comfort and support, that is rewarding for me. [Janet]

The majority of participants reported feeling appreciated. They described what they did as being valued and making a difference:

Well, the most rewarding is if I can keep him happy and calm for a day then I've done my job well for the day, I think. You can't always avoid upsets throughout the day...but you know if he goes to bed calm then I feel I've achieved something for the day. I feel like it's worth doing. [Marie]

I guess the rewarding thing is that I am able to do it and be there for them and they're so thankful. Oh my goodness they're always thanking us...[T]hey're always saying "I don't know what I would do without you. Thank you, thank you, I really had a great day." [Kathy]

Unfortunately this was not the case for everyone. However, even though Dorothy reported that she did not feel appreciated, it did not seem to impact the way she felt about what she was doing:

No it's not...even though verbally I might say "You don't appreciate what I do for you" and then he'll say "Oh yes I do" but... to me they're empty words, meaning nothing. It's just like, "I am ill and you are expected to look after me because...". Yeah, you know, the [reward] still to me is knowing that, even though he makes it so difficult, he is at home, he is still free to come and go, and so knowing that what I do matters. [Dorothy]

Participants took pride in the care they were providing. They reported that if they were to stop, the quality of care would go down and they found that to be unacceptable. Being able to be there for their loved ones for the remainder of their lives and contributing to the overall quality of life was something they identified as providing peace of mind.

He's fine and he has as good quality of life as he can, I think. So I should be getting satisfaction from that and I do. But it's taken me a long time to see that that's an ok thing to say, because you don't usually go around patting yourself on the back, but in fact it's true, I guess. [Marie]

Kathy even reported getting to know her Father on a much deeper level, which was really important to her, as they only had a limited amount of time left to spend together:

One of the...rewarding things is that I've gotten to know my Dad better. Especially when my Mom got dementia he started talking more. Like my mother would kind of take over everything but he is the person [I] talk to now. So that [is] the coolest thing.

Sub-theme 2: Transitions

Periods of transition can be challenging and caregivers identified a number of transitions they had a tough time navigating, including shifts in their roles and sense of identity, their own health and wellness and financial realities:

I am taking a further financial hit because I drive... to the Okanogan. So six round trips so far, even just ferry trip costs alone is like twelve hundred dollars and then when I'm there I usually...buy them services or buy them food or make them food...that's all right I am prepared for that but it is at a financial cost as well. [Eva]

Many reflected back on periods of transition as being very challenging times, and felt as though periods where changes in roles, responsibilities, and lifestyle occurred were times when they needed extra support:

I also have a counselor who is like my angel. She's just a huge resource to me. I only see her when I need to...I have not needed to see her [for a few years] but there were times, especially in that transition when I was going from wife to the caregiver...[I]t just kind of came on suddenly and I stopped working full-time. That was a huge transition for me! In lifestyle and in my role and in our marriage and relationship and everything. So you know she was there for me for that and

again if I felt overwhelmed or if I felt that I was slipping into, you know, a place emotionally that I felt like I needed some support I would contact her. [Maya]

Category: Roles/identity

Each participant reported providing care to someone they knew very well, either a parent or a spouse. They described having established roles, over time, within their relationships, and that these roles were now being challenged. Often a decline in health for the patient resulted in an increase in responsibility for the caregiver:

So as his health declines, my role as caregiver increases. So you know when we were first married and in the first many years that we were together...I mean I had to help him once in a while with the odd thing but now it's much more intense and you know much more consistent...

...He falls out of his chair. As he is getting weaker and weaker that's happening more often and he's falling more often. He used to be able to get himself back into his chair. Now there's no way, in fact I'm at the point where he's really unable to help himself at all if he falls out so I am lifting a dead weight. [Janet]

This change in responsibility was not just associated with specific caregiving tasks but also in the more general day-to-day tasks associated with maintaining a household:

Because of his fatigue I have picked up a lot more in terms of household chores. You know laundry, grocery shopping...he still does most of the meals but sort of general errands, cleaning the house. You know he can do a little bit but then he's too tired and has to lay down. So I'm sort of picking up all the slack on all the general household stuff. [Janet]

What used to be shared...duties in the house... [are now my duties]. For example, like, I now put out the garbage...I have to do any of the manual work, the lifting. He can't. He also has a shoulder injury that is related to his arthritis... so any manual work I have to do. [Gloria]

Caregivers reported that changes could happen gradually over time, often slowly sneaking up on them, or more suddenly, leaving them feeling overwhelmed and underprepared. It seemed even those who had anticipated changes would come still found the transitions to be challenging, not really understanding what it meant to be a caregiver until they were in it.

For most, this period of transition meant a change in relationship roles which some found to be heartbreaking. Where once they identified as someone's wife or daughter, they were now left questioning their relationships. Some got lost under a landslide of practical realities, often undetected, while others were faced with a life changing moment that left them reevaluating everything they once knew. Either way, they would need to make a decision, sometimes once, often over and over again, as to who they were and who they wanted to be. A few had resigned to their role as caregiver, accepting their new identity while mourning the loss of what was and what they hoped would be:

I feel only as a caregiver, I don't feel like a wife at all. I feel sort of dismissed. I know how he treats his caregivers; well he treats me with even less respect.

[Dorothy]

A couple of participants felt as though caregiving was who they were and what they were meant to do:

My daughter said “Mom, you’re just a mom to everybody”. I guess that’s kind of just me. I was thinking that before, you know, you think of why you’re on this earth and I think...my reason is to look after people... I have been doing it since I have been seven years old, basically... It’s just been part of my life and so now my parents, I’m looking after them and then my kids and my grandkids. So I just go “that’s what I’m doing”. I’m not feeling like “why me?” or that I’m stuck doing this, I just figure...I’ve just accepted it. And like I said, when I first retired I was kind of bummed like “I’m retired and this is my life?” but then after a while I just accepted it and wasn’t going to let it get me down or stress me out. [Kathy]

A few tried to find opportunities to maintain what they had, fighting to hold onto the relationships they had established and so desperately didn’t want to let go of:

We have been looking at how to bring services to him and although I, of course, will still go to visit him, I am trying to take myself out of some of the caregiving role for him, being more of a daughter and visiting with him. [Eva]

Rosa did not identify as a caregiver despite having renovated her home to be more accessible, quitting her job in order to be available for him, feeding him his meals, and taking him to all his medical appointments. When asked questions she would often respond, through tears, that she was not sure if the question was applicable to her as she was not providing *all* of his care. Caregivers reported that it was a struggle for them to find a balance between doing what they felt was in the best interest of the person they were caring for without compromising their own personal health and well-being:

I do take full responsibility. I signed up for this... I genuinely love [my parents] unconditionally and I want to reciprocate love to them but I don't want to do it at the detriment of putting myself in an early grave. [Eva]

Category: Health and wellness

When asked directly about the impacts of caregiving on health, all participants reported that they were healthy and most reported that their health had not changed as a result of being a caregiver. A couple even reported being in better physical condition than before they had taken on the caregiving role:

Well, my physical health may have improved because I have been walking the dog. So, it's falling to me so...I am physically doing more. So putting out the garbage... Physically, I would say my health has actually improved. [Gloria]

The other funny change, I mean, not funny but odd, that you might not expect, is that I am actually in better shape physically than I was, say, five years ago, because I've made such a commitment to getting stronger and working out at the gym and doing yoga and tennis... Fitness has always been important to me but three years ago I hired a personal trainer and really got on the bandwagon to get stronger. [Janet]

She explained that this was the result of having to do a lot of lifting in her role as a caregiver. She was concerned that she would not be able to help her husband back into his chair when he fell out of it and so she made the decision to work at getting more upper body strength.

Interestingly, although most participants did not report significant health changes when asked directly, many reported health changes as a consequence of caregiving in

passing while discussing other topics. These included both physical and mental health consequences. A couple participants mentioned not sleeping as well, decreased immunity, and feeling anxious:

I feel as though my own health has been leaned in upon since doing this rotation. Well, now I am going on my sixth rotation of going to help my parents since February. So I do find, as mentioned, that I'm feeling much more fatigued and I have encompassed feeling more anxious about juggling all the balls in the air... I am usually a really good sleeper, and it has affected my sleep and for the first time in my adult life I came down with Bronchitis. I have never had bronchitis and so I think the overstretch has weakened my immune system. Yeah, I'm waking up in the middle of the night and strategizing plans for work and my parents and my sanity (laughter). [Eva]

Also, a few participants reported problems with their backs and shoulders. A couple mentioned that they had put on weight since caregiving, but were not sure if this was the result of less activity or aging.

Throughout the interviews participants noted many activities they had either cut back on or stopped all together since taking on the role of caregiver. These include hiking, camping, volunteering, socializing with friends, going to the gym, swimming, church, spending time with family, cycling just to name a few. Limited time was the most frequently reported barrier to self-care reported by all participants.

The physical part I've really let lapse in the past five years. I did square dancing up until two years ago now and I used to go swimming regularly. I used to go to

the gym at least twice a week or sometimes even three times. Those things have all lapsed. [Dorothy]

Caregivers also found that often changes in the care recipients resulted in either them or their loved one no longer participating in activities they had previously enjoyed or had done to improve their own health. These activities included things that they each enjoyed on their own or that they used to do together and were now either unable or unwilling to continue:

I don't ride my bike anymore. That was kind of getting exercise going to and from work. G and I would take our bikes out if we were going to something we would take our bikes out because it was fun and exercise and everything all in one shot. I don't get any joy out of my bicycle anymore so I don't ride my bike. [Rosa]

I try to add exercise and that's getting harder all the time because he's decided he doesn't much care for that, which is odd because he was always a real athlete and very active, but that's gone...Physically I am not nearly as healthy as I should be or as I was because I'm having trouble-getting B moving and so we are not doing the vigorous walking we were doing. We used to go birding and hiking... We used to kayak and all sorts and now I just have trouble getting him around the compound around here. [Marie]

When one participant was asked why she didn't do any of the things she noted to be of benefit she stated: "Because, I've just thought of them!" (laughter). She confirmed that she just hadn't had the time to think of them before now. In addition to time participants reported concern over leaving their loved one alone or not having proper care for them while they were away.

Every time I came home something had happened...I think after a while I thought “well, what’s the use?” I come back and something’s occurred. [Dorothy]

I haven’t got a companion for him when I go out. I can’t leave him alone and be sure that he’s going to be healthy when I get back...If I had a companion for him, that I could afford, I’d be gone in a flash!” [Marie]

The issue of cost came up, with a few participants noting the cost not of the activity but rather of the care that would need to be put in place to allow them to participate in the activity. When one participant noted that she thought the going rate for hiring a caregiver was around thirty dollars I joking said “and you’re not likely to pay thirty dollars an hour to go exercise”. She responded through laughter:

No, no certainly not! I am not going to pay thirty dollars an hour to do anything.

[Marie]

A few participants noted trying to incorporate physical activity with the person they were caring for but noted that this also came with challenges.

I want to be able to do things and sometimes I need to be able to do those things on my own. When I go out with [my husband] I am strolling because wheelchairs don’t go that fast and I’m always mindful that he’s not too close to the curb so it’s different than if you were to go out for walk with a friend and you just get to talk to them. [Rosa]

Of those participants who were still employed, the overwhelming consensus was that self-care needs to be incorporated into the workday.

Further, each caregiver reported that stress was a significant concern and that it was affecting their ability to problem solve and stay organized. They reported feeling depressed, tearful, and less motivated to do things. Many described situations in which they were quick to react or respond in a way that was out of character for them:

I have always, throughout my life been given the feedback that I am an extremely patient person, but I find now that I am much more irritable. I don't have my normal patience so I have been acting sort of out of character. [Eva]

Being irritable and quick to react to things was concerning participants for two reasons.

First they worried about the impact it was having on the person they were caring for:

I think what it's done to me is I used to be the kind of person that would let everything go in one ear and out the other and now I react...I react to everything! For me being sort of a really pleasant person to be around, I have become a total bitch... I find myself yelling at him, which I don't even like about myself but you know you can only deal with somebody so long and let it roll off your back. Then you just finally have to say enough is enough! [Dorothy]

'Cause I did that with my mom the other day. I was just trying to put this fan together and she was like "What are you doing? Why are you in the kitchen?" and I was like AHHH! And then you know, like, she didn't deserve to be yelled back at. So that yeah, I could just be a bit more...show more patience? I think that would alleviate a lot if I could just be more patient and take those deep breaths and count to ten. You know when you're reacting to things and you go "I shouldn't have done that." [Kathy]

Secondly, they were concerned about the impact it may have on their own health later on.

Well, I think it probably hasn't shown up health wise yet but it probably will... me being so reactive to whatever is being said or done or having to account for everything. [Dorothy]

A couple participants recognized how their moods affected the people they were caring for, and reported that they felt as though it was their responsibility to set the mood:

It's my mood, I guess you'd call it, that sets the tone for the house at all times and I've just decided that we don't need friction in here. [Marie]

Finally, the process of aging was seen as relevant to the ability to provide care, and aging and caregiving, in turn, collectively had consequences for health. The majority of participants identified the transition into older age as a concern for the sustainability of their current situation and worried about how their loved ones health would change as well as their own. They recognized that they were having issues related to their health but were not sure if it was related to their role as a caregiver or the aging process:

I think it has changed, and especially in the last five years and I think the big thing is that my stress level has gone up quite a bit. I am 62 and you know, as we get older...we don't metabolize stress as well. I think our body reacts differently. It doesn't process stress as well. I think that is compounding the effects of stress. So I would say definitely I feel more stressed, more trouble sleeping, my energy. My energy is definitely not what it used to be and you know how much of that is aging? [Janet]

Category: Employment/financial

Many caregivers identified employment situations and changes in finances as being another transition with which they often struggled. For some it was the additional

expenses that came along with providing care for someone, for others it meant withdrawing from work in order to be able to provide care, and for some it was a combination of both. Janet identified being able to work from home on a part-time basis as essential to her being able to maintain her role as a caregiver while still managing to bring in some income:

At this point I felt that the greatest positive impact on my health is two things. One is that I was able to organize my work life so that I work part time and that I work from home. That's been huge, that's been huge for me. I've built my own client base and I'm very selective about the clients that I take on and part of that is making sure that there is flexibility in their demands, in their requirements for me. So that if I have to put everything... aside for a week when he is sick, I can.

Even though this worked well for her, she reported that she made this decision out of necessity and felt as though semi-retirement was premature. She would have liked the ability to continue to work full-time but felt as though that was simply not an option. For those caregivers who were still working full-time, each one reported that what would help them most was a more flexible work schedule. For some this meant being able to work from home while others wished they could arrange their hours differently:

I would have flexible work hours...definitely. Because then I would be able to...work late one evening and then go to a medical appointment the next. You know what I mean? So flexible working hours would be very helpful for me.

[Gloria]

Other caregivers felt as though they generally had no control over their work lives, and that decisions were being made for them:

Then things were getting much better and [my husband] was getting ready to come back to Victoria and they decided that I should have a three day a week job. So to cope with less income was supposed to be better for me....

...It was so mean the way they did it. They already had someone who was going to do the other two days and I got a choice of what day I wanted it to start, not “do you think this would work for you?”...[A]t the end of the year they said “Oh, we have no idea what you’re going through” and then at the beginning of the year, it’s like, they knew exactly what was best for me... Then she comes in and reorganized my desk on her very first day to suit herself and I thought, this is just plain mean. You know, you lose two days work and two days pay and then she started asking me to do things like I was working for her and it was just a really bad work thing...so I left that job and went to another full-time job. [Rosa]

A few caregivers explained that it was not just a loss in income that made the employment transitions difficult; there was an emotional component about a loss of self-identity as well. For years they had worked at building a career and took pride in their contributions. In a time when there were many changes going on in their lives, work was a constant. It was something they knew how to do and felt as though they had some control over. It was an opportunity for them to be around other people, socialize, and have a change of scenery. For many, it was an escape.

Sub-theme 3: Support

Participants reported a number of difference sources for support including the person they were caring for, family, friends, other caregivers, and the community. Participants however stated that they often felt like no one really understood their

situation and that sometimes they found it difficult to ask for help. When it came to more formal options for support such as respite participants were divided as to whether or not the traditional form of respite was helpful to them and each participant identified ways in which they had built respite into their daily lives.

Category: It takes a village

Several caregivers reported that their greatest form of support either came from, or had come from, the person they were caring for. They described them as the person they would go to when they needed to discuss something. Participants valued the opinions of the care receivers, and felt that they were the people who knew them the best and with whom they could be truly honest. Losing this support system partially or altogether was difficult for some caregivers to accept:

He's always had excellent judgment and he's been the right person to ask for things because I can go barreling into things and shouldn't. He's got way better judgment and that's going too now. [Marie]

Changes to the participants' support systems often resulted in seeking support from extended family. Caregivers identified a number of ways in which families were able to offer support. Some caregivers were able to share some of the caregiving responsibilities with other family members, which was helpful not only in the lessening duties, but also in being able to talk things over and make decisions together. "I am trying to look at the circumstance and trying to strategize with my siblings". [Eva] Others used family as more of an emotional support system, for example, talking on the phone or for some much needed respite:

...I go to Myrtle Beach to see my sister and brother-in-law because that's when I get totally spoiled. She looks after me and I don't have to do a thing. It's time away where I don't have to think about anything anymore. Somebody else does all the decision making as to what we have for lunch or dinner or whatever. I think that's very important to me. [Dorothy]

Some challenges were identified with respect to families and support. For instance, when one member of a family begins to require more support, it can take a toll on the relationships between the caregiver and other members of the family. There is only so much time in a day, and with the additional responsibilities associated with caregiving, something has to give. Caregivers frequently reported feeling as though other relationships had been compromised:

I think all of us in our own role, either hands on or hands at length, are being compromised with our own offspring and certainly to our own selves and to...our spouses. I think our spouses have just been put up on a bookshelf. [Eva]

Many of the participants were caught in the middle of providing care for their parents while still being needed by their children, while others reported not being able to spend as much time with grandchildren due to looking after a spouse.

Not all caregivers were able to rely on family for support. A few reported that this was due to a lack of geographical proximity, but most explained that it was the result of a lack of understanding, sometimes even resulting in criticism and judgment. Caregivers found this to be particularly difficult and expressed concern about what they would do if the caregiving role got to be too much or if anything were to happen to them. Regardless of the reason, caregivers were left needing to think of alternatives. For some, it was

important to have things figured out in advance, often identifying potential options for additional supports, while others found it acceptable to leave things more to chance.

Sub-category: Friends

All participants identified friends as a very important part of their support systems. They explained that, when looking after someone, there could often be a lot of care and support provided to the patient, often leaving the caregiver to feel quite invisible. They identified their friends as the people who supported them:

[There is] just so much frustration and that's usually when I phone one of my friends and actually I'm getting way better at that. I actually do that because it staves it off, rather than starts...if you do too much then you can really start to feel sorry for yourself and then that's really deadly because nobody cares, nobody cares, trust me! [Marie]

They described friends as the people they could go to for advice because they felt as though they would get an honest answer. Many used friends for support and companionship, especially when caregivers were going through difficult times. Rosa described how difficult it was for her to take a vacation after her husband was injured, and how she relied on a close friend for support: "I went on both trips with a good friend of mine who has been with me through all this. So she was prepared for me having a bit of a rough time." Some caregivers also reported that they had friends who were going through or who had gone through similar experiences, or who worked in fields where they were able to recommend resources:

I have good friends that I can talk to. I have a couple of friends that are in... or ...have been in similar situations so they sort of understand...I found out about

that through a friend who works in a retirement home. You know I have friends who are kind of networked in a way that they can kind of recommend things to me. [Janet]

Sub-category: Other caregivers

Other caregivers were frequently identified as being a huge form of support.

Caregivers wanted to talk about what they were going through with others whom they felt would be able to understand:

I don't want my whole life to be spent with other caregivers, that's for sure, but there is some point to going to one group or opportunity to hear about what other people are doing because you can learn a lot and invariably you all come up with some stories that have everyone in the room just howling. Laughing is something we don't do nearly enough so it's good. [Marie]

In addition to providing support, other caregivers were seen as an important resource.

Caregivers frequently described navigating the health care system as being a substantial challenge. While in the hospital, caregivers reported that they were often getting more information from other caregivers than from professionals:

It's such a community there that people are always letting you know if they're just a step ahead of you. They will say "Oh, did you know about this?" or "Did you know about that?" I found that people going through the same thing...it's the same at ICU, I mean everyone was giving hugs to strangers. You know some people were a step behind you, some people were just coming in and they needed what we were given when we got there. So I found that a lot of people that are on the same path are helping each other out. [Rosa]

Not all caregivers reported using support groups. However, for Marie, when asked where she would go if she needed support, it was the only resource she could think of that was available to her:

Other than the support group I belong to, which is about a dozen untrained caregivers, no, I guess I don't [know of other resources]. I'm not coming up with anything.

Sub-category: Formal support

Caregivers frequently reported concern over the sustainability of their roles due to a number of factors such as the workload, isolation, a lack of skills required, and getting older. They reported feeling that it was not reasonable to think that they would be able to continue without some form of additional support and all of them identified the community as a potential resource.

I don't think it's reasonable for an eighty year old to be the only caregiver for an older partner without there being more community help. My understanding of the community is that it's not there. There's not very much of it there and I'm not impressed with what they do for people at our level. [Marie]

Caregivers had mixed feelings about the availability of resources in their community with some reporting that they were lacking (as above), while most felt as though there were plenty available, though some searching was required:

I know there's tons of stuff out there. I've got those books with the community stuff. I would suggest getting one of those or just going on the Internet and looking at what the support is because it's amazing how much there is. So it's just looking for that. [Kathy]

Despite the fact that most of the caregivers felt as though there were adequate resources available, most reported that they had not used them. Caregivers identified a number of challenges to accessing help in the community. One potential barrier to accessing community support was the personal effort required to find it:

It makes you absolutely certain that you're outside of the system and there must be one somewhere and nobody cares. There isn't anybody who cares. Nobody is coming to the door to say "What can I do to help you?" That doesn't happen either. They're overwhelmed, and they're not going to do that. [Marie]

A number of caregivers expressed concern that there wasn't enough prevention happening. They felt as though help was available in an emergency, but unless they were desperate, there just wasn't anything available.

When you get sicker they come dashing in and it's wonderful but at the level we're at, I get the feeling that the system would just love it if you would just keep going on forever and just don't call. And we're not going to do anything because you're doing just fine and so you just look after yourself and I'll carry on- and I object! Sorry but I do. [Marie]

Another concern was around the availability of resources and the logistics of being able to use them. For most caregivers, time and energy were challenges. All caregivers frequently reported feeling exhausted and stretched to capacity. Finding community support just seemed like one more thing to add to their list of responsibilities, which for most was a real barrier. Many reported being waitlisted for resources, which was concerning, as often they were needed urgently. A few were able to supplement with paid

support, but for many this was not an option. A number of caregivers reported the need for some sort of work leave or tax credit to help them.

...I think that because this is not just a unique circumstance just to myself... I have a number of peers who are going through this. And how we have allocated tax dollars to maternity leave and paternity leave and we are an aging population and with health care in the first world we are living longer... But if there was a tax benefit for people to take time from their work to do an initial assessment of their elder parents circumstances and get services set up, even if it's waitlisted services, but that they have some paid time to do that, it would take the onus off of trying to work and do it all at the same time. Because when eldercare is needed it is primarily when their offspring are still working. [Eva]

Recreation centres, academic institutions, and not-for-profit societies were the most commonly used community resources, and were also identified as being where efforts should be focused for developing further supports.

Category: Accepting help

Support plays a major role in both the caregivers' and care receivers' lives and can be a very valuable asset. However, this does not mean that support does not come with some challenges. Often the idea of needing help was difficult for both the caregiver and receiver to accept. Asking for help was not something that most people were comfortable with. Caregivers reported constantly having to try and figure out ways to make both their lives, and the lives of those they care for, work. This often meant finding creative solutions to difficult problems and working together as a team. However, many caregivers explained that sometimes it could be challenging for both the caregiver and the

care receiver to balance their own needs with the needs of the other. Often when more support is needed, it is the result of a loss of independence for the patient, which can be a challenge for both to accept:

There was an incident where I said to him “I need you to come with me even if you just come for a few minutes, I need you to come over and be sociable and then you can leave and say you’re feeling fatigued, but I need you to come with me”. [Gloria]

Caregivers frequently reported that they would not be able to sustain their roles without the addition of further support and were also more likely to want help sooner than the person they were caring for:

...I’ll want it sooner! And that’s where he’ll say, “No, no, no, I want to be independent.” You know, or maybe it’s denial or whatever so I usually get there way sooner than he does...in everything. But eventually he comes around. [Janet]

Participants noted that it was commonly their responsibility to think of, and put in place, these additional supports, stating that their loved ones were not very proactive or active participants in the planning of their care needs. Most caregivers reported that, with this responsibility, comes a negotiating process.

I have a woman that comes once a week. Because my dad is such a private man this has been like a crow bar to get these services into him and to our mother. [Eva]

While receiving help can alleviate some of the burden reported by the participants, they also identified a number of challenges with receiving help. Caregivers appreciated the additional help, but they reported that it could also mean a loss of control:

Now if he were to be assessed and become part of the system, then I guess it's covered by MSP or part of it is covered by MSP. But then we're at the whim and mercy of the public system. You don't get a say in who is the caregiver, you just take what you can get. [Janet]

When asked if the loss of control was a concern for her, she replied:

Yeah, and probably more of a concern to him. Like I know that he would be quite particular as to who comes in and helps him. Especially at this point, I mean he's still cognitively all there. Maybe down the road if that shifts he might not care so much who it is, but at this point I know that it would be important to him that there be some sort of fit between him and the caregiver in terms of personality and language. [Janet]

For others, receiving help meant an intrusion into their personal space and a loss of spontaneity:

I go to bed Friday and go "Ahhhh, thank goodness, nobody is coming tomorrow or Sunday"... it is an intrusion into your life, into your home and that's what I have to shake. If I had more of that I don't know how I would be able to shake that... Sometimes I relish the days that I do the caregiving because say on a Friday night... see this putting him to bed has just started and I used to always put him to bed because this gave us flexibility. We could stay up and watch a movie, you know, we didn't have to go to bed at a certain time. We could stay up to 11:00 or 11:30pm. [Dorothy]

Not all patients were willing to receive help. This was particularly challenging when a person was resistant to supports that the caregiver had put in place or was not willing to modify currently.

This is too much. We were visiting her in the hospital every day for like 6-7 weeks. Then when she came home we were like, you know, how are we going to [manage]...she could barely get out of bed. She basically refused other people coming in to help. [Kathy]

Patients, however, were not the only ones who found it difficult to accept or ask for help. Caregivers noted that asking for help was not something they were comfortable with. As described by two participants who had set up help from friends or neighbours, but were concerned about imposing on them too much, they noted that they were concerned about the longevity of their arrangements and not wanting to use up resources, as they were saving them for when they were needed most.

I suppose, too, that you're not used to asking people for help. Yeah, well [my husband] will always say to me "Well, why don't you ask so and so to come over and do that?" But I am saving the "can you help me" for the really important stuff. [Rosa]

You know asking people over and over, I mean we only have so many people that he feels comfortable having that kind of relationship with and you know I don't want to impose too often... I know it's not really a big imposition but it's still...that thing about asking for help. And because I know it's going to be long-term, it's not going to be over in a year, I don't want to use up my resources. [Janet]

Category: Rethinking respite

As a result of the constant nature of caregiving, one thing that everyone could agree on was that it was nice to get a break. A greater amount of personal time was something that was important to each participant. However, each participant described what respite resembled differently. While some found the more traditional respite options sufficient, others reported concerns relating to the lack of flexibility around booking beds, the lack of programming available throughout the day, and the level of care provided. As a result, this left each caregiver to seek out less traditional respite opportunities, often found in simple moments throughout their day.

Sub-category: One size does not fit all

Caregivers explained that traditionally, respite involves placing their loved one into an institution where they receive care, most commonly for a week at a time. While this does provide caregivers with a much-needed break, it does come at some cost to both the patient and the caregiver. Caregivers reported being allotted a certain number of days each year for respite and that these placements needed to be booked six months in advance, making it difficult to accommodate preferences. For some caregivers this was not a problem, while for others, the lack of flexibility was a concern:

[It would be nice] if they had more respite days. Like you're only allotted so many weeks per year and it's also very difficult. It's sometimes very difficult to get the times but if you could have more facilities like the [local] respite hotel where you could, I assume, call up a few days before or maybe a week before and see if the person could be placed for two or three nights or something. That would be very, very helpful, I would think. [Dorothy]

Of the participants who were using or had used respite in the past, there were a number of concerns brought up regarding the quality of care provided. For patients who did not require much stimulation it was adequate, but for others it was not an option they were comfortable with:

I had misgivings about it because there is nothing to do, there are no programs; it's a hotel, it isn't a care facility. There's no program and I knew it wasn't going to work...I wouldn't have gone because sitting over there at [the local respite hotel] for two straight days with nothing to do and nobody to talk to, he wouldn't be worth picking up. He would have been some kind of puddle of gloom. [Marie]

Caregivers take great pride in how they care for their loved ones and find it unacceptable to leave them in a situation that is below the standard of care they have been working so hard to sustain. This change in care can be difficult for both the caregiver and patient to accept and requires both to make sacrifices, as explained by these two participants:

You know they're looking after a large amount of people so there would be areas obviously where things are missed. Just knowing from when he is in respite it's not the way that he is used to having it done. He also knows it's short term. In the long term, I don't think he would be able to cope with that. [Dorothy]

It would be very nice to have some respite that I didn't have to be so cautious about and maybe go and stay with one of the kids for a few days... Or get somebody to go up to Tigh Na Mara or something like that. Just for a change of scenery. [Marie]

A supportive loved one can make this easier on the caregiver; however, some still felt an enormous amount of guilt over placing their loved ones in respite care. Further, some felt

guilty about not being able to include their loved ones in their experiences: “So if I go somewhere I feel like I need to see it for him too, so he can share it. He’s such a good sport. I don’t know if I could be such a good sport if I couldn’t go places.” [Rosa] A couple of participants reported using respite to allow them to travel, visit friends and relatives, or just have the freedom to come and go as they pleased however, respite was seen by most primarily as a time to recover or get ahead, and more often than not it was the latter. Often caregivers were so focused on just getting a break that they found it hard to think of anything else - especially fun. One participant expressed her reasons for needing to get away as follows:

It’s both [needing a break and doing activities I enjoy]. It’s for sure both. In fact it might be the latter when I break it down because I hadn’t really thought about it. I’ve always just thought about it in terms of a break. You know, I’ve given up a lot. I mean, even in spite of the fact that I do a lot of self-care, there’s some of those things that I’ve mentioned like longer hiking trips, camping, or even girls weekend or whatever. Some of those things I really enjoy doing for myself and, yeah, I would like to be able to do those things. [Janet]

As mentioned above, others found the more traditional respite options to be inadequate, making it difficult to feel good about being away while they were worrying about their loved one.

Sub-category: It’s the little things

All of the participants identified less traditional ways in which they were seeking out respite in their own lives. Often this was seen in little things like making tea, meditation, phoning a friend, spending time with a pet, or reading:

I drink tea. Tea is a huge positive for me. A cup of tea- that's the British heritage- a cup of tea will fix anything. The actual physical going to make the tea is very calming for me because it is something I could do in my sleep twenty times over. So it's almost like a ritual... I can think whilst I am making tea. I make tea and I wait by the microwave, if I'm heating the tea up, I stand at the microwave and it gives me those few minutes of "Okay, this is what's next." ... Focusing on the dog, dog walks, dog pets- the animal interaction is extremely helpful for me.

Cuddling the dog at the end of the day, talking to the dog... [Gloria]

Just sort of relaxing...like without care. You know you just don't think of it, you just go on and have a swim and it's so relaxing. You go to church and you see all the regular people that you see all the time. You chit chat a little bit and you just don't think about anything else. [Dorothy]

Rosa even described a room that she had a designer help her to set up and decorate, not only as a place for her to escape, but also somewhere that was easy and accessible for including her partner. As he was no longer able to come into their home, it was difficult for them to find somewhere to be together away from the hospital.

Although respite was typically seen as a way for the caregiver to get a break, it was clear that participants desired opportunities to have shared experiences with their loved ones. There were so many activities that were no longer accessible to them; caregivers were constantly looking for things they could do with their loved ones. Further, all of the caregivers reported that social isolation was a concern either for themselves or for their loved ones. They were looking for options that would allow them to socialize with others and where their loved one would be included:

I don't know, I mean our rec centres are beautifully set up to have people gather and possibly they could have more programs for people in our situation. Where we could both go and watch a film and then have coffee and social or something like that... Anywhere you go where there are patients and caregivers, there are the same number of each, so the caregivers are going to have some sort of different conversation, which goes back to feeding the brain. It would be good. I sometimes feel like I am going to forget how to use the English language if I don't talk to more people. [Marie]

It was an important part of both the patients' and the caregivers' well-being to feel as though they were part of a community. One participant described her world as being very small as a result of a lack of places to go where she and her loved one were comfortable:

There's no space to put someone with Alzheimer's or some kind of dementia in at a table and just let them sit and enjoy themselves, without making somebody else uncomfortable. So it doesn't happen. There is virtually no social life for them. Wellness is just being able to live in society and being able to find a niche for yourself without problems...you can include somebody in a wheelchair or whatever it is. There should still be a place for everyone to fit in and have fun... to be an active member of a community. [Marie]

Chapter 5: Discussion

Research in the area of caregiving has increased significantly over the past two decades and along with this has come a rise in the number of programs, policies, and interventions. Many people, especially women, are taking on the role of caregiver and research is clear that this may come with any number of negative health consequences (Milbury, Badr, Fossella, Pisters, & Carmack, 2013). While there is a consensus that caregivers are at risk for both adverse mental and physical health issues, mental health has been the primary focus. Interventions, thus far, have shown positive results among caregivers in the research context however; they have not been translated well into practice. In addition, many programs designed to assist caregivers are reportedly underutilized and this has left researchers and staff to question why?

Most frequently caregivers have been represented in identifying the tasks they do and the stress related to performing those tasks often in relation to a specific disease process however, the experience of caregiving in general (e.g., not just spousal caregiving, or palliative or disease-specific caregiving) has been under studied and underrepresented in the empirical literature. The purpose of this study was to provide caregivers with a voice and a platform to share not only their experiences but also how those experiences affected their own personal health and wellness. This information is intended then, to start a greater discussion on the topic so that we may better understand what is needed to help this population thrive rather than simply survive.

Using qualitative thematic analysis informed by phenomenology, a methodological approach valued for its ability to better understand the lived experiences of the participants, this study aims to fill a gap missing in the literature by trying to better

understand the lived everyday experiences of caregivers and how these experiences impact their personal health and wellness. The resultant themes offer some structure with which to discuss the participants lived experiences. It should be understood however, that no one interpretation of these experiences would ever be complete. Credibility comes from the descriptive interpretive dimensions of the research that allow others in similar situations to see their experiences within the experiences of the participants and recognize them as their own. Throughout the research process effort was made to ensure that experiences were represented as accurately and truthfully as possible. Not only was credibility sought through the participants own validation of the final description of the themes but also through those of colleagues and friends who when hearing about the findings or reading them through the editing process found themselves relating to the experiences of the participants. They reported that they understood what they were going through and while each had their own personal experience caring for a loved one, they were able to identify with and see their own experiences and those of the participants.

This chapter begins by discussing the resultant themes as they relate to the current literature and then compares these findings to the caregiver identity theory presented in chapter two. The remainder of the chapter discusses the implications for practice, recommendations for future research, and finally offers a personal reflection.

Resultant themes in relation to the literature

Sub-theme 1: Intensive care

Intensive care was the first sub-theme to emerge and was further broken down into four categories: 'it's a marathon'; 'it takes stamina'; 'it takes planning'; and 'it's

rewarding'. This theme reflects both the hard work as well as the rewards described by participants, as part of the caregiving experience.

It's a marathon

At the beginning of each interview, participants were asked to give a bit of information regarding what their roles entailed. What seemed at first glance to be a pretty straightforward 'icebreaker' could have taken the length of the interview to answer. Interestingly, an important part of each response- beyond what participants actually stated verbally- was their body language while responding. They appeared almost defeated before they even began to describe their numerous responsibilities. Some allowed their heads to tilt backwards as they gazed upwards; some slumped in their chairs, or leaned on the table as if to relay, "Where do I even begin?" This sentiment was echoed in other studies looking at the experience of caregivers, where words such as exhausting, relentless (Dickson, 2010), and never-ending (Butcher, Holkup, & Buckwalter, 2001) were used to describe caregiving. Despite the commonalities in responses, each participant identified a variety of tasks unique to their situations and the care recipient's needs. Generally, the narrative that emerged capturing caregivers' experience can be conceptualized as running a marathon; indeed one participant [Eva] used this exact phrase.

For Marie, it was that her husband's dementia required her to be there to provide both physical and emotional support for him at all times. She felt as though she could not leave him alone or he might get lost, confused, or depressed. The need to compensate for the care recipient's memory loss was also reported by participants in a study examining the experience of providing care for a person in the early stages of dementia (Quinn,

Clare, Pearce, & van Dijkhuizen, 2008). Both Marie and Gloria explained that part of their job was to set the tone for the house; they needed to be positive at all times in order to keep everyone's spirits up, which could really take a lot out of them.

Other participants such as Janet reported their role to be more 'all or nothing'. They described the care needs of the recipient to fluctuate in that sometimes they were not needed as much, while other times they needed to drop everything immediately and provide constant care. Even though this type of inconsistent care may at first glance not appear to be constant in nature, Janet reported the need to quit her job and work much less and from home in order to be able to remain on-call at all times. The ongoing responsibility experienced by caregivers was prevalent throughout the literature. In a study looking at how caregivers of people with Multiple Sclerosis experience support, participants reported that they always felt responsible for the care recipient. They similarly described their roles as being 24 hours a day, seven days a week, and even when they were physically away from their loved ones, they still experienced worry and concern for them (McKeown, Porter-Armstrong, & Baxter, 2004).

In a study about how spouses are affected after assuming the role of primary caregiver following traumatic spinal cord injury, participants expressed that often times taking on the responsibility of providing care could have a significant impact on their lives. They described having to do everything and how they felt a total loss of control over their lives, as they would never be the same. For instance, one participant explained that she was not able to relax or 'switch off' from her role as caregiver, feeling as though it was her responsibility to be on top of things at all times (Dickson, O'Brien, Ward, Allan, & O'Carroll, 2010).

In addition to the number of tasks caregivers' associated with their roles, the longevity of the role itself seemed to be overwhelming. With no end in sight some participants expressed that they were not sure how much longer they would be able to continue while others such as Janet and Dorothy explained that it wasn't so much a feeling of being overwhelmed, but rather that the long-term nature of caregiving just seemed depressing. Either way, overwhelming or depressing, each caregiver expressed concern over a lack of time to themselves as a result of the constant nature of their role. Collectively they worried that they did not have the time to participate in activities they previously enjoyed or to properly take care of themselves.

It takes stamina

Considering the numerous tasks typically reported by caregivers, it is not surprising that participants in this study identified stamina as crucial to the role of caregiving. They further explained that stamina contributed not only to the success in completing the day-to-day tasks, but also in ensuring the sustainability of the role. Most participants recounted that their days were very full and that they struggled to find a balance between life, work, and their caregiving responsibilities. As a result very little time was left for anything else. However, despite the shared desire for more time to themselves, participants in this study all felt that one of the most important factors contributing to stamina was self-care.

Some of the participants highlighted different practices they had incorporated into their routines in an attempt to promote both physical and mental health, while others were not aware of doing anything. Some examples of self-care included: yoga, weight training, square breathing, and meditation. What was particularly interesting, however, was the

caregivers' motivation for maintaining their own personal health and wellness. The real driving force behind self-care practices was fear: the fear of not being able to provide care long-term and what might happen to their loved one if they themselves became unwell. Caregivers' perceptions that they have the sole responsibility of providing care for their loved ones have been reported in other research, though not in relation to effects on health promoting behaviours (McKeown et al., 2004). Participants in previous studies reported being fearful of becoming ill, and expressed concern about who would care for their loved ones if they were no longer able.

While caregivers all agreed on the importance of self-care, there were varying levels of commitment to the practice. To illustrate how difficult it could be to maintain even the most basic level of self-care, Dorothy described how after bathing her husband and cleaning his teeth in preparation for bed, she was often so exhausted that she would forgo her own care just to get to sleep sooner. This begs the question: if caregivers are having trouble finding the time and energy to maintain basic hygiene, how are they going to manage to incorporate physical activity and other health promoting behaviours into their days? A review of the current literature provides an overwhelming account of the negative health consequences associated with caregiving. While it is understood that health promoting behaviours would have positive health consequences for caregivers, phenomenological literature on the experiences of caregiving, health and wellness is lacking.

Leisure time and the value of freedom have been discussed in previous studies related to the experience of caregiving. One of the major themes that emerged in a study exploring caregiving experiences of spouses who provided care for stroke surviving

partners was loss, particularly as it related to leisure time and freedom (Coombs, 2007). Caregivers reported that most of their leisure time had disappeared as a result of having to either directly or indirectly provide care for their partners. If leisure time was available, participants noted that it was unusable as they were too exhausted to do anything other than lie down and rest. Additional challenges included loss of the ability to participate in leisure time activities with their partners (Quinn et al., 2008) and not wanting to leave their partners alone (Coombs, 2007).

Participants in the current study identified similar barriers preventing them from participating in health promoting activities. For example, Marie reflected on how she was unable to go hiking with her husband, while Rosa described no longer finding any joy from riding her bike, as this was something her and her husband used to do together. Additionally, Dorothy described how leaving the house often meant coming home to some sort of disaster, and thus felt it was no longer worthwhile to go out. She had previously enjoyed going swimming and to church with a friend, but was now staying home in an attempt to prevent- or at the very least, deal with- situations as they would arise. The concept of limiting activities outside the home due to fear that something might happen has been previously reported in the literature (Coombs, 2007). The loss of freedom described by some of the participants left them feeling confined to their houses, or as Marie put it, made their worlds become very small.

During the interviews, the topic of leisure time was approached with some hesitation, as if almost unfamiliar to participants. Most either reflected on what it would be like or what it was like to have the ability to participate in leisure activities, while a few just laughed, explaining that they had already accepted the loss of free time. Despite

a consensus on the benefits of self-care, it was difficult for caregivers to think about adding anything more to their days. Each participant identified self-care as something they would like to have more time for, but felt as though their leisure time was already so limited that they were too fatigued to use it for anything but rest.

It takes planning

As discussed in chapter four, planning played a major role in the lives of each of the caregivers in this study and three sub-categories were identified as part of the planning process: ‘one step ahead’, ‘it’s a moving target’, and ‘I didn’t plan on this’. The idea of being one step ahead came to light as participants frequently reported efforts to anticipate the needs of the care recipient before they arose. Also, they were continuously thinking ahead to prevent problems from arising that might harm their loved one or create extra work for them.

Planning was not only limited to the day-to-day aspects of caregiving. A few participants additionally reported planning ahead for the future. However, the majority of participants found that, with their current responsibilities, the thought of planning for the future seemed overwhelming and fruitless. In a study examining the transition to caregiving, participants identified two ways of dealing with thoughts of the future. One way involved active information seeking and the consideration of multiple options, while the other way was to hold off on planning for the future at all. For instance, one participant stated, “I really don’t know what the future will bring. You know I can’t dwell on it a lot because there are no answers at this point” (Adams, 2006, p. 21). Also, participants reported that:

Another reason for not making decisions on future care was simply the feeling of being overwhelmed enough with things as they are and the desire to wait until it was absolutely necessary to get more information (p. 21).

The majority of participants in the current study indicated that the main issue with planning was the unpredictable nature of caregiving. The phrase ‘it’s a moving target’ was used to relay the constant need to adapt as a caregiver- the need to be flexible and able ‘to go with the flow’. On one hand, caregivers reported the need to plan everything (i.e., wheelchair accessible transportation and venues, medications, formal care, etc.), while on the other hand the unpredictability of their roles meant that these plans could change at any moment. As a result, caregivers described a lack of freedom; the unpredictable nature of caregiving prevented them from participating in activities, engaging in social relationships, and maintaining employment.

These effects on the lives of caregivers have all been identified in previous studies (Chiou et al., 2009; Dickson et al., 2010). For example, a study by Butcher (2001) identified ‘moving with continuous change’ as one of the major themes to emerge. The unpredictable nature of caregiving was reported in this study through participant statements such as “well sometimes I get surprises when I least expect them” and “I never really know what to expect” (p. 48). Although not directly related to planning, the author does report that participants were aware of the unpredictability of their roles and that this may have created some challenges for participants.

Finally, despite all the planning and the acceptance of change, there were some aspects about caregiving that participants did not predict. For the most part, the participants were all approaching retirement or had transitioned into retirement. When

asked about how they anticipated their later years, they described a very different life to the one they were currently experiencing. Even Janet, whose husband had been a paraplegic for many years, reported that she did not foresee the degree to which her caregiving role had grown over time. Most caregivers believed their retirement would include leisurely mornings filled with coffee and a crossword, exciting adventures as they traveled the globe, and spending time with family and friends. This disparity between life as experienced and life as expected was similarly reported in previous studies where participants expressed that these changes were unanticipated and represented a loss of their anticipated futures (Dickson, 2010; 2011). Furthermore, they described how difficult it was for them not to mourn their former lives as they focused on the losses they had encountered (Dickson et al., 2011).

It's rewarding

The vast array of negative consequences of caregiving has been well established throughout the literature (Denno et al., 2013; Milbury et al., 2013). While a growing body of research is beginning to recognize the numerous positive gains acquired through the role of caregiving (Kajiwara, Nakatani, Ono, & Miyakoshi, 2015; Lou, Lau, & Cheung, 2015), the overwhelming amount of literature linking the term caregiver with burden and burnout has created a challenge for both researchers and caregivers to overcome. While each caregiver in this study acknowledged the challenges they faced, they were quick to report that despite these challenges, they wanted to provide care for their loved one, they experienced a number of benefits as a result of their role, and that they took great pride in their ability to add to the care recipient's overall quality of life. The positive aspects of caregiving were a common point of discussion for participants in this study. It should be

noted that the intention here is not to paint an entirely positive picture of caregiving, but rather to provide balance to the discourse. Further, this study is not the first to identify the rewards of caregiving. In a study by Dickson et al., (2011) participants reported a number of positive factors associated with caregiving, including: feeling an increase in empathy for other caregivers, adopting a more accepting outlook on life, becoming a stronger person, and becoming closer to the person whom they were caring for. Additionally, a study by McKeown (2004) reported that caregivers derived great pride in the role as caregiver and Butcher (2001) echoed these sentiments, stating that “to focus only on the hardships of caregiving would provide an unbalanced and incomplete picture of the experience” (p. 49).

Sub-theme 2: Transitions

The caregivers in this study identified three main areas of transition they found to be particularly difficult: roles/identity, health and wellness, and financial/employment. A variety of other studies have similarly reported one or more of these transitions in connection with caregiver distress.

A change in roles- more specifically the acquisition of the caregiver role- has consistently been reported as being a challenge for many caregivers. As the care recipient’s health declines, the caregiver may feel a responsibility to take on more of a caregiving role, which can lead to the caregiver struggling to maintain their previous identity (e.g. wife, daughter, employee etc.). As a result of this new role, there may also be changes in the caregiver’s mental and physical health. Further, caregivers may find that they are unable to assimilate the role of caregiver into their current work schedules,

which may lead them to reduce their work hours or retire (Jacobs, Laporte, Van Houtven, & Coyte, 2014; Latif, 2006).

Throughout the literature, taking on the role of caregiver has been reported as challenging. This is true for a variety of reasons. First, it can mean the need to acquire new knowledge and skills specific to the care needs of the recipient (Henriksson & Arestedt, 2013). In addition, the tasks and responsibilities associated with caregiving are time consuming and may result in the caregiver having little to no leisure time (Gahagan, Loppie, Rehman, Maclellan, & Side, 2007). As a result they may abandon previously enjoyed activities, spend less time with friends and family, and neglect their own personal care needs.

Others have also found that as the caregiver role increases, caregivers can experience feelings of loss as they mourn their previous identity and lose control over their lives. One qualitative study looking at the impact of assuming the primary caregiver role revealed that, due to the all-encompassing nature of the role, a change in the caregiver's identity could occur. It was thought that this was most likely the result of an upset in the relationships equilibrium (Dickson et al., 2010).

In addition, caregiving literature indicates that transitioning to the role of caregiving is something that happens gradually, over an extended period of time. In a study by Dickson (2012), participants described adapting to the role of caregiver as a "complex and distressing series of ongoing adjustments" (p. 7). They reported that while distressing, many of them had adjusted to their new roles relatively successfully. Nonetheless, participants noted that the adjustment process was an active one, where each made conscious decisions to adjust their lifestyles in order to facilitate the process.

Participants in the present study similarly described this gradual transition period. Additionally, participants saw challenges in that the role had the potential to sneak up on them, leaving them feeling trapped. However, it also allowed for some to make adjustments that would allow them to perform their duties with greater ease. For example, Janet began working from home, Dorothy was able to set up respite care and home support, and Rosa renovated her home to allow for visits with her husband who was in residential care. Likewise, other research reported that some of the adjustments made in order to adapt included: a reduction in work hours, the acceptance of formal supports, and the recognition that life would never be as it was prior to taking on the role of caregiver (Dickson et al., 2012).

Just as the transition to caregiver presented challenges, participants in the present study found that changes in their own personal health and wellness could be stressful. When asked what health and wellness meant to them, the consensus included a holistic model, encompassing aspects of both mental and physical health. It is interesting, however, that despite this well rounded definition, participants were primarily focused on changes in their mental health. This is consistent with the literature as many studies report negative mental health consequences (Denno et al., 2013; Pagnini et al., 2010) as a result of taking on the role of caregiver. This is not to say that research does not exist on the physical health consequences (Roth, Fredman, & Haley, 2015), but rather that it is not balanced.

Although a couple of caregivers reported that their physical health may have improved since expanding their caregiving roles, the majority of participants mentioned negative changes in their health and wellness. For instance, in a qualitative study of

caregiver's experiences in caring for people in the early stages of dementia, participants expressed that they became tired and upset more easily. They further explained that this would on occasion cause them to lose patience with the care recipient, which resulted in the caregivers feeling regretful (Quinn et al., 2008). Consistent with the literature, Dorothy, Kathy, and Eva all reported feeling more irritable and being quicker to react than they had been prior to being a caregiver. Eva explained that throughout her life she had always been described as a very patient person, which was in contrast to her most recent behaviour. She provided an example of a time when she felt so frustrated that she slammed a door so hard that the glass broke which was unsettling for her as it was out of character.

Finally, participants reported that the transitions within and out of the workforce were stressful. For example, when Rosa was forced to reduce her work schedule from five days a week to three she felt a loss of control over her life as well as her finances. Janet was able to semi-retire, leaving her full-time employment to start her own business working from home. While this provided her with the flexibility she required in order to maintain her role as a caregiver, she reported that she felt the change was premature and would not have done so had she had any other option. While financial consequences of the caregiving role were not commonly reported in the literature, one study found that participants linked good finances to good health and ultimately to a better quality of life (Vellone, Piras, Talucci, & Cohen, 2008). These participants explained that having money allowed them to access the best care, take vacations, and look after their own health. Other research has confirmed that caregiving is associated with reduced employment. Jacobs et al. (2014) found reduced work hours or retirement were ways in

which women were coping with the dual burden of participation in the workforce and their roles as caregivers.

Sub-theme 3: Support

Considering the amount of work typically reported by caregivers and the stressful transitional periods, it is not surprising that all participants reported the need for some form of support. Participants identified three main areas surrounding the need for, and use of, support: ‘it takes a village’, ‘accepting help’, and ‘re-thinking respite’. The participants in this study reported a number of benefits and challenges associated with each of these categories.

Caregivers often find it difficult to lose the support and companionship of their loved ones, especially spousal caregivers, and often needed to seek additional support from a number of places. ‘It takes a village’ was a descriptor used to represent the variety of resources caregivers reported using when assistance was necessary. These included: friends, family, other caregivers, and the community. Despite seeking some support, many caregivers reported not receiving enough of it and felt very much alone in their endeavor. Similar results have been reported by others (Dickson, 2011; McKeown, 2004). For example, McKeown (2004) explored how caregivers experienced their roles while looking after people with Multiple Sclerosis. Most participants reported the strong desire to look after their loved ones without assistance and waited until reaching a point of crisis before seeking support. This is an important consideration as all caregivers also reported how difficult it was for them to obtain support. This suggests that it is essential to have support on call or established before it is needed in order to avoid a situation where the caregiver is not able to cope, placing both the caregiver and the care recipient’s

health in jeopardy. Some of the barriers to attaining support reported by participants were a lack of information about sources of support, long waiting times for services, red tape and bureaucracy. Each of the above barriers contributed to participants feeling as though services were inflexible and unsympathetic to the needs of both the caregiver and care recipient. Similar to the participants in McKeown's study, participants in the current study reported that the greatest resources were from more informal channels such as other caregivers.

Additional challenges reported by the majority of participants in the present study and also reflected in the literature include a lack of understanding of the caregiver's situation and the care recipients' willingness to accept help (McKeown, 2004). Janet described how important independence was to her husband and how he would often present himself to family and friends in such a way as to minimize his deteriorating health. This was very challenging for her as friends and family were not able to understand what she was going through or how challenging her role was due to a perception that all was well. Another example was given by Rosa who shared that her family would offer advice or make suggestions that she perceived as criticism. The constant need to explain her decisions and defend herself created a significant barrier for her in seeking support from family. Although each caregiver identified the need for support, it was often looked upon as a necessary evil. That is, caregivers often reported that assistance was needed but quickly followed this statement up with a 'but'. For example, 'but it's just the loss of control', or 'the intrusion into your personal space', or 'the inflexible schedule', or 'the lack of quality support'.

Consistent with these findings, participants in a study by Adams (2006) exploring the transition to caregiving acknowledged that they were using help from family and friends but limited their reliance on them for reasons similar to those mentioned above. They perceived family members to criticize or advise in ways they did not find helpful and didn't feel as though family members understood the extent of their problems. Another concern presented by participants, related to seeking outside help, was the acceptability to the care recipient (Adams, 2006). As the care recipient was often included in the decision making process it was found to be a negotiation between what the caregiver felt was needed and what the care recipient was willing to accept. In Dickson et al.'s (2011) research examining adjustment and coping in spousal caregivers, participants reported that the role of paid caregivers could either facilitate or inhibit their adjustment depending on two main factors: the nature of the paid caregiver and whether or not the care recipient deemed them as being 'good' or 'bad'. In addition, it was suggested by the author of this study that it was possible that the paid caregiver may impede the primary caregiver's maintenance of personal control and self-efficacy (Dickson et al., 2011).

As presented in chapter four, 're-thinking respite' was coined to represent the pros and cons of traditional respite options. Two categories emerged when examining respite: 'one size does not fit all' and 'it's the little things'. The first category encompassed some of the benefits of traditional respite while also identifying areas in which improvements could be made, while the second category presented more creative ways which caregivers were finding relief within their day-to-day lives. For one of the participants who had experiences with traditional respite, there was a mixed review. While none of the

participants would go as far as to describe the options as good Dorothy did say that she felt as though the service was adequate and provided her with a much needed break and the flexibility to visit her sister. On the other hand Marie was much more cautious and felt that the lack of stimulation was not conducive to her husband's needs. She felt as though leaving him in respite would derail all the work she had put into maintaining his mental health. Other issues raised in relation to respite hotels were the lack of flexibility in scheduling, the need to book six months in advance, and the quality of care provided.

In the literature, respite has been identified as a requisite in order to travel to see family or take some time for themselves while others struggled with the time away and found that the guilt they felt robbed them of any feelings of relaxation or rest that were being sought (Dickson, 2011). For this reason most participants in the present study described finding relief in the little things like making tea, spending time with grandchildren, talking on the phone with a friend, or practicing meditative techniques.

Theme: One day at a time

Together, the sub-themes 'intensive care', 'transitions', and 'support' contribute to the overarching theme of this study: 'one day at a time'. Throughout the interview process, questions, regardless of their content, were frequently answered by indicating caregivers were just taking things as they came, one day at a time. For example, questions regarding planning into the future, setting up additional support systems, and incorporating health promoting behaviours were all met with the response that caregivers already felt stretched to capacity and that they had neither the mental nor physical energy to even think about adding one more thing to their already taxing workload.

This idea of taking things one day at a time was prevalent throughout the literature (Adams, 2008; Dickson, 2011). In a study by Quinn, Clare, Pearce, and van Dijkhuizen (2008), participants reported that taking things on a day-to-day basis was how they were coping and trying to stay positive. It was noted, however, that this coping mechanism was coupled with an avoidance of thinking about the future. This was true for the caregivers and care recipients, who both felt that the future often looked depressing and thus preferred to postpone dealing with it until absolutely necessary. Like those in the current study, participants stated that- in addition to being depressing- the future was also uncertain, making it difficult to predict what was needed. They were aware that change was inevitable, but expressed the desire to avoid worry and instead live each day one at a time.

The utility of the caregiver identity theory

The Caregiver Identity Theory states that the caregiving experience comprises what the caregiver is doing and the meaning that the caregiver places on these behaviours. This means that caregiving is made up of a variety of activities that will be different for each caregiver and are often related to the disease process of the care recipient. Secondly, it means that each caregiver will experience similar tasks differently. Findings from this study support both of these notions. Participants each described a plethora of tasks associated with different disease processes. Marie described the need to always be present as her husband had dementia and required constant supervision, while Janet, whose husband was a paraplegic, described her caregiving role as more of an 'all or nothing' situation. A few participants described their roles as boring and including very little activity, while others reported that their roles could be physically demanding as

the care recipient was losing their mobility and requiring a lot more assistance with personal care needs. Still others described taking on more domestic tasks such as cooking, cleaning, and transportation.

When it came to the meaning each participant placed on the activities they were providing, there were notable differences between wives and daughters. Wives seemed to have a much greater ability to assimilate domestic tasks and include them into an already established or expanded identity role of a 'good wife', where daughters were finding the addition of these tasks to require much more accommodation. Consistent with the Caregiver Identity Theory, relating to avenues of identity change, the wives in this study experienced less distress related to the assimilation of domestic tasks while the daughters' experienced greater distress and burden associated with accommodation.

The opposite was true for activities related to support. Wives described having a more difficult time adding in additional supports that may have eased some of the pressure and allowed them to maintain their role identity of 'wife'. However, this notion of trying to do it all was resulting in a greater emphasis on their caregiver identity which often compromised the role of wife, friend, or employee as discussed earlier in this section.

The identity maintenance process for caregivers, as described in chapter two, suggests that caregivers will do whatever they can in order to alleviate the distress that can happen as a result of a discrepancy between their behaviour and their identity standard. This can be done through little changes or through much larger ones, which are more likely to move the caregiver towards identity change (Montgomery & Kosloski, 2013). Most participants reported making changes such as setting up informal support,

sharing caregiving activities among siblings, and cutting back at work or retiring altogether in order to find a balance between their initial role identities and their new caregiver roles. However, Eva and Dorothy described their experiences as out of balance and requiring some adjustments. First, Eva described the overwhelming amount of daily chores as increasing the caregiving responsibilities beyond her level of comfort. In order to cope, she inquired about additional supports that could take care of domestic activities, allowing her to spend more time in her initial identity role of daughter. The second situation was that of Dorothy, who felt as though she was only acting as ‘caregiver’ and no longer as ‘wife’. There were a number of factors, which had contributed to this change in identity over the years, and it did not appear she had attempted to make adjustments in order to regain her initial role identity, nor did she desire to do so.

Other factors that may contribute to a change in identity, according to the Caregiver Identity Theory, are a change in the caregiving context or a role conflict. At the time of the interviews, most participants were within a particular phase of their caregiving career that required only moderate changes to their behaviours in order to maintain their balance between initial identity role and that of the caregiver. One exception to this was Janet, who described in great detail the process of negotiation that was taking place with her husband in relation to accepting more formal supports. The caregiving context was changing and she described the last time he fell out of his chair as one of the worst she had experienced. She was concerned that she would no longer be able to provide the support and care that he required while ensuring that they both remained safe. This change in the caregiving context, the decline of her husband’s health, was placing more pressure on her role as a caregiver than she was comfortable with. Over

the years, she had made accommodations such as retiring early and improving her strength in order to care for her husband. However, she was now engaging in behaviours that were not congruent with her identity standard and looking at formal supports such as lifeline and home care in order to prevent moving any further towards the caregiver identity role.

Role conflict, on the other hand, was an experience reported frequently among all participants. They each provided examples of activities they would like to participate in or relationships they would like to foster that were related to role identities other than that of a caregiver. Many reported that they had made adjustments to their employment situations including changing jobs, working from home, or retiring early. Each of them explained that they felt an enormous pressure on their role of caregiver that made their role as employee much more difficult or in some cases impossible to maintain. Another example of role conflict came about as Eva described feeling as though she had put her family on a bookshelf to return to at a later time. Her role of caregiver was greatly impacting both her role as mother and wife. All of the participants reported feelings of social isolation and it appeared as though the role of friend was one of the first identities caregivers let go of in order to accommodate the competing demands that came with the caregiver role.

Implications for practice

The findings from this study may help to provide a better understanding of the daily realities of caregivers: perspectives of the rewarding and challenging aspects and the significant role of contributions to the broad health care system. As discussed throughout this chapter participants offered many examples of what they perceived to be

the benefits, costs, and areas in which improvement would be welcomed. As much of the previous literature provided support for these experiences, it could be said, that participants in this study were similar in many ways to others who have or are providing informal care. Based on the findings of this study and that of previous research, it appears that caregivers could benefit from a number of modifications to the current practice of both care provision and caregiver support. Some of the areas highlighted include: More person centered respite opportunities, integration of positive aspects of caregiving into programming and support networks, validation of the caregivers experience through shared stories and early identification and/or implementation of support.

First, respite was seen by many as necessary in order for them to travel out of town, for example to see extended family. As most noted that arranging respite could be difficult due to limited availability, advanced booking times, and the quality of care this appears to be an area where changes could be made in order to ensure that respite opportunities are available to caregivers without adding to the burden of their roles and responsibilities. This could be done by allowing caregivers greater flexibility when booking both times and lengths of stays. It seems evident that identifying innovative strategies for respite are essential to improving the caregiving experience. For participants in this study, current opportunities for respite simply offer band-aid, tokenistic and fleeting solutions.

Some caregivers in this study were quick to highlight the many benefits they experienced as a result of their role while others had not thought about caregiving as being rewarding. However, after further discussion they began to recognize that there were benefits and found this discourse to be quite empowering. By reframing the

conversation around caregiving to highlight some of the rewarding aspects of providing care, support networks, programs, and interventions may be better equipped to provide a more encouraging and balanced picture of the caregiving experience. Similarly to the inclusion of positive aspects of the caregiving experience caregivers reported that it was helpful to have their feelings validated and that this came most frequently through the sharing of stories by other caregivers, especially related to negative emotions. For some the simple act of hearing that their experiences were similar to that of someone else's was enough to provide comfort and reduce feelings of guilt and distress.

Participants in this study and previous research have identified that support is often not in place early on in the caregiving experience and is frequently only sought as the result of a crisis. For this reason, it should be of particular interest to support networks and care providers that support needs to be introduced sooner rather than later. Adams (2008) explains that current measures are not as effective in recognizing the needs of caregivers in the early stages. By focusing on later needs, support networks risk missing key opportunities to prevent problems before they reach the point of crisis. For Adams (2008), the current service model offers new caregivers information about the anticipated trajectory of the disease and available community resources; however, it does not allow for the valuable opportunity for caregivers to share their experiences and their feelings, which may help to provide validation for caregivers, especially in the early stages of their role. Failing to provide early support to caregivers may lead to greater difficulty in addressing issues that arise down the road Kuhn and Fulton (2004) offer a model for a caregiver support group specifically targeting those caregivers in the early stages of their role.

Recommendations for future research

While this study examined the experiences of a group of female informal caregivers and how these experiences affected their own personal health and wellness much more research is needed in order to provide a richer understanding of the relationship between caregiving and health. First, there is a need for future research to look at the role caregiving plays in the caregiver's health over an extended period of time. Some questions that need further examination include: What are the needs and experiences of caregivers throughout the various phases of their role? Is there a time when caregivers are particularly vulnerable to experiencing adverse health consequences? How are caregivers, as a vulnerable population, best reached? And, what support is most effective throughout various stages of the caregiving experience? Given concerns of knowledge exchange and translation regarding caregiving interventions, it may be advantageous to adopt a paradigmatic outlook that “. . . is cognizant, appreciative, and inclusive of local and broader sociopolitical realities, resources, and needs” (Johnson, Onwuegbuzie, & Turner, 2007, p. 129). For example, a concurrent mixed methods design to address some of the pragmatic issues raised in this study (Leech, 2012), integrating quantitative, qualitative data collection methods and analyses – caregivers' journaling, photovoice/photo-elicitation and focus groups, in addition to objective measures of caregivers' self-care health indicators.

In addition, it is critical to investigate the positive aspects of caregiving. It is an aspect of care provision that has been reported by many caregivers and one that caregivers want to talk about. Better understanding the positive aspects of caregiving may help clinicians and practitioners to work more effectively with the family caregiver. For

example, once factors related to positive gains have been identified, these could be used to tailor intervention methods in order to generate a more positive caregiving experience. Also, positive aspects of caregiving may be important determinants of the quality of care provided to older adults. A more positive appraisal of the caregiving experience results in less care recipients being placed in an institution and greatly increases the likelihood of the caregiver continuing to provide care. Finally, an important potential contribution of this line of inquiry is to provide information to enhance theories of caregiving adaptation and psychological well-being.

Further, in order for consistency in care provision and support services it is imperative to engage both health professionals as well as caregivers in the design process when creating health promoting support programs. As such, a community-based, participatory approach seems entirely appropriate where caregivers, health professionals and researchers collaborate throughout the research process. One particularly fitting design is the multi-site translational community trial, a hybrid design that borrows and blends aspects of a multisite RCT infused with the principles of community-based research (Katz, Murimi, Gonzalez, Njike, & Green, 2011).

An aspect that this study did not explore was the influence gender, culture, age, socioeconomic status factors etc., may have on the caregiving experience. As the participants in this study were from a mostly homogeneous group of women research would benefit from a greater effort towards diversity during participant recruitment. In Canada's increasingly multicultural society, understanding diverse perceptions of caregiving in terms of cultural beliefs and traditions will be important to the field.

Lastly, while it is important to recognize the many distinguishing characteristics among different groups of caregivers, this study has shown that commonalities do exist among caregivers in general. As such, it is important to further explore these commonalities in order to inform practice. Details with respect to the commonalities between various groups of caregivers could then be used in conjunction with information specific to individual populations in order to provide the best support for caregivers overall.

Strengths and weaknesses of the study

This study fills an important gap in the caregiving literature by providing voices from caregivers themselves and how their contributions to their care recipient reflect back on caregivers' own health and wellness. The diversity of and purposefully selected sample of participants is both a strength and weakness of this study. The experiences of caregiving were shared among all participants regardless of the specific disease afflicting those for whom they cared, living and caring circumstances, and the role of the caregiver as daughter, wife, or friend. Moreover, despite the often well-intentioned policies regarding respite and support, caregivers themselves are rarely consulted beyond initial programmatic ideas, to be engaged throughout the implementation of the very initiatives meant to alleviate their caregiving burden. A limitation of this research includes a lack of diversity in the sample in terms of culture and race, and thus is silent on how cultural traditions may influence the caregiving experience. Finally, although data saturation was reached in this study, a larger and more diverse sample size, including men in caregiving roles, may have confined the caregiving experiences to this small sample of participants.

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Appendix A

The following letter of invitation was provided to participants



**University
of Victoria**

School of Exercise Science,
Physical & Health Education

Care-full: Exploring the health and wellness issues facing women caregivers

Thank you for taking the time to let me speak with you today about my master's research study.

The purpose of this research is to better understand the need for and access to health promoting services for women caregivers. This study is intended to highlight some of the challenges experienced by women caregivers related to their own personal health and wellness. It is anticipated that the results from this study may inform the development of future health promotion initiatives aimed at improving the health of women caregivers so that they may continue to fulfill their role of caregiver without compromising their own personal health.

I am inviting you to participate in my research project because during my past experience as a formal and informal caregiver I have become acquainted with your role as a caregiver. I am interested in interviewing 8-10 adult (aged 18 and over) women providing care to: a parent, or spouse/partner, or adult family member/friend, who live in Victoria and understand English. Participation in the study includes an interview, which will include a variety of health related questions. If at any point during the interview you become uncomfortable with any of the questions, such as feeling stressed or overwhelmed when reflecting on your role as a caregiver or as it relates to your own health, you do not have to answer them. If you feel as though you would like further support to address some of the topics covered during the interview, I will provide you with a list of contact information available for you on local counseling and support services.

The audio-recorded interview would take about an hour of your time and can be scheduled at a time and place that is convenient to you. Before the interview, I will ask you to sign a consent form that explains the purpose of the study and how I will keep the information that you provide me confidential. You may also wish to review the transcript of our interview, and this may take an additional 15-20 minutes.

Please know that your decision to participate or not will in no way affect the quality of care or services that your friend/family member receives, nor our relationship as peer caregivers.

If you are interested in participating, or have questions about the study, please phone [REDACTED] or email [REDACTED] me.

Thank you for your time,

Holly Heath

Appendix B

The following questions were used as an interview guide

1. Please tell me about your role as a caregiver. Who do you care for and how long have you been doing this?
2. What would a typical day look like for you?
3. What do you feel are the most challenging and rewarding aspects of being a caregiver?
4. How would you define health and wellness? How do you see yourself in this description?
5. Has your health changed since becoming a caregiver? If so, how?
6. What types of things do you do to contribute to your health and wellness?
7. What do you feel has the greatest positive influence on your health and wellness? The greatest negative influence?
8. What changes would you like to make that you feel would improve your health and wellness? Why?
9. Why don't you currently do these things? What would make it easier to do them?
10. If you had questions about how to improve your health and wellness where would you go to find this information or who would you speak to?
11. If you needed support as a caregiver are you aware of any resources available to you?
12. What kind of resource, service, program or policy would you recommend be offered to help caregivers such as yourself improve their health and wellness?
13. Is there anything else that you would like to share with me about your experience being a caregiver and how that has or has not influenced your health behaviours?

Appendix C

The following consent form was provided to each participant.



Interview Consent Form

You have been invited to participate in a study entitled “**Care-full: Exploring the health and wellness issues facing women caregivers**” that is being conducted by Holly Heath and Joan Wharf Higgins.

Holly Heath is a Graduate Student in the School of Exercise Science, Physical & Health Education at the University of Victoria and Joan Wharf Higgins is a faculty member in the School of Exercise Science, Physical & Health Education at the University of Victoria and you may contact them if you have further questions by emailing hheath@uvic.ca or jwharfhi@uvic.ca.

What is the purpose of this study?

The purpose of this research is to better understand the need for and access to health promoting services for women caregivers. The research questions are: (1) what are the health promoting behaviours of women caregivers? (2) What are the needs of women caregivers to increase control over and improve their health? (3) What are the facilitators and barriers to increasing control over and improving the health of women caregivers?

Why is this study important?

There are over 93,000 family caregivers in the Greater Victoria area providing care for an adult family member or friend. This includes providing care for individuals who are elderly, chronically ill or living with a disability. Taking on the role of family caregiver can come with a number a challenges including but not limited to higher stress, social isolation and less time for self care. As a result from the increase in responsibility caregivers may experience burnout and decreased health, ultimately leading to health issues, which may or may not require them to discontinue their role as caregiver. This study is intended to highlight some of the challenges experienced by women caregivers related to their personal health and wellness. It is anticipated that the results from this study may inform the development of future community-based health promotion initiatives aimed at improving the health of women caregivers so that they may continue to fulfill their role of caregiver without compromising their own personal health.

Participant Selection

You are being asked to participate in this study because you have expressed an interest in participating and identified yourself as meeting the following inclusion criteria: (1) woman caregiver providing one or more of the following types of care (a) eldercare to a parent, (b) care for a spouse or partner, (c) care to another adult family member or friend. (2) 18 years or older, (3) live in Victoria, BC, and (4) understands English well enough to participate in the study.

What is involved?

If you agree to voluntarily participate in this research, your participation will include being interviewed for approximately 45-60 minutes either in person or on the phone. You may also wish to review the transcript in case you would like to correct any information or remove any information that you feel identifies yourself. This review process may also take another 15-20 minutes to complete.

Possible Harms

You are being asked to participate in an interview, which will include a variety of health related questions. If at any point during the interview you become uncomfortable with any of the questions, such as feeling stressed or overwhelmed when reflecting on your role as a caregiver or as it relates to your own health, you do not have to answer them. If you feel as though you would like further support to address some of the topics covered during the interview, Holly will provide you with a list of contact information available for you on local counseling and support services.

Benefits

The potential benefits of your participation in this research include improving future initiatives for women caregivers. The benefits to society and the state of knowledge include: a better understanding of how the specific needs of women caregivers may benefit from these health promoting initiatives. A summary of the findings will be made available to the Family Caregivers' Network Society at the end of the study.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you can decline to answer any question(s) and you may withdraw completely at any time without any consequences or any explanation. If you do withdraw from the study please know that the information you provide us, up until you withdraw, may be used in summarized form with no identifying information. If you choose to withdraw prior to approval of your transcript and prior to the removal of any identifying markers you may choose to have your data included or destroyed.

Confidentiality

Your identity within the study will remain confidential as all individual records and results will be analyzed and referred to by number code only. For accurate data collection, we would like to audiotape the discussions and will ask your permission to do this before the start of the interview. Should you not want us to record the discussion, we will take notes instead. Transcripts of the interview will not include any real names or other identifying information. No true names will appear in any written report unless you indicate below that you would like the information that you share to be attributed to you. In this case, please know that you will not remain anonymous.

If there are audiotapes of the interview, they will be erased following transcription. If you wish to review the transcript for accuracy and change anything that you feel identifies yourself, I will remind you about your rights to ensure that your consent to participate is ongoing, and ask that you initialize such a statement at the top of the transcript.

Files are kept in secure locked offices in the School of Exercise Science, Physical and Health Education at the University of Victoria. The offices remain locked and only those directly

involved in the study will have access to your records and results. You will not be referred to by name in any reports or research papers unless you have indicated that you wish to waive your confidentiality. Reports or papers, including the thesis, may be presented to community organizations (e.g., Family Caregivers' Network Society) and to the research community including conferences, journals and academic websites. A report including the findings will be made available to the Family Caregivers' Network Society and a personal copy may be requested. Your individual name will remain confidential, as they will not be discussed with anyone outside the research team. All information will be kept for 3 years, after which it will be destroyed.

Please be assured that you may ask questions at any time. If you require more than one interview session you will be asked to review and initial the consent form and given the opportunity to ask any questions again before continuing with the interview. Should you have any concerns about this project or wish further information please contact

- Holly Heath; [REDACTED]
- Joan Wharf Higgins; [REDACTED].

You may verify ethical approval of this study or raise any concerns you might have about your rights or treatment as a participant in this study by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you agree to participate in this research project.

I would rather not be named in the results of the study (I wish to remain anonymous):
 _____ (Participant to provide initials)

[WAIVING CONFIDENTIALITY] PLEASE SELECT STATEMENT only if you agree:

I agree to be identified by name / credited in the results of the study: _____
 (Participant to provide initials)

I agree to have my responses attributed to me by name in the results: _____
 (Participant to provide initials)

Name of Participant

Signature

Date

A copy of this consent will be left with you, and the researcher will take a copy.

Appendix D

Certificate of approval



Office of Research Services | Human Research Ethics Board
 Administrative Services Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada
 T 250-472-4545 | F 250-721-8960 | uvic.ca/research | ethics@uvic.ca

Certificate of Approval

| | |
|---|--------------------------------------|
| PRINCIPAL INVESTIGATOR: Holly Heath | ETHICS PROTOCOL NUMBER 15-066 |
| UVic STATUS: Master's Student | Minimal Risk - Delegated |
| UVic DEPARTMENT: EPHE | ORIGINAL APPROVAL DATE: 23-Apr-15 |
| SUPERVISOR: Dr. Joan Wharf Higgins | APPROVED ON: 23-Apr-15 |
| | APPROVAL EXPIRY DATE: 22-Apr-16 |
| PROJECT TITLE: Care-full: Exploring the health and wellness issues facing women caregivers | |
| RESEARCH TEAM MEMBER None | |
| DECLARED PROJECT FUNDING: None | |
| CONDITIONS OF APPROVAL | |
| This Certificate of Approval is valid for the above term provided there is no change in the protocol. | |
| <p>Modifications To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.</p> <p>Renewals Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.</p> <p>Project Closures When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.</p> | |
| Certification | |
| This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants. | |
|  Associate Vice-President Research Operations | |

15-066 Heath, Holly

Certificate Issued On: 23-Apr-15