FROM LOVING HUSBAND TO LOVING CAREGIVER: THE LIVED EXPERIENCE OF INTIMACY AND SEXUALITY IN THE TRANSITION TO CAREGIVER FOR MEN WHO CARE FOR THEIR FEMALE PARTNER WITH DEMENTIA

by

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ABSTRACT

Dementia is a syndrome in which memory, thinking, behavior and the ability to perform everyday activities deteriorates. It is estimated that there were 47.5 million people living with dementia worldwide in 2016 and this number is projected to increase exponentially in the future. It has been suggested that informal family caregivers are the invisible and hidden backbone of health and long-term care systems in Canada.

Spousal caregivers are often informal caregivers for their loved one with dementia. A diagnosis of dementia for one spouse has a major impact on all aspects of the marital relationship. Research has shown that satisfaction in sexual and intimate relationships increases the quality of life and overall health of older adults. A gap in the literature exists in understanding men’s experiences of sexuality and intimacy in their relationship with their wife with dementia. A qualitative phenomenological study was conducted to describe men’s lived experience of sexuality and intimacy in their relationship with their female spouse with dementia.

Three men were interviewed and the essence of the lived experience is described as a transition from loving husband to loving caregiver. Two themes were developed to support this essence: 1) caregiver first and 2) a new form of intimacy. These themes are explored in detail with quotes from the men woven throughout. A discussion of these findings and comparison to current literature are presented as well as future recommendations for research and implications for practice.
DEDICATION

Thank you to my mom, for many years of support and an always listening ear.

To Jordan, for pushing me when I felt like giving up.

Thank you to my trusted college in the MN program, Melissa, for an ongoing listening ear and sounding board throughout this program, as well as my work family for pushing me to complete this program.

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CHAPTER ONE: INTRODUCTION

Dementia is a term used to encompass diseases that develop when nerve cells in the brain die or deteriorate and no longer function properly (Alzheimer Association of Ontario, 2012). Millions of people are living with dementia globally, and as many as 115.4 million are expected to be facing this diagnosis by the year 2050 (Alzheimer Disease International, 2010). In Canada, it is estimated that over 500,000 Canadians have Alzheimer’s disease or a related dementia (Alzheimer Society of Canada, 2017a). Alzheimer’s disease and dementia impact individuals, families, healthcare, and society.

It has been suggested that informal family caregivers are the invisible and hidden backbone of health and long-term care systems in Canada (Fast, Niehause, Eales, & Keating, 2002; Alzheimer Society of Canada, 2010). It is estimated that there are 22 million informal caregivers in the United States, and most of them are family members. It was estimated that 3.8 million Canadians aged 45 years and older are informal caregivers (Statistics Canada, 2016).

Informal caregivers of those with dementia are noted to be a the most vulnerable group who are at risk for poor health outcomes and burnout related to caregiving (Canadian Institute for Health Information, 2010; Evans & Lee., 2013; Rinaldi et al., 2005; Shim, Barroso, Gilliss, & Davis, 2013). Many caregivers of those with dementia are spouses and it is necessary to understand how to promote health and wellbeing in this care population to lessen the burden on health and social care systems. Research has shown that billions of dollars (Alzheimer Society of Canada, 2010; Fast et al., 2002;
Lilly, Robinson, Holtzman & Bottorff, 2012) may be saved annually in healthcare spending with the aid of informal caregivers.

There seems to be a silence around the topic of intimacy and sexuality in older adults with healthcare providers (Bamford, 2011; Hawkins et al., 2009). This silence gives relevance to this study. The stereotype that older adults are asexual can be a barrier to delivering programs, policy and practice to reach spousal caregivers who have concerns in this area (Allen, Petro & Phillips, 2009; Deacon, Minichiello & Plummer, 2006). It is necessary to support caregivers’ sexuality and intimacy to promote their autonomy, dignity and privacy. Indeed, the sexual rights of spousal caregivers including the freedom to access sexual health care services, information and education about the expression of sexuality and intimacy needs to be be respected (Rheaume & Mitty, 2008).

van Manen’s (1997) approach to phenomenology was appropriate for this study. The lived experience of male caregivers of their female partner living with dementia and the impact this role has on their intimate and sexual self has not been deeply investigated. This knowledge is needed to increase the sustainability of caring for those with dementia at home, as satisfaction with sexuality and intimacy is liked to increased health and well-being in the older adult, but is often lost when assuming a caregiving role, resulting in a potential decline in health (Alzheimer Disease International, 2010). Further, if spousal caregivers can be supported to maintain their sexual and intimate self-identity, they may be able to engage in the caregiving role for longer periods of time as this often acts as buffer for the negative consequences of caregiving on the health and well-being of the caregiver (Harris, Adams, Zubatsky & White, 2011). This may mean the care recipient
could live at home longer, and as a result, part of the strain on the health and social care systems associated with the care people with dementia may be reduced. van Manen’s (1997) approach is helpful when the researcher’s intent is to understand the lives of individuals within their own context and deriving the meaning from their lived experiences (van Manen, 1997).

This phenomenological study was designed to gain an understanding of the lived experience of sexuality and intimacy for male caregivers of their partners with dementia. The goal of this research was to extract the essences of the lived experience of the participants and create a piece of writing that reflects this lived experience. Data were collected using a demographic form, semi-structured interview and field notes. van Manen’s (1997) principles of data analysis were used in the reporting the findings. I used principles of rigor and I followed the ethical principles throughout the research process.
CHAPTER TWO: LITERATURE REVIEW

Introduction

This chapter reviews the literature to develop a background about informal spousal caregivers of those with dementia and their experiences of sexuality and intimacy in the context of the caregiving relationship. A review of dementia is presented along with the research related to caring for people with dementia. This is followed by an overview of the impact of caregiving on one’s sexuality and intimacy.

The Reach of Dementia

Dementia is a term used to encompass diseases that develop when nerve cells in the brain die or deteriorate and no longer function properly (Alzheimer Association of Ontario, 2012). With dementia, memory, thinking, behavior and the ability to perform everyday activities deteriorates (ADI, 2010; Alzheimer Association, 2017b; Alzheimer Society of Canada, 2017b; World Health Organization 2012). It is estimated that there were 35.6 million people living with dementia worldwide in 2010 and this number is projected to increase to 65.7 million by 2030 and 115.4 million by 2050 (ADI, 2010). In Canada, it is estimated that 564,000 Canadians have Alzheimer’s disease or a related dementia (Alzheimer Society of Canada, 2017a). In 2016, it was estimated that 1.1 million Canadians were directly or indirectly affected by dementia (Alzheimer Society of Canada, 2017a).

Dementia is most prevalent in individuals who are 65 years of age and older, with one in nine having Alzheimer’s disease (Alzheimer Association, 2017a). In the United
States, there are currently five million people living with dementia (in total) and this number is projected to reach 16 million by 2050 (Alzheimer Association, 2017)). The prevalence of early onset dementia (diagnosed before 65 years of age) continues to increase, with dementia diagnosed in as many as 70,000 Canadians under the age of 65 and 50,000 under the age of 60 (ADI, 2010; Alzheimer Society of Ontario, 2012). Early onset dementia represents 2-10% of dementia diagnoses in Canada (Alzheimer Society of Ontario, 2012; Alzheimer Society of Canada, 2010). The Alzheimer’s Association (2017a) reported that 200,000 individuals under the age of 65 have Alzheimer’s disease in the United States. Worldwide, those with early onset dementia make up 6-7% of those living with dementia (Flynn & Mulcahy, 2013). Almost 65% of Canadians who are living with dementia are women (Alzheimer Society of Canada, 2017a). Similarly, in the United States, women are nearly twice as likely to be living with dementia (3.4 million) than men (1.8 million) (Alzheimer Association, 2017a). One in six women of the age of 60 are at risk of developing Alzheimer’s, while only one in 11 men are at risk of the same (Alzheimer’s Association, 2014). It is suggested that there are more women (than men) living with dementia because women generally have a longer lifespan than men, and the chance of developing dementia dramatically increases with increased age (Alzheimer's Association, 2014).

Types of Dementia

There are four main types of dementia, including Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (Alzheimer Disease International, 2010; Alzheimer Association, 2017b; Alzheimer Society of Canada,
2017b). When individuals exhibit signs of more than one type of dementia, they are said to have mixed dementia (Alzheimer Association, 2017b; Alzheimer Society of Canada, 2017b).

Alzheimer’s disease is the most common type of dementia, accounting for 60-80% of all cases (Alzheimer Disease International, 2010; Alzheimer Association, 2017b). Although the exact etiology of Alzheimer’s disease is unknown, it is thought to be caused by a build-up of proteins in the brain often referred to as plaques and tangles (Alzheimer Association, 2017b). Symptoms of Alzheimer’s disease are memory loss that disrupts daily life (e.g., difficulty remembering names and recent events, difficulty solving problems and completing familiar everyday activities), confusion with time or place, problems with speaking or writing, misplacing items, changes in mood, and withdrawal from social activities (Alzheimer Association, 2017b; Alzheimer Society of Canada, 2017b).

Vascular dementia, the second leading form of dementia, accounts for almost 20% of cases (Alzheimer Association, 2017b; Alzheimer Society, 2017b). Stoke and other brain injuries are often the cause of vascular dementia. Depending on the area of the brain that is affected by the injury, different symptoms will arise (Alzheimer Association, 2017b). It is characterized by a sudden onset with symptoms including slowed thinking, difficulty to plan and impaired judgment, rather than the characteristic memory loss associated with Alzheimer’s disease. Late onset symptoms as the disease progresses include mood changes, memory problems, balance problems, dizziness and personality changes (Alzheimer Association, 2017b; Alzheimer Society of Canada, 2017b).
Lewy body dementia is the third most common type of dementia (Alzheimer Association, 2017b; Alzheimer Society of Canada, 2017b). Lewy body dementia occurs because of abnormal deposits of a protein in the brain, and accounts for 10-25% of all dementia cases (Alzheimer Association, 2017b; Alzheimer Society of Canada, 2017b). Lewy body dementia involves symptoms like those of Parkinson’s disease and Alzheimer’s disease, with early signs such as sleep disturbances and muscle rigidity. Individuals with this form of dementia often develop other symptoms such as progressive dementia, fluctuating cognition sometimes accompanied by vivid hallucinations, spontaneous tremors, sleep disturbances, falls and unexplained loss of consciousness (Alzheimer Association, 2017b; Alzheimer Society of Canada, 2017b).

Frontotemporal dementia only affects the frontal and temporal lobes of the brain (Alzheimer Association, 2017b; Alzheimer Society of Canada, 2017b). Frontotemporal dementia is the rarest form of dementia (Alzheimer Association, 2017b; Alzheimer Society of Canada, 2017b), with no current predication of the population that is affected. While the brain changes associated with frontotemporal dementia are often present with brain changes in Alzheimer’s disease, symptoms of frontotemporal dementia are often seen at a younger age than other forms of dementia (under 60 years of age) (Alzheimer Association, 2017b). The symptoms associated with frontotemporal dementia are inappropriate actions, loss of empathy, lack of judgment, repetitive behaviours, apathy, and changes in eating habits (Alzheimer Society of Canada, 2017b).
Outcomes of Dementia

Dementia is one of the major causes of debilitation and dependency. It is the fifth leading cause of death in those aged 65 years and older (Alzheimer Association, 2017b; Mitchell et al., 2012). Dementia has lower mortality rates (median survival time from the time of onset of symptoms ranges from 3.3 to 11.7 years) than other non-communicable diseases such as stroke, cardiovascular disease and all forms of cancer (Alzheimer Association, 2017b; Ferri et al., 2005; Todd, Barr, Roberts, & Passmore, 2013).

Dementia often results in significant morbidity because individuals live for many years between the onset of symptoms and death (Alzheimer Association, 2017b). The quality of life of those living with dementia is directly related to the quality of the care they receive because they eventually lose their autonomy and decision-making capabilities, which makes them reliant on caregivers to advocate for them (Dilworth-Anderson, Pierre, & Hillard, 2012). With one person developing Alzheimer’s disease in the United States every 67 seconds, and Alzheimer’s disease being the 6th leading cause of death, it places a great financial strain on the social and health care systems (Alzheimer Association, 2017b; Luengo-Fernadez, R., Leal, J., & Gray, A., 2010).

Dementia and Alzheimer’s disease is the only cause of death in the top ten in America that cannot be cured or prevented. Deaths from Alzheimer’s disease have increased 68 percent between 2000 and 2010, while deaths from other major diseases have decreased (Alzheimer’s Association, 2017b). Furthermore, Alzheimer’s disease is said to be the most expensive national condition resulting in a projected 259 billion dollars spent caring for those with dementia in 2017 (Alzheimer Association, 2017b).
Diagnosing and Treating Dementia

Dementia is currently diagnosed using medical and family history, physical examination, cognitive testing and imaging [e.g., mini Mental State Examination, Computed Axial Tomography (CAT) Scan and magnetic resonance imaging (MRI)] (Alzheimer Association, 2017c; Holzer, Warner & Iliffe, 2013). Brain atrophy, which is often indicative of dementia, can be detected through MRI. Currently, there is extensive research involving the detection of dementia in relation to biomarkers in plasma and cerebrospinal fluid (Holzer et al., 2013). Dementia is often under diagnosed due to the denial that individuals experience when they first notice symptoms in themselves and in their loved ones and lack of public knowledge about dementia and its symptoms (Harris, et al., 2011.)

Dementia treatment cannot stop or reverse the symptoms of dementia, but it may slow its progression. Treatments include administration of medication (e.g., cholinesterase inhibitors and N-methyl-D-aspartate receptor antagonists), stimulation of cognitive processes, lowering cholesterol levels, exercise, and controlling inflammation of body tissues (Boyd, 2013; Brady & Weinman, 2013; Holzer et al., 2013).

Caring for People with Dementia

Access to healthcare is a prerequisite to achieve the best possible health for those living with dementia (Dilworth-Anderson et al., 2012). People with dementia may receive care either in the home or in a residential care facility.

Care Provided at Home
The Canadian Institute for Health information (CIHI) (2010a) reported that one in five seniors, who received long-term care at home in 2007-2008, were living with a diagnosis of Alzheimer’s disease or another related dementia. In a study of 131,000 seniors who received publicly funded home care, CIHI (2010a) researchers found only 2% managed without supportive care, suggesting that many of these seniors would have difficulty remaining alone. According to the last published Statistics Canada report, more than half of seniors (56%) were reported to live in a different household than their caregiver (Statistics Canada, 2012). It was found that of the 2.2 million Canadians receiving some type of formal care inside the home, seniors were most likely to be receiving this care with 10% in the age range of 65-74 years old, 21% between 75-84 and 45% over the age of 85 (Statistic Canada, 2012). Even with this care, it is suggested that some senior’s needs are remaining unmet or are only partially met (Statistics Canada, 2012).

Many strategies are being created nationally which outline the importance of home care and seniors living in their home for as long as possible (Canadian Medical Association, 2016). However, while those with dementia age at home, their caregivers often experience declining health status, suffer from anxiety and fatigue, and cope with dwindling financial resources (Carstairs & Keon, 2009; Kasper, Freedman, & Spillman, 2014, Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013, National Alliance for Caregiving and AARP, 2016). For seniors to continue living in their homes, community supports need to be strengthened, education and resources need to be provided to informal caregivers and there needs to be increased access to said supports (Canadian
Medical Association (CMA), 2016). For example, in Ontario, the “Home First Program” is trying to reduce the amount of time seniors wait in hospital by identifying risk associated with discharge to the home, and focusing on the quality of life for caregivers and care recipients (CMA, 2012). However, for those living with dementia at home, the dementia often progresses to a level that individuals can no longer live at home, even with support (CIHI, 2012). Care may be moved to a formal care facility due to lack of support, disease progression, or caregiver burnout. In Canada, acute care beds are limited due to the number of alternative level of care (ALC) beds, which are often occupied by those with dementia whose caregivers are no longer able to take care of them at home (CIHI, 2012). Despite advancements in support for informal caregivers through new reporting systems, assessment tools and initiatives to predict caregiver distress and to support the transition home from acute care (such as Ontario’s Home First Program), there continues to be a need for increased support (CIHI, 2012).

**Care Provided in a Residential Care Facility**

About 8% of seniors reside in a residential care facility (Statistics Canada, 2012). Fourteen percent of the 5.4 million Canadians who reported caring for a senior (informally) said they were providing care inside a residential care facility (Statistics Canada, 2012). This shows that a senior moving to a residential care facility is not a predictor of decreasing informal caregiver involvement. Research suggests that people with dementia who are at risk for wandering were seven times more likely to be placed in a residential care facility than those who did not wander, and those who were not married were twice as likely to be institutionalized compared to those who were married (CIHI,
2010a). Often decreased fulfillment from caregiving can be predictive of the institutionalization of a spouse with dementia (Dourado et al., 2010). Many studies examine the association between depression and quality of life in a residential care facility among people with dementia, showing that those who live in residential care facilities are more depressed and may experience poorer quality of life (Barca, Engedal, Laks, & Selbaek, 2011).

**Challenges in Accessing Care**

Globally, rural communities have limited resources for dementia care compared to urban areas. This means families residing in rural areas often have difficulty accessing services (Kalaria et al., 2008). Care facilities designed to support those with dementia are often a great distance from the home, and some community support services do not reach those in rural areas. Geographical location of the residential care facility is often a barrier for families to visit their loved one. Some families are unable to travel the distance or do not have the resources to travel the distance (Kalaria et al., 2008).

In areas where services are available and easily accessible, those with limited financial stability may also be disconnected from health and social care. There are financial strains for informal and social care alike. Dependency on a family member has been linked to the creation of poverty due to the financial strain associated with the loss of an income when a family member stays at home to care for a dependent family member (Kalaria et al., 2008), which is often the situation when family members become informal caregivers to those with dementia. Income and social status play a large role in the provision of care to those who have dementia and the ability to access essential
services. About 60% of healthcare spending initially designated for caring for people with dementia in the home is being spent on care provided in residential care facilities (Pinquart & Sorenson, 2004). This unequal government spending leaves family caregivers feeling that their role as a caregiver is taken for granted in all aspects of healthcare and society.

**Informal Caregiving: Who are the Caregivers?**

It has been suggested that informal family caregivers are the invisible and hidden backbone of health and long-term care systems in Canada (Alzheimer Society of Canada, 2017a; CMA, 2016). Informal caregivers are those who provide ongoing care and assistance without pay for family members and friends in need of support, predominately in the home (Alzheimer Society of Canada, 2017a). A Statistics Canada (2012) report estimated that 5.4 million Canadians aged 45 years and older are informal caregivers.

Most informal caregivers to older Canadians are spouses or adult children of the care recipient. Twenty-five percent of caregivers are seniors themselves, and 33% are over the age of 74 (Statistics Canada, 2012). In Canada, 43% of informal caregivers balance the role of caregiving with a job and family responsibilities (Statistics Canada, 2012). More than 60 percent of Alzheimer and dementia caregivers are women, with an estimate of 2.5 times more woman than men providing 24 hour care for someone with Alzheimer's or dementia (Alzheimer’s Association, 2014). Recent literature suggests that although caregiving was traditionally a woman’s role exclusively, more male caregivers are emerging (Poysti et al., 2012; Russel, 2008). This caregiving role adopted by men
may be in part due to more women being in the workplace (Baker, Robertson, & Connelly, 2010; Russel, 2008).

Informal caregivers assist with transportation, meals preparation, house work, financial responsibilities, medication management, personal care, feeding, and navigating the health care system and services. Informal care can range from a few hours a day to around-the-clock care (Carstairs & Keon, 2009). The Rising Tide Report by the Alzheimer Society of Canada (2010) reported that in 2008, 231 million hours of informal care was provided to persons with dementia in Canada and this number is expected to increase to 756 million hours by 2038. The total cumulative economic burden of the provision of informal care to persons with dementia (including total direct costs, opportunity lost for the informal caregiver, indirect costs and monetary economic burden) was 14.9 billion dollars in 2008 and is projected to increase to 872 billion dollars in 2038 (Alzheimer Society of Canada, 2010).

Consequences of Informal Caregiving

Caregivers of people with dementia endure continuous cycles of physical, psychological, financial and emotional challenges related to long term dementia care, and are likely to experience poor health, anxiety and fatigue (Carstairs & Keon, 2009; Kasper et al., 2014, Lilly et al., 2012, National Alliance for Caregiving and AARP, 2016). Informal caregivers of those with dementia are more susceptible to social isolation and psychological distress, clinical depression and high levels of emotional stress (Evans & Lee, 2013; Kasper et al., 2014, Pinquart & Sorenson, 2006a). One in six informal caregivers experience distress- whether it be psychological or physical (CIHI, 2010).
The level of distress of informal caregivers is proportional to the intensity and amount of caregiving tasks performed and whether the caregivers feel they have a choice in being a caregiver or not; that is, there is often higher levels of distress when caregivers do not have a choice in caregiving (Kim, Chang, Rose, & Kim, 2011; Pinquart & Sorenson, 2005). The distress level of caregivers is more related to the changes in the caregivers’ life due to the role of caregiving, rather than the characteristics of the disease itself (Quinn, Clare, & Woods, 2009).

Financially, informal caregivers feel that they are not able to juggle work, expenses, and caring for someone (Statistics Canada, 2015). Currently, on a provincial level, Nova Scotia is the only province that provides support to low-income family caregivers and Manitoba is the only province that has legislation that recognizes the role of caregivers which guides the development of a framework to support these caregivers (CMA, 2016). On a federal level, there are some financial supports such as the Family Tax Credit, the Caregiver Tax Credit, and the Compassionate Care Benefit, but together these supports are piecemeal in the grand scheme of caregiver distress and they have eligibility restrictions (CMA, 2016).

Informal caregivers often feel “forgotten about” or “alone” when caring for a family member with dementia at home (Lilly et al., 2012). In a study of 23 caregivers residing in British Columbia, Lilly et al., (2012) found that informal caregivers wanted to receive more support from the community care system. When they do not feel supported, informal caregivers experience exhaustion, high levels of burden, loss of self and self-neglect, which often causes caregivers to withdraw from their roles (Benedetti, Cohen, &
Taylor, 2013; Carstairs & Keon, 2009; CIHI, 2010; Lilly et al., 2012; Statistics Canada, 2015). This can place the care recipient at risk for abuse and neglect in the caregiving relationship, and it places greater strain on the healthcare system when the care recipient can no longer be cared by the informal caregiver (Carstairs & Keon, 2009).

**Supporting Informal Caregivers**

Many studies use quantitative methods to measure the effectiveness of different interventions to support informal caregivers. These interventions include psycho-educational support and multi-component interventions that focus on caregivers’ physical and psychological well-being (e.g., exercise, nutrition) (Pinquart & Sorenson 2006a; Thompson et al., 2007). According to two systematic reviews, interventions for supporting informal caregivers are most effective when they provide opportunities for the caregiver and care recipient to both be involved, encourage active participation, and include both individual and group educational programs (Pinquart & Sorenson 2006a; Thompson et al., 2007).

Caregivers have reported that the most effective coping strategy for dealing with the stresses of their role is to simply accept the disease (Pinquart & Sorenson, 2006a; Shim, Barroso, & Davis, 2012). Still others use emotion focused coping strategies, such as wishful thinking, denial, suppress feelings, self-blaming and avoidance (Pinquart & Sorenson, 2006a). Referral to support groups, self-help materials and peer support are less effective for informal caregivers (Thompson et al., 2007). Given the variability in caregivers’ age, gender, ethnicity and burden of caregiving, the lived experience of each individual caregiver needs to be understood to offer the best support for that caregiver.
Spousal Caregivers

Of the nearly 8 million reported family caregivers in 2012 by Statistics Canada, 8% were caring for their spouse (640,000 people) (Statistics Canada, 2015). Due to marital and familial obligations, spouses are often in the role of informal caregiver for a longer time than other family members (Hayes, Bolstein, & Zimmerman, 2010). Spousal caregivers spend ten times as many hours in a caregiving role and act as caregivers for four years longer than other informal caregivers (Hayes, Bolstein & Zimmerman, 2010).

The marital role is often over-simplified in the realm of caregiving. Spousal caregivers may feel the need to live up to marital vows, even though their own health may be declining, and they feel more burdens because of caregiving (O’Shaughnessy, Lee, & Lintern, 2010). Evans and Lee (2013) stated that spousal caregivers try to support the role that the care recipient (spouse with dementia) played within the marriage. It was difficult to encourage the care recipients to play the role they traditionally did when their cognitive ability declined. This means that the caregiving spouse takes on the role of the caregiver as well as the role the care recipient used to play in the marriage.

For some spouses, the caregiving experience provides them with an opportunity to cherish the relationship that remained with the care recipient instead of focusing on what had been lost (Shim et al., 2012; Torge, 2014). Spousal caregivers may feel a sense of pride when caregiving as they are able to honor their marital vows, even if caregiving requires sacrifice of their previous life (Torge, 2014). Positive experiences were also reported when caregivers did not focus on their own needs solely, but recognized feelings...
of sadness and frustration due to their life changes since becoming a caregiver (Shim et al., 2012).

Spousal caregivers often have more negative experiences than other informal caregivers. They have higher levels of loneliness and depression than adult children caregivers, and are more likely to report distress than other informal family caregivers (CIHI, 2010b; Evans & Lee., 2013; Rinaldi et al., 2005; Shim et al., 2012). They are often older adults who are balancing their own health issues with those of their care-recipient, and caregiving often exacerbates their own health issues (Shim et al., 2012). A study by de Vugt et al., (2006) found that spousal caregivers of those with dementia are at risk of cognitive decline and at risk of dementia themselves as they are generally also older adults as well.

Spousal caregivers were more likely to experience distress if: a) the care recipient has moderate to severe cognition problems such as forgetfulness or confusion, b) they spend 21 hours or more a week with the care recipient, c) the care recipient shows signs of depression, d) the care recipient has impairments in activities of daily living, e) they reside with the care recipient, and f) use of negative coping strategies (CIHI, 2010b; Kim et al., 2011). The caregiving burden has been shown to increase if the care recipient has behaviour issues, and if there was a decrease in emotional closeness between spouses as a result of the disease (Rinaldi et al., 2005).

It is often assumed that having a spouse is predictive of caregiving ability (Davies 2010). Often, simply being a spouse, it is assumed that the spouse will be the default caregiver if one is needed. However, there are different factors that impact the caregiving
ability and success as a spousal caregiver. The quality of the relationship the spousal caregiver had with the person with dementia prior to the onset of caregiving often impacts their ability to be a caregiver (Harris et al., 2011; Hayes, Bolystein, & Zimmerman., 2009; Fauth et al., 2012). For example, some spousal caregivers who had a previous abusive relationship with the care recipient do not report any positive experiences in caregiving, and they focused on their own unmet needs rather than considering the needs and feelings of the care recipient (Shim et al., 2012). When closeness between spouses declines, it has been shown to also play a role in how satisfied caregivers feel in the role of caregiving (Dourado et al., 2010; Fauth et al., 2012).

**Gender Differences in Spousal Caregiving**

There are mixed results on gender differences in the spousal caregiving experience. Some studies report there are distinct differences in how men and women approach the role of caregiving (e.g., Akpinar, KKu‘cμ’kgu‘cJu , & Yener, 2011; McDonnell & Ryan, 2013; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi 2007; Poysti et al., 2012; Thompson et al., 2007, Yee & Schultz, 2000), while others report there are no differences (Baker et al., 2010; Fitzpatrick & Vach-Hasse, 2014).

**Female caregivers.** Female caregivers provide more care, have higher levels of burden and depression, exhibit poorer health and report a lower level of subjective well-being than male caregivers (del-Pino Casado, Frias-Osuna, Palmonio-Moral, & Martinez-Riera, 2012; Pinquart & Sorenson, 2006b; Poysti et al., 2012; Simonelli et al., 2008; Thompson et al., 2007, Yee & Schultz, 2000). Women are less likely to seek help from family and friends than men because they perceive caregiving as an extension of their
role as wives and partners (Montgomery, Rowe, & Kosloski, 2007; Poysti et al., 2012). Akpınar et al. (2011) went on to describe this perceived extended role can lead to burden in females as they may have considered their role as a caregiver finished when their children grew up, and now find themselves back in the role of the caregiver. Women may be at risk for more negative consequences associated with caregiving because they have reported less satisfaction with caregiving than men (Akpınar et al., 2011; del-Pino Casado et al., 2012). In a study by Akpınar et al. (2011), women experienced more distress than men in terms of time dependency related with tasks to be completed and developmental, physical and social burdens; yet both women and men experienced similar levels of emotional burden.

**Male caregivers.** In cultures where caregiving is not seen as a man’s role or when it is not expected that men be experts in the role, male caregivers experience less stress and burden (Akpınar et al., 2011; Poysti et al., 2012). Although men may experience a sharp learning curve as they take on the role of caregiver, men are successful caregivers as they are proactive in researching the disease process, have strong coping mechanisms, possess problem-solving skills, seek help if they feel it needed, and may enjoy the role of caregiver as it is often a new role for a man to take on (Akpınar et al., 2011; Sanders & Power, 2009). Baker et al. (2010) stated that men who reported decreased level of burden and who could find positivity in caregiving was due to their beliefs about masculinity. Men are more cautious when expressing their concerns and feelings, and men may not admit to having difficulties within the role (Akpınar et al., 2011; del-Pino Casad et al., 2012).
Poysti et al. (2012) speculated that males experience less distress in caregiving as they are unaware of community services, prefer family independence in caregiving and see caregiving as a task. Even if men are aware of community services, they feel that they are losing control if they access these services (Baker et al., 2010; Poysti et al., 2012). Men often possess a strong devotion to caring for their wives because they can reciprocate the love their wives gave them. Although this does not exclude them from negative effects associated with caregiving, it plays a role in their ability to remain a caregiver (Sanders & Powers, 2009). For example, with a sample of 17 husbands, Sanders and Powers (2009) found themes of adaption to new roles and changes in the relationship with the onset of dementia. In this qualitative study, men expressed the need to protect their wives not only in a physical manner but also in regards to their self-esteem. A sense of pride was noticed when men described their adaptation to the role of a caregiver as the husbands felt they were being useful, showing love, and showing commitment. In some cases, once men had to provide personal care, they were unable to remain the sole caregiver (Sanders & Powers, 2009).

The nature of care and coping skills. It has been suggested that the increased stress in female caregivers is a result of the comprehensive nature in which women approach caregiving, which leads to women using more services (Brazil, Thabane, Foster, & Bedard, 2009; Calasanti & King, 2007; Poysti et al., 2012). Poysti et al. (2012) added that men are generally more cohesive than women and seem to stick together with other caregivers, resulting in less distress. Hayes et al., (2009) stated that men provide more care in an instrumental way and women provide care in an emotional way. The
increased distress experienced by female caregivers has also been linked to the emotion based coping mechanisms employed by women rather than problem solving coping used by men (Akpiniar et al., 2011; Calasanti & King, 2007). McDonnell & Ryan (2013) added that this problem-solving coping style along with using available resources helped men create meaning in caregiving and to feel satisfied in the role.

**Context of Spousal Caregiving**

Other researchers suggest that it is the personal context of caregiving, not gender that is relevant for the caregiving experience (e.g., del-Pino Casado et al., 2012; Poysti et al., 2012). Research has shown that there are no differences between women and other family caregivers, including male spouses, in such outcomes as resilience, patience and relationships (Netto, Jenny, & Phillip, 2009; Raschick & Ingersol-Dayton, 2004; Rozario, Morrow-Howell, & Hinterlong, 2004). Additionally, in a cohort study of 335 dyads, Poysti et al. (2012) found that despite husband caregivers having more comorbidities and their wives having more severe dementia, they did not experience as many negative outcomes as female caregivers.

**Spousal Transition to Informal Caregiving**

The transition from the role of the spouse to caregiver when one spouse develops dementia is difficult for all couples, even those with strong healthy preexisting relationships (Davies, 2010; Evans & Lee., 2013; O’Shaughnessy et al., 2010). In a qualitative review of 23 studies, Evans and Lee (2013) found that the transition to caregiver is often described as a slow progressive process before a diagnosis had been made. Changes in the marital relationship are not always a linear process due to the
uncertain nature of the cognitive changes in a spouse with dementia. It was found that spouses felt both relieved and angry after a diagnosis, and that the transition was made easier or more difficult depending on the feelings surrounding the diagnosis. Evans and Lee (2013) also found there was a transition for one partner to the role of caregiver as well as a transition for the care recipient as they became a dependent individual where they were once independent. The caregiving spouse stepped up to new roles and responsibilities, while the care recipient stopped performing their normal everyday roles and responsibilities.

According to Adams and Sanders (2006), caregivers of people with dementia characterized the transition experience from spouse to caregiver by an increased level of burden after the initial diagnosis, with lower levels of burden in the middle stages of the disease and increased burden again with the terminal stages of disease. The transition to primary caregiver from primarily a spouse may be marked by events such as a formal diagnosis of dementia, or a move to a residential caregiving facility (Quinn et al., 2009). Quinn et al. (2009) suggested that with the push for early diagnosis of dementia by caregivers, the transition to caregiver is happening at an earlier stage than previously seen as spouses are forced to confront an earlier diagnosis. This end point of the transition process was perhaps best explained by Baxter, Braithwaite, Golish and Olson (2002) who stated it was like being a ‘married-widow’.

The transition to caregiver can change all aspects of the previous relationship (Harris et al., 2011). Spousal caregivers often feel like they are starting over with a new partner. Evans and Lee (2013) stated that spousal caregivers feel they are losing a spouse,
and with that, comes a loss of marriage. Existing literature suggests that the transition to
caregiver is accompanied by denial, delays in seeking a diagnosis, delays in seeking help
for themselves and the care recipient, anticipatory grief, and finally, acceptance of the
new reality (Harris et al., 2011; Hayes et al., 2010). In the early stages of dementia,
family members notice personality changes in their loved one and withdrawal from social
activities. Spousal caregivers often feel like they are starting over with a new partner.
Spouses often experience anticipatory grief due to the loss of intimacy and mutuality
between married couples when one partner has dementia. The uncertainty of being a
caregiver is often coupled with feelings of resentment and increases the level of
perceived burden (Harris et al., 2011).

**Spouses Find Meaning in Informal Caregiving**

Although caregivers are not always searching for meaning in caregiving, positive
experiences are often created by finding meaning in caregiving. In interviewing 11
informal caregivers, Shim et al., (2013) found that meaning can be discovered in the very
act of caregiving, in loving their spouse, or in being challenged to grow from the
experience. Spouses found meaning in the ability to keep their loved one at home and in
the commitment of marriage (Shim et al., 2013). Shim et al., (2013) also asserted that
husbands who cared for their wives could find meaning in caregiving as they felt they
were returning the love that was shown to them over the many years of marriage. By
expressing empathy and focusing on the needs of the care recipient, caregivers found
positive meaning in caregiving (Shim et al., 2012). Caregivers felt thankful for every
aspect of the relationship that they had left (Shim et al., 2012) and did not expect the care
recipient to reciprocate the time and effort they gave. This positive interpretation of caregiving arose when caregivers could accept their spouse’s disease and changes it brought to their relationship. As such, finding meaning in caregiving may not be a fixed trait but rather a choice, suggesting that caregivers may be able to transform negative meanings in caregiving into positive meanings in caregiving (Shim et al., 2013).

Evans and Lee (2013) stated that spousal caregivers of those with dementia exhibit less hope for the future than other spousal caregivers. O’Shaughnessy et al., (2010) found that couples had mixed feelings about the future; they sometimes felt accepting and realistic about the future while other times they felt unsure, fearful and uncertain. They were accepting of the disease processes but felt uncertain of the changes it would bring. Spousal caregivers often used denial as a coping strategy when faced with the overwhelming fear of the future. Evans and Lee (2013) stated that spousal caregivers have a fear of facing the future alone-- either by themselves, or with a partner who is not cognitively who they used to be. However, Evans and Lee (2013) stated that in looking towards the future, spousal caregivers could consider new social connections they may meet on their journey. Conversely, Davies (2011) stated that couples were able to face the future with a sense of being together with one another and holding their relationship in a positive light.

**Sexuality and Intimacy in Caregiving**

**Sexuality, Intimacy and the Older Adult**

Sexuality exists throughout the lifespan and individuals have the right to sexual expression (Rheaume & Mitty, 2008). While sex often refers to the actual physical act of
intercourse, sexuality encompasses much more including social and psychological aspects (such as relationships with others, mental connections, and feelings and emotions), individual beliefs, values, rights, sexual expression, pleasure and intimacy (Kessel, 2001; Rheume & Mitty, 2008). According to the World Health Organization (2006):

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors. (p. 5)

Moss and Schwebel (1993) defined intimacy as “the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal (although not necessarily symmetrical) relationship” (p. 33). This definition is suitable to caregiving spouses and care recipients with dementia because both spouses express the need for and want to give intimacy (reciprocity), but both may not be able to express it in the same manner due to the disease processes of dementia (therefore not symmetrical). Intimacy includes five different areas: commitment, mutuality, emotional intimacy, cognitive intimacy, and physical intimacy (Rheume & Mitty, 2008). Although intimacy can be shared between any people participating in a relationship (parent-child,
friend-friend), for the purpose of this study, the intimacy shared between spouses will be
the focus.

Stereotypes about sexuality and intimacy exist and it is commonplace to believe
that the older adult no longer has a need for sexuality and intimacy or that they become
asexual (Benbow & Beeston, 2012; Dourado et al., 2010; Heath, 2012; Ward & Manchip,
2013). While there is known to be a decline in sexual intimacy with increased age due to
loss of partner and health declines, older adults who remain in relationships are able to
express intimacy in other ways and remain physically and emotionally satisfied with their
partner (Davies et al., 2012). Santos-Iglesias, Byers, & Moglia (2016) found that having
a satisfying sexual life is an important component of an older adults’ quality of life and is
related to positive outcomes such as relationship satisfaction.

Ward and Manchip (2013) stated that although older adults may continue to
express their sexuality, they are often aware and conscious of the attitude and stereotypes
about this behaviour and may feel engaging in sexual expression is improper. Barriers to
sexuality and intimacy in the older adult include: lack of opportunity, lack of privacy,
negative attitudes of healthcare providers, lack of information and age-related conditions
in men and women (Rheaume & Mitty, 2008; Ward & Manchip, 2013). Harris et al.,
(2011) found that such barriers prevented certain spouses from being able to connect with
their partner emotionally and physically.

Literature has started to challenge these broad assumptions about sexuality and
intimacy in the older adult because sexuality and intimacy are basic human needs and
intrinsic to an individual’s sense of self and well-being (Heath, 2012; Rheaume & Mitty,
A study by SAGA Health in 2011 reported that 85% of participants aged 50 years and older had a decrease in sexual activity compared to when they were younger, but 61% described it as more fulfilling. Ward and Manchip (2013) echoed this finding by stating that their research found that sexuality is of interest to older adults and expressions of affection increase with age.

**Sexuality, Intimacy and Dementia**

The onset of old age or cognitive impairment does not erase the need for affection, sexuality and intimacy. According to the Alzheimer's Society of Canada (2010), an individual with dementia may show more interest in sex, less interest, or no interest, appear sexually aggressive due to loss of cognition, lose the ability to recognize interest of their partner, have changes in the ability to perform sexually, be irritable, and may appear depressed. The way in which people living with dementia express their sexuality and intimacy, and the way in which this expression is perceived by others may be altered (Benbow & Beeston, 2012; Dourado et al., 2010; Heath, 2012). In a study by Dourado et al. (2010), 28% of spouses caring for their partner with dementia reported a pre-existing sexual relationship with their partner. Kuppuswamy, Davies, Spira, Zeiss, & Tinklenber (2006) found that spouses reported a decline in sexual activity prior to the onset of dementia.

Sexual expression and advances made by individuals with dementia is often referred to as problematic or inappropriate, or named hyper-sexuality (Bamford, 2011; Ward & Manchip, 2013). It is important to recognize that while behaviour by an individual may be labeled as inappropriate, it may be because the behavior offends one’s
attitudes and beliefs, and perhaps appears offensive without knowing the context of the behaviour. For example, Bamford et al., (2011) presented a case study where an individual would undress at the same time every day, regardless of location. While this was seen as inappropriate, it was due to the professional sport that the person had been involved in and the schedule was to change clothes at this time due to the training schedule.

A diagnosis of dementia for one spouse has a major impact on a marital relationship, companionship, and sexuality and intimacy between one another (Beart, 2008; Dourado et al., 2010; Evans & Lee., 2013). It contributes to changes in sexual activity, decreased marital intimacy and causes an inversion in family roles (Dourado et al., 2010). In a mixed method study of 36 couples in which one has varying degrees of impairment related to dementia, Dourado et al. (2010) found that nearly 64% of care recipients and 56% of caregivers reported that they engaged in sexual activity. Thirty-three percent of caregivers reported that the disease process affected their spouse’s ability to understand the sexual relationship. There was a statistically significant relationship between those spouses who were sexually dissatisfied and the degree of impairment from dementia in their spouse, such that those caregivers whose spouse had mild dementia were more sexually dissatisfied than the other groups. The couples included in this study as well as those in a qualitative study by Kuppuswamy et al. (2006) identified erectile dysfunction and loss of female sexual desire as the cause of decreased sexual activity and satisfaction. It is also common for the care recipient to blame their caregiving spouse for their changed sexual relationship (Kuppuswamy et al., 2006).
From an ethical standpoint based on the principle of respect for individuals and their right to privacy, intimacy cannot be forced on an individual even if they display signs of needing/wanting human contact (Mattiasson & Hemberg, 1999). In caregiving, there is a type of intimacy that cannot be avoided due to the tasks associated with caregiving and it lies in the space between privacy and personal space (Rheaume & Mitty, 2008). Simonelli et al. (2008) compared a group of 50 dyads consisting of a caregiving spouse and a care recipient with dementia and a control group of 50 dyads consisting of healthy spouses (i.e., no cognitive impairment). They found no differences between the groups in relation to the love they have and felt with their spouse, but there were statistically significant differences in satisfaction with their affective and sexual lives (with those with healthy spouses feeling more satisfied). This difference may be attributed to the higher burden degree associated with the degenerate nature of dementia.

Similarly, in focus group study of 14 dyads, Davies et al., (2012b) found that the spouses of those with dementia felt more burden and had a greater change in relationship aspects, such as communication and cohesion, than the spouses of those with mild memory impairment (MMI). Both groups experienced a loss of affection from their spouse, and while both groups expressed worries about the future, the spouses of those with MMI seemed to have better outlooks and coping mechanisms. A study by Davies et al. (2012b) found that spousal caregivers and the care recipient with Alzheimer’s disease reported continuing with physical intimacy at least once a week and the frequency and type of intimacy did not vary based on gender.
Intimacy is important for both members of the relationship to build self-identity, emotional closeness, trust, and to validate self-worth (Hayes et al., 2010). The self-identity of the care recipient is changed due to the loss of cognitive functioning and when this occurs, the self-identity of the spouse must change as well (Adams, 2006; Hayes et al., 2010). Due to the loss of intimacy, the self is often lost and the caregiver has difficulty validating their worth as a person and a caregiver (Hayes et al., 2010). For spousal caregivers, the self-identity of caregiver often overshadows the other parts of themselves such as their sexual and intimate self (Drummond et al., 2013; Harris et al., 2011; O’Shaughnessy et., 2010). The caregiving role is all encompassing, leaving little room in one’s life for sexual and intimate expression. That is to say that sexuality and intimacy often get pushed aside due to all of the other necessary caregiving duties, such as keeping their spouse safe, helping with everyday activities and cleaning up after them (Drummond et al., 2013).

Intimacy can be difficult in a relationship when one partner has dementia and the other is acting as a caregiver, Harris et al. (2011) interviewed caregiving spouses who reported that although they tried to maintain an intimate relationship with their spouse, it was difficult due to the ambivalent and disinterested attitude of their partner. Evans and Lee (2013) also found that spousal caregivers felt lonely in their marriage as the level of closeness and companionship had decreased or disappeared. Similarly, through interviews with 20 spousal caregivers, Adams (2006) found that spousal caregivers reported feeling closer and more protective of their spouse with dementia, but also had less interest in sexual relations because the care recipients’ judgment was impaired.
Spousal caregivers have also stated that sexual intercourse was not a part of their relationship prior to caregiving, and if it was, the care recipients were no longer interested in sexual intercourse. Some caregiver spouses spoke about trying to maintain a sexual relationship but were faced with rejection, which led them to feel like giving up (Drummond et al., 2013).

Intimacy between caregiver and care recipient is experienced differently between husbands and wives. Men have reported feelings of sadness when they lost intimacy with their wife, while women have reported feelings of anxiety with the loss of intimacy (Dourado et al., 2010). Men have reported difficulty in knowing if the wife is consenting to intimate and sexual acts or if it is an altered state due to the dementia (Davies, 2010; Harris et al., 2011, Hayes et al., 2010).

Women often struggle to be intimate with a husband who they feel they are “mothering” due to the caregiving role and the perception that their husband no longer resembles the person they once knew (Davies et al., 2010; Harris et al., 2011; Hayes et al., 2010). Many women have reported that they did not want to initiate intimacy or sexual activity as they did not have the stamina or energy after the tasks of caregiving (Dourado et al., 2010). Drummond et al. (2013) went on to describe intimacy a key component in creating a positive caregiving experience for women, as they may feel rewarded in maintaining physical and emotional closeness with their partner. Some female spousal caregivers also reported that the societal idea that older women are asexual or undesirable added to their feelings of wanting to give up on sexual and intimate acts (Boylstein & Hayes, 2011; Drummond et al., 2013; Harris et al., 2011).
However, some participants stated that they wished there was more sexuality and intimacy present in their relationship. Spouses also reported that the care recipient needed increased emotional attention, and showed this by asking “do you love me?” or wanting to be held or close to their spouse, which lead to caregivers feeling that intimacy remained in their relationship.

**Coping with Changes in Sexuality and Intimacy in the Caregiving Relationship**

Although sexual activity may disappear or decline, intimacy and affection can be expressed in other ways. Spouses had close relationships with friends and tried to maintain parts of the relationship with their spouse. Some caregiver spouses reported expression of affection towards themselves by engaging in relationships with others or taking time for themselves (Drummond et al., 2013; Sanders & Powers, 2009). Affection can be expressed between spouses through hugging, holding hands, cuddling and doing nice things for each other. Spousal caregivers can also rely on their memories of the intimacy once shared with their spouse to feel calm in times of distress. Even though the spouse’s memory often was no longer intact, intimacy expressed between couples may act as a bridge to the past (Harris et al., 2011). Some women have described sexual acts that were still existent in the relationship as more than simply a form of pleasure, it meant that both spouses are in a good mood and are happy (Drummond et al., 2013).

When the caregiving spouse is able to separate the symptoms of the disease from the personhood of their spouse, they are better able to relate to their spouse in an intimate way (Harris et al., 2011). Early therapeutic intervention is recommended to help spousal caregivers modify activities, behaviours, and expectations about the future of the
relationship. These modifications may help maintain relationship satisfaction, decrease burden, preserve quality of life, and delay time-to-placement in a care facility (Davies, 2010; Davies et al., 2012b). Spousal caregivers have identified a need to express their concerns about intimacy, but it is rarely discussed with the care recipient, friends and family, and healthcare providers alike. A discussion about sexuality and intimacy is often an uncomfortable topic in society and spousal caregivers have felt the impact of this discomfort (Drummond et al., 2013; Rheaume & Mitty, 2008).

**Summary and Critique of Existing Literature**

Through a quantitative lens, many existing studies focus on the degree of caregiver burden, effect of social support on the caregiving relationship, health of caregivers, and factors predicting the institutionalization of the care recipient. Current literature about caregivers of those with dementia has also largely focused on female caregivers. With women accounting for two thirds of people living with dementia, the prevalence of male caregiving is starting to increase so caregiving is no longer exclusively a women’s role. Men, however, are historically under-represented in the caregiving literature (Alzheimer’s Association, 2014).

Current research has largely focused on the problematic sexual behaviors that arise when an individual has dementia and is living in a residential care facility; prevalence of sexual dysfunction (e.g., erectile dysfunction) among individuals with Alzheimer’s disease, and changes in sexual behaviour (Black, Muralee, & Tampi, 2005; Davies et al., 2012; de Medeiros, Rosenberg, Baker, & Onyike, 2008;). Some researchers have looked at how Alzheimer’s disease affects intimacy in spouses in the context of
caregiving (Hayes et al., 2011; Davies et al., 2010b; Harris et al., 2011). Findings from such studies suggest that caregivers struggle with the ethics of engaging in intimate acts as they once did with a partner who no longer recognizes them or becomes confused.

There is little known about the impact of intimacy and sexuality in caregiving and how spousal caregivers use intimacy to form meaning in the context of caregiving, especially from the perspective of male spousal caregivers. Research has suggested a need for the importance of studying this lived experience of caregivers for a more holistic understanding of the challenges caregivers deal with instead of focusing on their stress-coping methods (O’Shaughnessy et al., 2010; Shim et al., 2013). Caregiver experiences can be vastly different even if they are exposed to similar situations and circumstances, depending on how a caregiver interprets and constructs meaning in caregiving. It is also clear from this review of the literature that intimacy between caregiver and care recipient is experienced differently between husbands and wives. Thus, focusing on gender is critical to understand how men cope with the caregiving experience including the strategies they use and challenges they face.

From this review of the literature, it is clear that informal caregiving places a great strain on spousal caregivers and may be detrimental to their health and well-being. Since satisfaction with sexual and intimate acts is linked to health and well-being of adults (Woloski-Wruble, Oliel, Leefsma & Hochner-Celnikier, 2010), it is important to understand how caring for a spouse with dementia impacts sexuality and intimacy in the context of the spousal relationship and how this in turn shapes the caregiving lived experience of spousal caregivers. More research about sexuality and intimacy between
spousal caregivers and care recipients has the potential to contribute to the quality of life for both individuals (Harris et al. 2011). For example, intimacy shared between spouses seems to act as a buffer for the negative consequences of caregiving on the health and well-being of the caregiver (Harris et al., 2011). Further, if spousal caregivers can be supported to maintain their sexual and intimate self-identity, they may be able to engage in the caregiving role for longer periods of time. This may mean the care recipient could live at home longer, and as a result, part of the strain on the health and social care systems associated with the care people with dementia may be reduced.

With a lack of research about satisfaction with sexuality and intimacy, it is difficult to draw conclusions about how to help couples optimize their satisfaction. Therefore, this study will explore how caregiving spouses of those with dementia experience and understand their role as caregivers, and how this role impacts their role as sexual and intimate beings. The study will ask spousal caregivers how the lived experience of caregiving and the health risks associated with it affect their own sexuality and intimacy and sexuality and intimacy with their partner. Examining this lived experience may help identify ways to support spousal caregivers to address meeting intimacy and sexuality needs.

**CHAPTER THREE: METHODOLOGY AND METHODS**

**Introduction**

Chapter three will describe the methodology of the research study and method used. In the methodology section, I will describe the philosophical framework of
phenomenology. In the methods section, I will describe sample, sample size, setting, data collection, and data analysis. Criteria for establishing methodological trustworthiness and ethical issues are also discussed in this chapter.

**Methodology**

The methodology section of this chapter will introduce the reader to the history of phenomenology and appropriateness of phenomenology for this study. By immersing oneself in the philosophical underpinnings of a research methodology, a researcher is able to find the appropriate methodology for the question of interest (Starks & Trinidad, 2007).

**Qualitative Research Methodologies**

Qualitative research methodologies enable researchers to explore questions of meaning, view topics from a sociocultural point of view, examine processes in society and in institutions, develop a theory to explain processes humans go through, or increase sensitivity to a topic or issue (Melyn & Fineout-Overholt, 2011; Starks & Trinidad, 2007). Historically, qualitative research methodologies have been described as placing low on commonly referenced hierarchies of evidence (Gallagher, 2012). Qualitative research is essential when little is known about a topic, or when the topic is known but lacks depth and detail (Melyn & Fineout-Overholt, 2011; Starks & Trinidad, 2007).

There are several qualitative research methodologies, one of which is called phenomenology. There are three types of phenomenology: interpretive, descriptive, and combination phenomenology. Edmund Husserl was the pioneer of descriptive phenomenology and his student Martin Heidegger drew on his foundations to extend into
the realm of interpretive phenomenology (Gallagher, 2012). Descriptive phenomenology has its roots in epistemology and examines the study of how individuals come to know the world they live in, while interpretive phenomenology takes an ontological approach to the lived experience of how individuals experience being in the world (Dowling, 2007). Max van Manen’s phenomenology is a combination of interpretive and descriptive phenomenology (1997). For this study, I will describe how phenomenology will make a valuable contribution to what we know about the lived experience of spousal (men) caregivers of those with dementia and how they ascribe meaning to their intimate and sexual self through this experience.

**History of Phenomenology**

Phenomenology has its roots in the 18th century as a critique of positivism (Gallagher, 2012; Starks & Trinidad, 2007). Positivists attest that the complex can be best described in its basic components and supports reductionism and mechanistic principles (McEwen & Wills, 2011). Phenomenologists were critical of natural sciences and positivists for assuming that an objective reality exists independent of individual consciousness (Gallagher, 2012), as objectivity does not allow research participants to articulate their individual lifeworld or experience of an event.

Phenomenology is closely associated with Eastern philosophy in the early 1900s, most notably the works of German philosopher Edmund Husserl and his student Martin Heidegger. Phenomenology is not only a philosophy but also a research method used to capture the lived experience of individuals through textual expression (Reiners, 2012). Phenomenology is the study of essences which are extracted through studying the human
lived experience (Melynk & Overholt, 2011; Gallagher, 2012) and is used when the goal is to gain an understanding of an experience (Melynk & Overholt, 2011; Reiners, 2012). Lived experiences can be perceived on a variety of dimensions and are unique to everyone. Often the phenomenological statements that appear in research are obvious and they are not necessarily new information, but remain important as researchers often explore for deeper meaning-- such as in meanings of everyday human life (Sokolowski, 2000). This speaks to the importance of recognition of the subjectivity of the lived experience, and that phenomenological interpretations cannot be generalized.

Phenomenology involves the use of thick description (Hesse-Biber & Leavy, 2012; Reiners, 2012; Wears & Karsh, 2007). Thick description speaks to a nuanced description of not only the lived experience in of itself, but also the context of that lived experience. This description allows an outsider to understand how meaning is created and to also understand the common features of an experience (Hesse-Biber & Leavy, 2012; Reiners, 2012; Wears & Karsh, 2007).

The goal of hermeneutic (interpretive) phenomenology, as described by van Manen (1997), is to come to an understanding of the lived experience and capture it through interpretation so that we can grasp its significance (van Manen, 1997). To gain a full understanding of the lived experience, van Manen (1997) stated the experience must be described as well as interpreted. To truly understand both descriptive and interpretive phenomenology, the work of Edmund Husserl and Martin Heidegger will be discussed.

**Edmund Husserl (Descriptive Phenomenology)**
Edmund Husserl (1859-1938), a German philosopher and mathematician, is considered the father of phenomenology (Gallagher, 2012). He developed a philosophy in which mind and matter could not be separated, as human consciousness is present in all things (Dowling, 2007; Gallagher, 2012). The inspiration for Husserl’s work came from Franz Brentano (Moran, 2000). Husserl adopted Brentano’s concept of intentionality as the fundamental core to understanding and classifying conscious acts (Moustakas, 1994). Intentionality is the principle that every mental act (memory, imagination, emotion and perception) is related to some object (Moran, 2000). An experience involving memory, imagination, emotion, and perception was what Husserl thought to comprise intentionality. Related to intentionality, Husserl believed consciousness is always intentional and purposeful and it has meaning (Hesse-Biber & Leavy, 2012). It is the internal experience of being conscious of something, which cannot be separated from our being.

Husserl developed descriptive phenomenology, in which every day experiences are set aside- the researcher sets aside their previous experiences and current potential biases (Melynyk & Overholt, 2011; Reiners, 2012). Husserl was interested in how an individual perceives reality, how someone thinks about an experience, or how they perceive consciousness (Gallagher, 2012; Reiners, 2012). By understanding how people perceive experiences, we can develop insight into how individuals create understanding of society (Hesse-Biber & Leavy, 2012). Husserl believed that the fundamental source of knowledge was from experience (Dowling, 2007) and that the description from a human about a certain experience would be a universal description (the essence) (Wojnar, &
Swanson, 2007). Husserl attested that there was no need to search beyond the data as the experience is described as what it is and as it is lived (Lavetry, 2003).

With many hermeneutic and existential phenomenologists rejecting Husserl’s notion of transcendental phenomenology (that phenomena can simply be reduced to its parts), Husserl revisited this idea and began to refer to the lived experience as the lifeworld (Dowling, 2007). Husserl argued that the lifeworld is understood as what individuals experience pre-reflectively; that is, before we have had a chance to understand it or apply means to help explain it (Dowling, 2007; Gallagher, 2012; Hammond, Howarth, & Keat, 1991; Reiners, 2012). This means that attempts to understand the lived experience should be free of biases from the person trying to understand it (Dowling, 2007; Hammond et al., 1991).

Husserl maintained that bracketing is necessary to reduce your pre-assumptions and judgments about an experience or phenomena (Dowling, 2007; Hammond et al., 1991). According to Husserl, personal biases interfere with achieving pure consciousness (Wojnar, & Swanson, 2007). For a researcher to arrive at an unbiased understanding of the lived experience, all previous feelings and suppositions related to their consciousness must be suspended (Dowling, 2007). Husserl believed this suspension allowed the researcher to view the experience through a new lens (Melnyk & Fineout-Overholt, 2011). The process whereby researchers reflect on their own emotions, feelings and beliefs about a situation, and set them aside is called phenomenological reduction or bracketing (Dowling, 2007; Melnyk & Fineout-Overholt, 2011). Husserl believed that through bracketing a researcher could gain insight into the common features (the essence)
of the lived experience (Wojnar, & Swanson, 2007) and yield essential or universal knowledge of consciousness (Melnyk & Fineout-Overholt, 2011).

**Martin Heidegger (Interpretive Phenomenology)**

Martin Heidegger (1889-1976) was a student of Husserl and also a German philosopher (Dowling, 2007). With influence from the Danish thinker Soren Kierkegaard, Heidegger was one of the first phenomenologists to combine existential matters with phenomenological methodology (McConnell-Henry, Chapman, & Francis, 2009). Heidegger agreed with Husserl’s thought that experiences needed to be valued for what they are, but did not agree with his view of the importance of description over understanding (Dowling, 2007). Heidegger rejected the theory of knowledge and focused on the science of being by advocating for the use of hermeneutics as a research method. He focused on the ontological view that the lived experience is open to interpretation (Dowling, 2007).

Heidegger believed that the primary phenomena of concern was the meaning of being, and used the phrase “being-in-the-world” to refer to the way humans exist and are involved in the world (van Manen, 1997). He believed in being-in-the-world, not simply knowing the world. Heidegger proposed that humans could not remove themselves from their experiences (bracket), and still give meaning to and name those experiences (Wojnar, & Swanson, 2007). By incorporating hermeneutics, researchers can look beyond the description of the core parts of experience and find meaning in everyday experience (Reiners, 2012). Heidegger maintained (and contradicted Husserl) that
consciousness is not separate from the world of human existence (Dowling, 2007). This means that people could not be separated from the world in which they lived.

Whereas context was a peripheral thought for Husserl, context was central to Heidegger as he believed humans were inseparable from their lifeworld (Wojnar, & Swanson, 2007). Heidegger’s phenomenology takes a broader look at social influence, political influence and cultural contexts that add meaning to the lived experience (Wojnar, & Swanson, 2007). Heidegger asserted that individuals come to an experience with a background or familiarity, and their sociocultural background gives a frame of reference to an experience and acts as a basis of what might be found in the individuals lived experience (Dowling, 2007; Hesse-Biber & Leavy, 2012; Wojnar, & Swanson, 2007). These factors all lead to the ability to interpret a lived experience.

By using the hermeneutic circle, the researcher is able to address their own influences on the interpretation of the phenomena (lived experience) instead of bracketing them, as suggested by Husserl. The hermeneutic circle is the process of understanding a text, and refers to gaining understanding a text as a whole by looking at the individual parts of one’s understanding of each individual part with reference to the whole (Lavetery, 2003). In the hermeneutic circle, interpretation is based on an understanding of the lived experience from prior interpretation (Lavetery, 2003). The hermeneutic circle requires researchers to engage in reflection of their interpretation of the lived experience, and requires the researcher to continually revisit their own interpretation of the lived experience as it essence develops.

van Manen’s Approach (Descriptive and Interpretive Phenomenology)
Max van Manen’s phenomenology combines the epistemological (descriptive) work of Husserl and the hermeneutic (interpretive) work of Heidegger. van Manen’s research method focuses on unraveling the meaning of the lived experience (Dowling, 2007). van Manen uses a human science approach to phenomenology, and offers some solutions to researchers using this method as it continually undergoes changes as interpretation of a lived experience evolves (Dowling, 2007). Human science requires concepts, methods and theories that are fundamentally different than those of natural sciences; human science studies human life by understanding the lived experience (McEwen & Wills, 2011). van Manen’s methodology includes description, reduction, essences, and intentionality (Wojnar, & Swanson, 2007). These concepts are involved in the description of the participant’s experience. The aim of van Manen’s phenomenology is to produce insights into human experience. He believes the focus is on the phenomenon, while the outcome is a written construction which explains the meaning of human phenomena and leads to understanding the lived experience of meaning (Dowling, 2007). van Manen’s approach to phenomenology includes the descriptive side of Husserl’s work, but also incorporates the need for interpretation when examining the lived experience (Dowling, 2007). Like Heidegger, van Manen does not believe bracketing is realistic because it is not possible to remove oneself from an experience as a persons’ own assumptions may remain present without awareness (Dowling, 2007).

Derived from Heidegger’s idea “being-in-the-world”, the existential aspects of the lifeworld incorporate the concept of pre-understanding of hermeneutics and acknowledge the experience of a phenomenon as a whole experience (Dowling, 2007). The four
existential aspects of the caregiver’s lifeworld are: 1) lived space (spatiality), 2) lived body (corporeality), 3) lived time (temporality), and 4) lived human relation (relationality or communality) (Dowling, 2007; Max van Manen, 2011). Lived space describes how space affects the way individuals feel (Dowling, 2007). In this study, when spouses became caregivers, the feeling of “home” may have been replaced with a feeling that this once safe space is now different with a focus on caregiving and burden. Lived body refers to the fact that we, as humans, are inseparable from our bodies (van Manen, 1997). Caregivers are likely to neglect their own needs when caring for a spouse with dementia, and perhaps experience the loss of the shared intimacy and sexuality that used to exist and give comfort and conformation of personhood. For van Manen (1997), lived time is subjective, while for spousal caregivers lived time may represent the loss of time for personal tasks due to the time required for caregiving. They may feel also that their time involves grieving as their loved one is “slipping away”. Lived human relation represents the way in which individuals shape and frame their experience (van Manen, 1997). Lived human relation can also be about the interactions with others and the relational space (van Manen, 1970). For spousal caregivers, the caregiving relationship may affect how they perceive their intimate and sexual self.

**Research Methodology**

Because of the subjective nature of the lived experience, a qualitative research design/methodology was used, interpretive phenomenology. This study examined the meaning spousal caregivers ascribe to sexuality and intimacy in relation to caring for a spouse with dementia and it therefore attempted to capture their voices as they reflected
on individual lived experience and interpreted the meaning of these lived experience. The research process was guided by van Manen’s (1997) six methodological themes. These six themes included the following: (1) choosing a phenomenon of interest to the researcher; (2) investigating the experiences as individuals live them; (3) reflecting on the themes of the phenomenon; (4) describing the phenomenon through writing; (5) maintaining an orientation to the phenomenon; and (6) balancing research context by considering parts of the whole. These steps guide researchers when reviewing literature to capturing themes from the analyzed data. Consistent with using van Manen’s method, the research process was not linear as the research activities occurred simultaneously.

**Appropriateness of van Manen’s Approach**

van Manen’s phenomenological approach was appropriate a good fit for this study. The lived experience of spousal caregivers of individuals living with dementia and the impact this role has on their intimate and sexual self had not been adequately investigated. This, as evidenced by literature reviews conducted in preparation for this inquiry, is necessary in order to sustain caring at home for those with dementia. Satisfaction with sexuality and intimacy for spousal caregivers can increase health and well-being in the older adult, but can often be lost when assuming a caregiving role, contributing to potential decline in caregiver's health (Alzheimer Disease International, 2010). van Manen’s (1997) approach is helpful when the researcher’s intent is to understand the lives of the individual caregivers within their own context, and to derive the meaning from this lived experience (van Manen, 1997).

**Developing a Research Question**
In keeping with van Manen’s methodological theme, turning to a phenomenon of interest, an extensive literature review was completed prior to conducting this study. For van Manen (1997) stated that the lived experience occurs in a person’s lifeworld before the experience undergoes reflection. Such reflections lead to finding meaning in an experience. The experience must be reflected upon. To orient to the phenomenon, the researcher needs to identify an interest in finding meaning in the lived experience being examined. Developing the phenomenological question required reflection on the researcher’s personal experiences. In van Manen’s (1997) words, the researcher in this way develops the question by “living” and “becoming” the question. Since the researcher’s interest caregivers for those with dementia stems from personal and professional experience, the following question resulted from these reflections: What is men’s lived experience of sexuality and intimacy in their relationship with their spouse with dementia?

Sample and Setting

The researcher turned to the phenomena of interest (the first step in van Manen’s six phenomenological steps) by determining the sample, setting and recruitment process. Participants were selected using purposeful sampling, wherein the researcher searched for informants who would be able to provide perspectives relating to the research question (Melnyk & Fineout-Overholt, 2011). All participants were men who provided informal care to their female partner who had dementia. Inclusion criteria also focused on the care recipient who could either being alive or deceased, but the caregiver needed to have acted in this role at some point during their partner’s illness. Participants needed to speak and
read English. van Manen does not indicate a specific sample size for his method. Three participants were in this study. Data collection occurred at a location and time that was convenient for the participant and researcher. Care was taken to use a location that was private, safe and free of interruptions (Melnyk & Fineout-Overholt, 2011).

**Recruitment**

Many attempts were made to recruit participants. Study posters were placed in family physician offices in the both Ontario and New Brunswick, (see Appendix A/AA) but participants were recruited in only New Brunswick. The poster described the research project and gave my research contact information. Presentations were made to members of support groups organized by the Alzheimer Society. Social media was used as a means to advertise and recruit for the study. Individuals interested in participating in the study contacted the researcher by phone or email for more information about the study and to determine their eligibility for study participation. Three participants were successfully recruited through word of mouth. Recruitment of these participants will be further discussed in the discussion chapter.

**Data Collection**

To begin the process of engagement, I developed a demographic form to gather useful data related to the context of the participant and their spouse with dementia (see Appendix B). This demographic form was designed specifically for this research study. Participants were successful in completing this demographic form in five minutes.

Consistent with van Manen’s approach to phenomenology, the major source of data collection for this study was interviews. Through interviewing participants, I
engaged in the second step of van Manen’s (1997) six methodological themes--
investigating experiences as they were lived. van Manen (1997) argued that deciding on
the type of interview needs to be determined by the question that prompted the study in
the first place. Since the purpose of interviewing was to explore the meaning of the lived
experience of intimacy and sexuality in the caregiving relationship, a semi-structured
interview technique was used. Open-ended, semi-structured interviews allowed
participants to focus on areas that are important to them. I also used probing questions
throughout the interview to further develop the essence of the lived experience of the
participant. Fielding and Thomas (2001) stated that probing is key to interviewing, but it
needs to be used sensitively as to not cause discomfort in the participant. My role in the
interviews was to guide the discussion and help the participant stay focused (van Manen,
1997).

The interviews were audio recorded and later transcribed. Interviews were on
average 60 minutes, which is the typical length of a semi-structured interview (Hansen,
2006). The interview questions were formulated based on a literature review and the
study’s research question (see Interview Guide in Appendix C). The interview questions
were developed to tap into the existential aspects of caregivers’ lifeworld, making it
possible to understand the human experience that is lived and shared when persons are caring
for a spouse with dementia (Dowling, 2007).

I made field notes immediately after the interview. These notes were essential for
reflecting on the interview and on how the next interview could be adjusted to be more
effective. The field notes were used as a second source of data collection. These notes
included non-verbal cues that were present throughout the interview, as well as important phrases that the participant stated. I also kept notes about my own personal feelings or biases about participant responses, and I set them aside until reflecting on the interview, van Manen (1997) argued that it is important for the researcher to see the experience as it is lived. I interpreted the meaning of the lived experience and developed a description of the experience in keeping with van Manen’s methodology. van Manen (2007) believed that the researcher needs to reflect upon their own experience, values and beliefs to become aware of the meaning and influence of her own experiences. However, van Manen questions that a researcher can completely bracket their presuppositions since individual assumptions may endure without the researcher’s awareness (Dowling, 2007).

Interviewing may positively impact the coping of caregivers if performed ethically and in a sensitive manner (Funk & Stajduhar, 2009). Some participants report therapeutic benefits being interviewed and to talk about their personal experiences (Lowes & Gill, 2006). Congruent with the philosophy of phenomenology, interviewing and talking about the lived experience has been shown to validate participants’ feelings and provide opportunities for self-reflection, growth along with a sense of purpose and empowerment (Corbin & Morse, 2003; Lowes & Gill, 2006). It is important that the interview is concluded properly by giving closure to the interview (Jackson, Daley, & Davidson, 2008). I concluded each interview by thanking participants for their time and for sharing their experience. Abrupt endings were avoided so that if the participant had anything to add they were invited to do so. I asked concluding questions regarding what motivated the participant to enroll in the study, if they found the experience beneficial
and if there was anything they would like to add. Throughout the interview, if emotional responses were present, I supported the participants by listening and being present in those moments.

**Data Analysis**

In using van Manen’s phenomenology, the researcher used the self as a starting point, and used reflection and intuition to illuminate themes during data analysis (Dowling, 2007). I reflected at length on the completed interviews and the transcribed data. I spent a lot of time immersed in the data simply reflecting on the experience and what was said by the participant as I started data analysis. I also used intuition as I listened to and observed subtle non-verbal cues from the participants which I made notes on immediately after the interview. Data analysis occurred concurrently with the collection of data. As interviews were completed, transcribed, and analyzed, I continued to recruit participants. By entering the hermeneutic circle, the researcher is better able to interpret and understand the meaning of text (Kvale, 1996). There are three steps in the hermeneutic circle: naive reading (reflecting on the essential themes), structural analysis (describing the phenomenon through writing and rewriting) and comprehensive understanding of the whole (considering the parts and the whole) (Kvale, 1996). In the naive reading, the text is read multiple times and the researcher remains open to new themes to emerge from the text (Lindseth & Norberg, 2004). For the structural analysis, I used van Manen’s (1997) selective highlighting approach to isolate themes from the collected data about the lived experience of sexuality and intimacy of husband caregivers of spouses with dementia. Using this approach, I searched for themes and highlighted
sentences that stand out about the lived experience. These themes were then reflected on in reference to the naive reading of the text (Lindseth & Norberg, 2004). For example, the initial themes that emerged were “overcoming negative experiences” and “a new normal”. After more immersion in the data and back and forth with my supervisor (which includes the structural analysis) the themes became “caregiver first” and “a new form of intimacy” which encompassed the ideas from the first themes that emerged. In the last step of the hermeneutic circle, all themes were reflected upon in relation to the research question and the specific study (Lindseth & Norberg, 2004). Themes were written and rewritten to develop a meaning of the lived experience by using the hermeneutic circle. During the analysis, there was a constant back and forth process between reviewing the data and interpreting and describing the lived experience.

**Trustworthiness**

The model of rigor used in this study was that of Lincoln and Guba (1985). This model addresses four components of trustworthiness that are relevant to qualitative research: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability.

Credibility is the element of trustworthiness that allows a reader to trust and recognize the experiences that are contained within the research from participants’ direct experiences (Lincoln & Guba, 1985). The description of the experience by the researcher was one that others who have lived a similar experience would have been able to recognize. I simultaneously wrote the findings of the research while interviewing other participants. Immersing myself in the data and using the participants’ exact language in the description of the experience to strengthen the credibility of the study. I used many
direct quotes to describe the essence of the lived experience and in the themes that describe the essence.

Transferability refers to how applicable the research findings of the experience are in other contexts with similar participants (Lincoln & Guba, 1985). One way in which I established transferability was by collecting and reporting demographic information of the participants and their spouses. By collecting this information, we have a clear idea of who the participants were and therefore can perhaps apply to others of similar demographic. Transferability can also refer to the method used for the research study, in that the description of the method would be applicable to another study. This can be accomplished with an in-depth description of phenomenology.

Dependability is achieved if another researcher is able to follow the process used by the researcher throughout the study. This process is often called an audit trail (Lincoln & Guba, 1985). This was achieved by describing the purpose of the study, discussing how the participants were selected, describing the data collecting methods, describing how common themes were pulled from the research findings, and describing the methods used for rigor.

Confirmability is achieved when the other aspects of trustworthiness have been completed. The researcher has to have a self-reflective attitude throughout the process to show how the researcher’s own perceptions might impact the study (Lincoln & Guba, 1985). I used field notes after each interview to write about personal feelings and biases.

**Ethical Issues**
Ethical approval was obtained from the University of New Brunswick’s Research and Ethics Board before commencement of data collection. There was no known risk to participants but it is important to consider that when interviewing caregivers, there is risk of them feeling guilty, feeling they betrayed their loved one's trust, or exposing a sense of failure as a caregiver (Aronson, 2003). As a result, it was important for me to be aware and sensitive to causing the participant disruption to the participant in the interview process (Funk, 2009). When interviewing participants about their lived experience, I was conscious of the possibility of unintended harm to the participant. It was possible that the participant had perhaps not previously processed their feelings and may have felt unexpected grief or negative feelings experienced in the interview process (Bloom & Crabtree, 2006). As a nurse, I was educated to be aware of person’s response and the risks to their well-being. If I sensed any discomfort from participants, participants had the option to stop the interview and restart when, or if, they felt comfortable to do so. This did not occur in the three interviews. Two men expressed grief emotions during the interview but they did not need to stop the interview. At the end of the interview, there was a debriefing which included an opportunity for participants to ask questions. I offered participants a list of resources in the community that they might find helpful (e.g., support groups). None of the participants were interested in having this list (see Appendix D).

**Informing Participants**

Once potential participants expressed interest in the study, I contacted them by telephone to explain the study, determine study eligibility, and set up an interview.
Individuals who expressed interest in being interviewed met with me at a time and place that was convenient and safe in person, and in one instance, by phone. The nature of the inquiry was further explained in the study’s information letter and consent form, given to the men at the time of the interview (see Appendix E & F). They were made aware that their participation was voluntary and that they could withdraw at any time without risks. Participants also were informed that they could stop the interview at any time, and continue only if and when they were ready. They were informed that they could decline to answer any questions during the interview. Participants were made aware that there were no perceived risks and benefits of participating. In the information letter, it was clarified that if any information was disclosed that indicated harm to others (e.g., elder abuse) that I, as a nurse, was required to report this information. Participants were given the information letter in person, or via email, prior to the interview, and reviewed at the time of the interview.

**Consent**

Informed consent was obtained prior to interviewing the participant. By obtaining informed consent without threat or persuasion, the researcher ensured the autonomy of the participant (Hewitt, 2007). Participants received written information about their participation in the study via phone before the interview and in person before the start of the interview. I emailed the study’s information and consent form to the one participant who was not available to meet in-person. All participants were offered an opportunity to ask question and sign the written consent form before any data collection was initiated.
The participant who was not available to meet in person gave his consent over the phone via audio recording.

**Private Information and Data Security**

I listened to and transcribed the digitally-recorded interviews, removing any identifiable information so as to maintain the confidentiality of the participants. Only I had access to the anonymized transcriptions for the analysis. Additionally, I coded each interview transcript with a code number so as to avoid linking data with participant names.

All research information including signed consent forms and research notes are stored in a secure, locked drawer (in my own office) to which only my supervisor and I have access. Signed consent forms are stored separately from interview data in order to maintain confidentiality. The interview recordings were permanently removed from the digital recorder after the interview was transcribed. An electronic copy of the study data is stored on my password protected computer file for a period of 1 year until research analysis has been completed. All recordings are saved in the cloud on a password protected account for 7 years from the time of data collection. Only my supervisor and I were involved in analyzing the data, from which all names and other identifying information have been removed.

**Chapter Summary**

This interpretive phenomenological study was designed to gain an understanding of the lived experience of sexuality and intimacy for husband caregivers of spouses with dementia. The goal of this research was to extract the essences of the lived experience of
the participants and create an account of writing that reflects this lived experience. Data were collected using demographic form, semi-structured interview and field notes. van Manen (1997)’s principles of data analysis were used in reporting the findings. Principles of trustworthiness were used and ethical principles were followed, as presented in this chapter.

CHAPTER 4: FINDINGS

Introduction

In chapter four, the findings of my study of male caregivers of their female partners with dementia are presented. Included in this chapter are the participants’ stories, with a focus on the main findings, the essence of the participants’ lived experience and supporting themes. The essence of the participants lived experience was from loving husband to loving caregiver. There were two themes that emerged from the data to support the core themes: (1) caregiver first and (2) a new form of intimacy.

Demographic Summary of Participants

All participants were Caucasian males, ranging in age from 54-79 years of age at the time of interview. These men were married to their female partner, two participants had been married for 40+ years, and one had been married for less than 20 years. They had all been caregivers for 2-6 years. One of the participants was currently working full time at the time of the interview and was not yet at retirement age. Another participant
was working at the time of his wife’s diagnosis of dementia but gradually reduced his hours to retire early to provide care for his wife at home when she was no longer capable of self-care. The third participant was already retired at the time he became a caregiver. (see Table 1).

**Table 1**

**Demographic Data of Study Participants at the Time of Interview**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Number of Years Married</th>
<th>Number of Years Caregiving</th>
<th>Employment Status</th>
<th>Racial/Cultural Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>John</td>
<td>67</td>
<td>42</td>
<td>6</td>
<td>Retired</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Samuel</td>
<td>79</td>
<td>49</td>
<td>3</td>
<td>Retired</td>
<td>Caucasian</td>
</tr>
<tr>
<td>David</td>
<td>54</td>
<td>17</td>
<td>2</td>
<td>Working</td>
<td>Caucasian</td>
</tr>
</tbody>
</table>

The participants’ partners of were in their early-late fifties when diagnosed with dementia with a mean age of diagnosis of 55.3 years. Two participants whose wives were still living were caring for them at home (at the time of the interview) while the third participant cared for his wife at home before she moved to a long-term care facility, however at the time of the interview his wife was deceased (see table 2).

**Table 2**

**Demographic Data of the Characteristics of the Spouse with Dementia**

<table>
<thead>
<tr>
<th>Pseudonym for Spouse</th>
<th>Age When Diagnosed with Dementia</th>
<th>Residence</th>
<th>Status at the time of Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elizabeth</td>
<td>55</td>
<td>Home</td>
<td>Living</td>
</tr>
</tbody>
</table>
Table: Participant Profiles

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Setting</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marie</td>
<td>58</td>
<td>Home and Care Facility</td>
<td>Deceased</td>
</tr>
<tr>
<td>Joyce</td>
<td>53</td>
<td>Home</td>
<td>Living</td>
</tr>
</tbody>
</table>

Participant’s Stories

The following is a summary of each participant’s story. It includes a description of participants and their relationships with their wives.

**John.** John was a 67-year-old man at the time of the interview. He lived in a rural neighborhood. His wife was diagnosed with dementia at the age of 55 and was she was 62 at the time of the interview. John and his wife still live in their home with help six hours a day from a care worker. At the time of the diagnosis John, who was still working full time, admitted that he did not notice symptoms of dementia in his wife. It was her co-workers who noticed changes in her behaviour. They noticed that she made repetitive actions. She told repeated stories. Sometimes, she seemed forgetful. After co-workers brought these changes to John’s attention, he took his wife to the family doctor. The family doctor then referred the couple to a local gerontologist. John explained that when his wife’s mental abilities were tested to assess her memory, ability to solve problems and other thinking skills, and she scored very low on the tests, suggesting she had dementia. He was still working when he first took on the caregiving role, but eventually he had to retire when his wife was no longer safe to be left home alone. Outside of caregiving, John enjoyed golfing, working on his cars, doing yard work, and going for drives. John described their relationship as independent in that they each had their own
hobbies and interests. There were some activities they did as a couple like getting groceries and playing cards with friends.

Throughout the interview, John described his experiences with caregiving as mostly negative, yet his body language was open and relaxed. John seemed to take on his new role to the best of his ability and did not criticize himself when something went wrong. His wife’s safety seemed to be the central focus for him. Although John had no regrets about being his wife’s caregiver, he did speak about his losses like how things used to be with his wife and the hobbies he no longer had time to do. He explained that he had felt resigned to his new daily routine.

**Samuel.** At the time of the interview, Samuel was a 79-year-old retired man living in a rural area. His wife, deceased, was 58 years old at the time that she was diagnosed with dementia. Samuel and his wife were married 49 years at the time of her death. He cared for her at home for three years at which point his wife moved to a care facility for the last years of her life. Samuel spoke with great fondness about his time caring for his wife. His occupation required him to work odd hours; he often left for work at one or two o’clock in the morning and that his wife was at the door when he left for work so she could kiss him goodbye (every time). He explained that if he had been the one to be diagnosed with dementia, his wife would have cared for him and he felt that he could give back by caring for her. They had done everything together during the marriage, including getting together with friends or going on trips. It was clear from the stories Samuel told that his wife’s happiness was a priority. He talked about how she loved to go for drives, and as soon as she would wake up in the morning she would ask to
go. He said that sometimes they would come home from a drive and she would turn around five minutes later and ask to go for a drive. He said with a laugh and a smile that “She almost put me in the poor house for the amount of gas I had to buy”. He described that near the end of her living at home needed to take “nerve pills” due to the stress of caring for her well-being and safety. He was tearful near the end of the interview in talking about her passing. He said, “She was mine from the time she was 14 years old. It’s really hard to let your best friend go.”

David. David was a 54-year-old man at the time of the interview and had been married to his wife for 17 years. He had been his wife’s caregiver since her dementia diagnosis two years ago, when she was 53 years old. They live in an urban area. At the time of the interview, David was working full-time since his wife managed at home alone during the days. His wife was at the stage in her disease that she knew something was happening to her and was bothered that she is unable to use her mind like she once did. His wife’s hobby was writing and it was also her job. As a couple, they passed time by having intellectual conversations with one another—talking about politics, current work endeavors, and talking about each other’s creative pursuits in the arts. David stated that they did not have much of a physical relationship during their marriage, more of an intellectual relationship. He stated they often spent time in the same room, each doing their own creative work or playing video games together. Since his wife’s diagnosis, David has been trying to work with his wife to help her create her ideas for her writing. He writes for her and then asks her more questions to learn more. For David, being the caregiver for his wife is not new. Throughout their marriage, his wife had many health
problems including mental health and vision problems. David revealed that for their entire marriage he cared for her in one way or another. Since her dementia diagnosis, the only change for him, was her mind had not functioned to the degree it had before. He compassionately stated he could take his wife’s place as it was very difficult for him to watch these changes in her. David was very interested in this research study, and expressed that participating in the interview was therapeutic for him, since it allowed him to talk about his experience and reflect on it in new ways. He had never had the opportunity to talk about his experience to this extent as it is not something friends and family wanted to discuss due to discomfort.

**Main Findings**

The essence of the caregiver’s experience and the themes that describe the lived experience will be presented in this section. In describing the essence of the lived experience, the original research question will be addressed: What are men’s lived experience of sexuality and intimacy in their relationship with their female partner who has dementia?

**The essence of the lived experience.** The essence of the lived experience for men who care for their female partner with dementia is described as a transition from loving husband to loving caregiver. In this, the men interviewed changed their everyday lives, behavior and responsibilities from that of a husband and partner to that of a husband and primary caregiver. The transition to caregiver was described as a gradual change in which some of the wives stopped performing some tasks. As they stopped doing these tasks, the men would gradually take on more responsibilities. For example, Samuel stated, “She
used to do the sweeping always you know, then one day she just stopped doing it.” John talked about how he was able to continue working when his wife was first diagnosed with dementia, but as she gradually was could do less and be unsupervised less he reduced his hours to a point that he was not working at all.

In this gradual transition to caregiver it was clear that participants felt they had little choice in whether to become a caregiver or not. The men gave little thought as to “why” their wives’ caregiving became their responsibility. John stated, “I just did what I did, did what I had to.” Samuel echoed this by saying, “It was just something you had to do” and he would “do it all over again” if he had to. They often took on the caregiving role because there was no one else to help them at the time of diagnosis.

The transition to being their wife’s caregiver was difficult for the participants. They witnessed their wives change from the person they had been once were in their marriage to a person who was dependent, and at times like a stranger. At one point, John was tearful when recalling an incident in which his wife was aggressive towards a grandchild due the effects of medications she was taking. As the way’s their wives interacted with their partners changed, the men were troubled as they noticed changes in their wives’ behaviors and abilities. For David, the loss of his wife’s intellectual abilities was the most difficult:

My wife has struggled with mental health issues and went blind at a young age as well. I have cared for her around the house for many years but she was still able to use her mind to write, or discuss thoughts with me. Now I am taking care of her in that way as well. I try to stimulate her to write, like I write it down for
her. But, her thoughts are not as complex as they used to be so that is difficult for me to watch... to see her change in that way.

Common to all participants was that they wanted to have their wives back to the way they were before their diagnosis. David talked about “taking it away” [her diagnosis] “in a heartbeat” if he could be with the wife he used to know.

Two participants found it difficult to become their wife’s caregiver, having had little to no experience as a caregiver. Only one participant had such experience. For David, caring for his wife was not new. For many years, he had been the primary caregiver for his wife due to other health conditions. Despite his caregiving experience, David recognized that his wife’s dementia diagnosis required a different type of caregiving than what he was used to: “she has always depended on me to a certain degree, but now I have to help her with other aspects such as helping her process her thoughts.” His wife now required constant care and attention, rather than the periodic assistance she required with her other health problems.

**Themes**

Two themes emerged from the collected data that describes the essence of the caregiver’s lived experience. These themes are: (1) caregiver first, and (2) a new form of intimacy. These themes show how men lived their experience with their spouse with dementia. As discussed earlier, van Manen (1997) outlined the four lifeworld existentials of lived time, lived body, lived space and lived relations.

**Caregiver first.** The theme of caregiver first explores how the caregiving experience was shaped through the lens of the lifeworld existential of lived time. In the
transition from loving husband to loving caregiver, participants were always their wives’ caregiver first and husband second.

Being a caregiver meant taking caring of their wives’ personal and medical needs. Taking care of their wives when they were incontinent was particularly demanding for participants, from the physical tasks to the psychological nurturing that were needed with this loss in bodily functioning. It was uncomfortable and embarrassing for the men and for their wives. As John was particularly concerned, and said:

_I think one of the most difficult parts for me is the bathroom part... like knowing when she needs to go, or cleaning her up if she doesn’t make it in time._

_Sometimes I feel frustrated with her but I know that it isn’t her fault._

Samuel spoke of similar experiences:

_Cleaning up the messes in the bathroom was the hardest part. There would be a mess all over the bathroom and trying to get her cleaned up she wouldn’t hold still. Then I would have to scrub. I’ve done laundry here three o’clock in the morning._

Another important caregiving role was that of advocate. Participants observed their wives’ behaviors to assess and prepare for changes that suggested disease progression, then they reported these changes to healthcare providers. For example, John spoke of a time when his wife was prescribed a new medication. He noticed, “she was being mean to the grandkids which was completely unlike her.” He notified the doctor, who changed his wife’s medications. With this medication change, his wife’s behaviors returned to what they had been before she had started the new medication.
Concerned for their wives’ safety, participants made the home as safe an environment for their wives as they could. For example, with regards to meal preparation, John worried that his wife might be injured in the kitchen. He was fearful that she would put her hand on the stove and sustain burns, and because she had a high pain tolerance level, she may not detect the heat from the stove until she was injured. “I try to keep her out of the kitchen now, it’s just easier if it’s just me in there then I don’t have to worry she will hurt herself.”, he emphasized.

Much of the care the men provided to their wives had been unfamiliar work to them. Participants learned how to provide personal care to their wives by asking other family members for advice. From his daughter, John got “lots of tips about how to bathe her and that type of thing” who is a licensed practical nurse, and his mother helped with meals because she lived close by. Participants used the “learning as you go” approach to caregiving. As John said:

> I give her a bed bath type of thing. Sometimes I get a little lazy about washing her legs and underarms but I wash the parts that matter. Kind of just figured it out as I went along you know.

Similarly, Samuel initially washed his wife in the shower, but she would get out before the shower was completed, and walk around with her body covered in soap and soaking wet. From this experience, he learned to give her bed baths instead.

Participants explained that an important part of the caregiving role was to support their wives in being as independent as possible. David learned to cue his wife to do most of her own bathing or toileting. He added that his wife seemed to loose more of her
ability to be independent every day and some days were worse than others. Similarly, Samuel’s wife continued to be responsible for managing the banking even as her disease progressed. He supervised her and prompted her if she forgot a step in doing the banking. Samuel explained,

*I always let her do the banking right up until the end, she seemed to know how to do it even though she didn’t know how to do other things. I had to learn to do it though, had to watch her you know because she might forget certain parts of it.*

When their wives were no longer able to perform these tasks due to their disease progression, participants assumed sole responsibility for completing them. John shared, “She used to be the main cook around here. And now I do all that. My meals are nothing fancy but they are alright for us.” Taking on these tasks gave the men an appreciation of what their wives did for them – most of which was invisible to the men until they did them. For example, John realized his previous perspectives on women’s work:

... *the men at work often joked, you know how men are, about what a woman’s role in the house is and that type of thing. And now I think to myself, if they took a walk in their shoes (like I have) they might not be as quick to say that.*

Being a caregiver became a part of their way of being, the separation between being husband and caregiver became blurred for participants. They felt like they were unable to be just a husband, as the role of caregiver came first for the caregiving relationship to survive. “The caregiver part still comes in when we go out and do things
as a couple. It’s there always. It’s gotta be… gotta be if it’s going to work.”, Samuel said in a resigned way.

Participants described always being caregivers, even when they were away from their wives. Separating themselves from their wives was difficult as they could not put themselves first in the relationship, their relationship needed to always be about their wives and meeting their wives’ needs. David confirmed this in his interview:

My activities now are almost entirely working and taking care of her. That involves a lot of psychological support but also everything from watching her, making sure that she takes her pills and help her with a bath, that kind of thing….

I am a caregiver first.

Similarly, John said:

Well, as a couple we try to go out to friends. When we go out, I have to feed her, so that cuts down on a lot of things we used to go to. I mean, I don’t mind, but sometimes It’s easier to stay home. A lot of times we go out to friends have a couple drinks or something to eat, but I most generally tend to her first and whatever. But yeah, the caregiver part is there when we are out. It’s there all the time.

Because being a caregiver had to be a priority in their relationship, it was difficult for participants to maintain their previous hobbies and interests. John specifically talked about the frustration involved with being a caregiver as he was no longer able to do the activities he previously enjoyed.
It was quite a change for a while. It made me about half mad because I didn’t have my freedom, I couldn’t do what I wanted to. I guess the biggest change for me is being tied here.

The loss of freedom that was experienced by the caregivers is captured in van Manen (1997)’s lifeworld of lived time. Participants explained that time seemed to drag on like the day would never end with caregiving role. Being a caregiver first as a theme also speaks to the lifeworld van Manen describes as lived time. Participants comments were: “I have to do this all over again” every day when the day begins. Participants reflected sadly about the past they had shared with their wife before the dementia began, good times enjoyed as well as sacrifices their wives made throughout their lives.

Even with help, even when they knew what they were doing was out of love for their spouse, the caregiving took a lot out of the men. They got overwhelmed from the consuming nature of the caregiving role. As John shared, “It’s a big, a mighty big job. I don’t see much positive in it.” He talked of feeling “stuck” in the caregiving role because every morning when he woke up he had to “do it all over again.” David felt like he lost his personal time because there was no time for anything but caregiving: “…and there is no time for myself, not only recreational things but anything… there’s no time to get groceries, no time to fix the fence, no time for anything.”

Likewise, Samuel lamented:

It pretty near got the best of me last summer. My nerves had got the best of me. I was played out. You know what I mean when I say played out? It ain’t a job any man would like…. I don’t think.
Despite taking its toll, participants could, with probing, identify positive aspects of being a caregiver. Being their wives’ caregiver was an honorable role for the men. It allowed them to “give back” to their wives, taking of their wives, just as their wives had taken care of them. For Samuel:

*I didn’t mind looking after her truly and actually. She always looked after me, you know what I mean? I never came home from work when there wasn’t a meal ready if it was ten o’clock at night or twelve o’clock at night there was still food ready to eat.*

Caring for their wives gave them a sense of pride, that they were good caregivers. For example, Samuel felt that he “did good by his wife” and that he had nothing to be ashamed about. Another participant shared that caregiving tested him as partner: “I didn’t mind doing one bit of it... the greatest gift is a great test.” The caregiving experience allowed the men to reflect upon themselves as individuals, where they learned new things about themselves. They were more patient and flexible than they expected to be. One participant felt that his caregiving to his wife was confirmation that he was in fact a “good” person.

*I have done a lot of questionable things in my life, when I was young, and at work. I haven’t always been nice to others. I feel that by taking on and succeeding at this role of caregiver it says that I am a good person at the end of the day.*

This theme also explores how the experience of being a caregiver is shaped by van Manen’s (1997) lifeworld as lived space, lived body and lived relations. This theme represents how the participants interact with the world around them as well as in their
relationships with themselves and their spouses. It also sheds light on how the caregiving role affected their health. One participant’s health declined as the stress of caring for his wife became overwhelming. “It almost got the best of me near the end, I had to take nerve pills. “Because he needed to care for his wife during the day and evenings his health declined- he felt he needed to be available around the clock to ensure she was safe. The decline in his health led him to place his wife in a long-term care facility. He felt he could not manage caring for her when his own health was not optimal. This comment speaks to the lifeworld van Manen (2011) describes as lived body. In placing his wife’s needs first, his own health was at risk. The caregiving role affected the way his body was in the world. The theme of being a caregiver first also speaks to the lifeworld van Manen describes as lived time. Participants felt time went on forever in the day. They shared, “I have to do this all over again” every day when they woke up own lived space, the space we know and occupy shapes the way we find ourselves and the way we feel (van Manen, 2011). On the other hand, these men wanted their wives to be able to stay at home since it was familiar place for them. They did not want to disrupt this lived space for their wives, but on the other hand the men felt stuck in their homes due to the caregiving role. Referring to his home, one participant said, “the worst part of it all is being tied here.” The men’s feelings of wanting to give back and to engage in a role in which they viewed as honorable speaks to the relationship they created over the years with their wives. van Manen (2011) described this meaningfulness that we create in our lives with other people as lived relations. This meaningfulness helped the men overcome the difficulties in caregiving, to make it feel as if it was worth it.
A new form of intimacy. This theme explores the participants’ intimate relationships with their wives in relation to van Manen’s (1997) lifeworld existentials of lived relations and lived body. When I first asked the men about the intimacy in their relationship with their wives, they struggled to talk about their relationship and how it had changed since their wives’ dementia diagnosis. While this did not seem to be of importance or concern, the men disclosed that they had not given their intimate relationships much thought. It was not a priority for them—there were too many other activities that interfered with this part of their relationship.

Given the opportunity to reflect on their intimate relationship, participants spoke about a new sense of intimacy they had with their wife after she was diagnosed with dementia - one that did not involve sexual or physical relations. This new form of intimacy was demonstrated through the bond between two people that is built through love and trust, and created through acts of caring for another. Through the gentle and protective tone participants used when speaking about their wives, it was evident that their spouses’ well-being and happiness was central to their existence. As John said:

*She likes to stand in front of the t.v. when it is on. She stands there watching and when some type of music will come on she starts to dance. I sit there and watch her and laugh; she must be happy.*

Two participants spoke about taking their wives for drives because it brought happiness to their wives, and in turn, made them feel happy.

*She would get up first thing in the morning and say ‘let’s go for a drive’. I took her for a drive a lot of times with her nightgown still on. We would drive down*
through town and when we would come back to the driveway she wanted to come home. We would be just in through the door and she would say ‘you think that we should go for a drive?’ I don’t know if she forgot that quick or what. But I would just turn around and go back out.” (Samuel)

I take her for a drive in the evenings and from the moment she sits her bum in the car she never stops talking. I don’t know what she is saying... its jibber-jabber you know? But she can be quiet all day and when we go out I know she is happy because she comes to life. (John).

The men described having the occasional hug or light touch, but that was the extent of their physical intimacy. As John said, “...we didn’t used to be really affectionate but at night and what not, you know, it would happen.” He went on to compare to their intimate relationship since his wife’s diagnosis: “I’ll be sitting in the chair she will come over and maybe touch me on the head, but that’s about it. I’ll always give her kiss on the top of the head.” Similarly, Samuel spoke about how his wife stopped being as affectionate after her diagnosis:

Before she would quite often, you know, ask for a hug. She would always come to the door with me when I was leaving for work. But afterwards, she didn’t very often ask for any affection. Once in a while I would grab her when she walked by but that was about it.

All the participants spoke of being present with their wife as part of this new form of intimacy. Indeed, their physical presence was comforting to their wives. The men reported feeling validated when their wives wanted them around and noticed when they
were missing. It seems that the space shared between the caregiver and care recipient was a representation of the intimacy that continued in their relationship. John talked about his wife noticing his presence:

_We always got along. Now she notices when I am missing. I mean I sit next to her and cuddle up to her she notices a little bit. I think if you took her away she would be wondering where I am._

David echoed this by saying, “As long as I wasn’t away too long she would be okay… but if I was gone any amount of time she would come looking for me.” Similarly, Samuel seemed to take pride in the fact that his wife always remembered him more than anyone else. He said:

_She always knew me. Up until the day that she died she knew who I was. She didn’t always say so but I could tell… I could tell she knew I was her husband and that I would take care of her._

For one participant, being intimate meant engaging in what he called “intellectual intimacy”. The participant described “intellectual intimacy” as the way in which he and his wife connected with each other through reading and writing together, sharing written work, and expressing ideas and feelings. David explained how he maintained this intimate relationship with his wife:

_She currently is trying to record her thoughts, but since she can’t read or write anymore I am typing her thoughts for her. I write it down, read it back to her and then make suggestions of things she can tell me about. There is a chunk of time each day devoted to it._
van Manen (1997) describes lived relationships as the physical presence with one another in which we reveal parts of our lives to one another. Lived relationship captures the intimate relationships between the participants and their wives. This sense of intimacy evolved from a physical and sexual intimacy to something based in the foundation of their marriage, trust and love for one another. The lived relationship between each other is the very base of creation of the new form of intimacy. When we deeply know another person, and have built a relationship with them, we are able to transcend ourselves and work through challenges as a working unit (van Manen, 2011). Through memories of good times and reflecting of times their wives put them (the men) first that the participants found meaning in the role of caregiver. The use of memories to find meaning in caregiver was also found by Shim et al., 2013. Hirschfield (1983) was one of the first to describe caregiving in a more positive sense. He suggested that the act of caregiving- and the positive adaptation of the role, is comprised of acknowledging mutuality within the relationship and recognition of each member of the relationship (Hirschfield, 1983). In remembering the times that their wives put them first, these men have the desire to mirror this and give back to their wives. One participant said, “I had a car accident one time and I couldn’t even wipe myself when I went to the bathroom so she did that… so no, I don’t mind doing what I am doing.” In creating meaning in the caregiving role, reflecting on mutuality of the relationship, and reciprocating the care that was given to them throughout their marriage, they are creating the new form of intimacy between caregiver and care recipient. This is how the transition from loving husband to loving caregiver comes to be.

Chapter Summary
In chapter four, the research findings were described. The demographic characteristics of the participants and their wives with dementia were presented. Descriptions of each participants story and their relationship with their wives was given. This was followed by a discussion of the essence of participant’s lived experience and supporting themes. The essence of the participant’s lived experience was the transition from being loving husband to being a loving caregiver. The theme entitled “caregiver first” described how the men felt compelled to prioritize the needs of their wives above their own. Participants derived meaning from being the caregiver first to persevere through the difficult times and feeling that they were giving back to their spouse. The theme “a new form of intimacy” described how participants prioritized their pre-existing intimate relationship as low importance and non-existent but perhaps without their overt knowledge could create a new sense of intimacy. This new sense was created through the selfless act of caregiving, and by the actions of the participants to ensure their spouse’s safety and happiness.

CHAPTER FIVE: DISCUSSION

Introduction

Chapter five is a discussion of the research findings. The purpose of this research study was to understand the lived experience of men who care for their female partner who has dementia, specifically, their experiences of sexuality and intimacy within this caregiving relationship. Using phenomenology, I developed the essence of this lived experience, as well as themes which describe the essence of the lived experience. I will
discuss this essence as well as the themes in depth as well as compare them to what was found in the literature. In this chapter, an in-depth discussion of the lived experience as a novice researcher will also be presented including a discussion of recruitment difficulties and the insights learned throughout this experience. This chapter concludes with the limitations of this research study as well as recommendations for future research studies and for healthcare practitioners.

**Essence of the Lived Experience**

The essence of the lived experience was developed to address the original research question which is: What is men’s lived experience of sexuality and intimacy in their relationship with their female partner who has dementia? This essence is described as a transition “from husband to primary caregiver”. This transition was characterized as a gradual transition in their lives in which they did not have a choice whether to be a caregiver or not. This transition was difficult- emotionally and mentally- in which they felt frustrated, felt loss, and felt as if they were in a never-ending role at times. Participants in this study gradually took on more responsibilities as their wives’ disease progressed and their wives were no longer able to manage their own previous responsibilities. The gradual adoption of the caregiver role became more complex over time as the participants had to assume more roles as their wife stopped performing them. These activities ranged from banking, cooking and cleaning, to personal care. The transition as described by the men in this study is consistent with what Evans and Lee (2013) reported. Evans and Lee described the transition to caregiver as a slow process leading up to the diagnosis of dementia, at which point the caregiver took on more roles
as they felt it necessary after receiving a diagnosis. Interestingly, like the participants in the Evans and Lee (2013) study, two participants did not notice a lot of changes in their wives prior to diagnosis (e.g., no memory loss, behavior changes, needing help with activities of daily living) and they were not “waiting” for a diagnosis. This led the men to feel overwhelmed and frustrated in the transition - they did not feel prepared to take on the caregiving role.

The themes that support the essence of the lived experience are: (1) caregiver first (2) a new form of intimacy. These themes represent the lifeworld of the three interviewed participants. The lifeworld is described by van Manen’s (1997) four lifeworld existentials including lived body, lived time, lived space and lived relations. These lifeworld existentials were woven through the themes, some more prominent than others. Importantly, no single existential is more evident than another.

**Caregiver first.** The first theme describes that being a caregiver always had to come first for the men in this study, despite whatever else was going on in their lives. It was a priority for them. The men spoke of how they were no longer able to primarily be a husband to their spouse but also (and foremost) had to be a caregiver. The participants talked about loss of freedom, not being able to put their own wants or needs first, and having no time to do the things that needed to be done or activities they wanted to do.

Due to the all-encompassing nature of being a caregiver, the participants did not take time for themselves. They also felt that time with their wives was slipping away due to the disease. Consistent with previous literature, the men took solace in their memories
because it helped them focus on and remember happier times with their wives (Drummond et al., 2013; Harris et al., 2011; Sanders & Powers, 2009).

In the caregiver role, the men in this study took on new responsibilities. Taking on responsibilities such as meeting their wives’ physical and medical needs as well as advocating for their wives was described as a steep learning curve. As found in the literature (Akpinar et al., 2011; Sanders & Power, 2009), the men in this study were able to rise to the task of caregiving. They did not feel they were expected to be proficient in the caregiving role because it was not traditionally a “man’s” role. It is common for men to see caregiving as a challenge and to have strong coping mechanisms (Akpinar et al., 2011; Baker et al. 2010; Sanders & Power, 2009). In this study, the men relied on extended family for help and accepted each new challenge in caregiving head on instead of feeling defeated. Poysti et al., 2012 found that men used problem solving coping mechanisms and focused on the tasks at hand which resulted in reducing the level of burden. Similar to a study by Torge (2014) who reported the spousal caregivers in the study noted that caring was simply part of their lives. These participants reported taking on the caregiving role because it was “just what you do”.

When participants were asked about accessing supportive care services, some reported that they did access these services, while others were aware of them but did not use them. The literature shows that men often do not access supportive cares services because they view it as a sense of losing control (Baker et al., 2010; Poysti et al., 2012). For the men in this research study, the distance from the services was a barrier to accessing services and supportive care more than the fear of loss of control. In reference
to the Alzheimer’s Society, one participant said, “yeah I know they exist, but they’re a 45-minute drive from here” (meaning this was too far to travel). Another participant said, “I had personal support worker who came (to assist with caring for his wife) but they would always call in sick and there would be no one to replace them, so I might as well not had them come.” Due to the rural nature of where he lived, there were not a lot of personal support workers who worked there, so if one was unavailable due to being sick there was not often a replacement. In the study by Shim et al., (2013), men were active in seeking supportive help such as support-groups, and help from churches and other organizations. This was not the case with two of these participants who did not actively seek help in this form (although they were aware of the help that is available) and the third participant found that although he had sought some of this help it was not beneficial or overly helpful.

The participants in this study did however, seek help from friends and family. Shim et al., (2013) also state that this was true of the men in their study. Some literature suggests that male caregivers perceive lack of control if they seek help from others (Baker et al., 2010; Poysti et al., 2012).

Important to the participants in this study was to help their spouse maintain as much independence as possible. As reported by caregivers in the study by Evans and Lee (2013), the men in this study also helped their wives with dementia to preserve the role they had traditionally played within the marriage (e.g., banker, cook), and only took it over when their wife was no longer able to complete it.
Participants often felt “stuck” in their role as a caregiver but explained that it was a worthwhile venture. These men expressed feeling overwhelmed and consumed by the role of being a caregiver. They spoke of having little to no personal freedom anymore. Despite these challenges, the participants described that it was worth it because it was an honorable role in which they could give back to their spouse. They described doing good by their partner, and being a caregiver was a great gift. The participants created meaning in the role of caregiving by honoring the relationship they had built with their wives over the years. This was important for the men, since it is through the relationships we engage in and build with others that we develop a sense of purpose (van Manen, 2011). The theme of having no personal or free-time is consistent with other studies that found the loss of personal time and free-time is often more distressing to caregivers than is the actual duties of caregiving (Kratz et al., 2015; Torge et al., 2014).

In this role, the men could find a patience and flexibility they did not know they had. This sentiment is also reported in previous research studies. For example, Shim et al. (2013) described that for some spousal caregivers, the experience of caregiving allowed the caregiver to focus on what remained within the relationship instead of focusing on what was lost. For others, it was a sense of honoring their marital vows, and being able to “give back” to their spouse despite the sacrifice that it often entailed (Cahill, 2000; Russell, 2001; Sanders & Powers, 2009; Shim et al. 2013).

Participants in this study felt a sense of pride in being able to care for their wives, and acted as their protector during the caregiving journey. Similarly, to the study by Sanders and Powers (2009), the participants believed that their wife was central to their
lives and they wanted to make sure she was safe and well cared for above anything else. While these men would not choose this situation given the chance, they had pride in being able to successfully care for their spouse. This finding was similar to that of Shim et al., 2013 who found that giving back to their spouse in caregiving created a sense of pride as their wives not only cared for them and their families, but had significantly impacted their lives.

This theme shows how the participants interacted with the world around them (lived space) (van Manen, 1997). Often the feeling of being at home in the space we are in is comforting and can be where people feel at most rest, but for these participants, being home created a sense of claustrophobia within their lives. Participants expressed feelings of being tied to their homes (ie: John said “the worst part is being tied here”, meaning he couldn’t come and go as he used to) due to the caregiving role. It was difficult, if not impossible, for them to come and go as they wished. This demonstrates how their space affected how they felt. This sense of claustrophobia was not found in the literature.

**A new form of intimacy.** This theme emerged from the participant’s descriptions of their intimate relationships with their wife. This new form of intimacy was formed from the bond they had as partners built on love and trust which was developed through many years of being together. It was created through acts of caring for one another. The happiness and well-being of the participant’s wives was central to these men. They spoke in a gentle and protective tone when speaking about their wives and often smiled or laughed when remembering a certain time from their past together. John and Samuel
spoke of taking their spouses for drives in the car and how their spouse seemed very happy in these times. This activity was one aspect of their old life and by maintaining this activity they felt they were able to contribute to their wife’s happiness. Youell, Callaghan and Buchanan (2016) identified that “everydayness” was central to the act of intimacy within the relationship- to continue to engage in their routine everyday activities, even when this is not possible.

Feeling protective of a spouse was reported in the literature as a way that couples feel closeness with one another even after a diagnosis of dementia (Adams, 2006). Being present with one another was also a part of this new intimacy that was formed. For the participants, it was important that their wives remember them. Youell et al., (2016) recognized that although there was a paradox of losing intimacy and of maintaining a sense of intimacy in the presence of dementia, and that the sense of connection was the highlight of this complexity. I believe this to be true of the participants in this study. Although the relationship had become more complex with the addition of the caregiver role, a sense of being present with their spouse helped in the transition from loving husband to loving caregiver. This lived relationship helped the participants transition to caregiver and speaks to how the men sometimes felt lost within the caregiving identity. The men were often at a crossroads between wanting to protect and care for their spouse while also navigating the new role of caregiver and accepting this role.

Previous research studies have explored many topics surrounding the intimate and sexual relationship between caregiver and care recipient. Some caregivers report changes within their sexual and intimate relationships, while others remain sexually active with
their partner (Dourado et al. 2010; Kuppuswamy et al., 2008). However, participants in this study did not seem concerned about any changes in their physical and sexual intimacy. Thus, a discrepancy between this study and previous studies may have emerged because the men in this study were satisfied with their intimate relationship with their wives. After reflecting on each interview after it happened I tried to incorporate more probing questions with each successive interview in attempts to delve deeper into the experience of sexuality and intimacy. Even so, I gleaned little about this experience from these participants.

Similar to Drummond et al.’s (2013) study, the men in this study stated that sexuality and intimacy often get pushed aside in the caregiving relationship because the role of caregiver is all encompassing. The men lamented the overwhelming nature of the caregiving role and identified that the loss of sexual intimacy was not important or of concern. Male spouses created meaning in the role of caregiver by being present with their wives. They spoke of how their wives noticed if they were missing, which seemed to create a sense of pride if the wives noticed their absence. In previous literature, it was noted that spousal caregivers of persons with dementia found meaning in caregiving by giving back and giving love (Shim et al., 2012). There are different ways in which caregivers create meaning, but if the caregiver can find meaning in the caregiving role, they can have a more positive outlook on the experience (Shim et al., 2012). The participants in this study, when asked, reported there was no positive side to caregiving. However, while this seems to be a negative outlook, their stories show that a positive side exists (for example: when they talk about the pride created in caregiving and being able
to give back). Perhaps these men were unable to verbalize the positive when asked “is there any positive side to caregiving?”. They all showed a non-defeatist approach at caregiving, they did not give up when faced with new challenges. Without the ability to seek positive meaning or to be aware of positivity in the role, these men were at risk for adverse health outcomes and caregiver burnout. This did happen to one participant who eventually needed to move his wife to a care facility.

**Lived Experience as a Researcher**

As a novice researcher, undertaking the research process for a Master’s Thesis Project was a daunting process for which there was a steep learning curve. This section will outline the challenges I encountered with this research project. I describe the steps I took to overcome them. Challenges included: researching sensitive topics, recruiting participants, interviewing participants, managing emotions during the research process as a novice researcher and maintaining a supportive relationship with the research supervisor.

**Researching Sensitive Topics.**

Sensitive research topics were described in 1988 by Cowles as topics in which harm may come to participants or may result in powerful emotions such as anger, sadness, embarrassment, fear and anxiety. Sieber and Steinley (1988) added that sensitive research includes topics that may cause distress to the researcher. While many topics of nursing research may be considered sensitive, Enosh and Buschbinder (2005) suggested that there are some topics that may be more sensitive than others, such as domestic violence, political activism, homicide and rape, mental health, death, abortion and sexual
health (Davies, Bolding, & Hart, 2004; Enosh & Buchbinder, 2005; Lipscomb, 2010; Mitchell & Irvine, 2008; Possick, 2009; Seiber & Stcinlet, 1988; Sollund, 2008; Walls, Parahoo, Gleminig, & McCaughan, 2010;).

My research project focused on the sensitive topic of men’s experiences with sexuality and intimacy while caring for their wife living with dementia. This topic is sensitive for a few reasons. First, any research related to dementia is sensitive due to vulnerability of persons with a cognitive impairment and therefore these persons are vulnerable. Secondly, this research project focused on sexuality and intimacy within the context of the caregiving relationship. Sexuality and intimacy, especially in the presence of a cognitive impairment, is an intimate and sensitive topic. There are often questions of consent within a sexual relationship with a person who has a cognitive impairment (Hillman, 2016). Due to cognitive impairment, persons with dementia may have the desire to engage in sexual activity, but may not have the insight required to make appropriate decisions about sexual activity (acts that are legal or socially acceptable (Hillman, 2016). Golander and Raz (2000) said that often sexuality in dementia often brings up issues of consent as a larger phenomenon in which persons with dementia are questioned on their ability to be responsible and in order to make decisions based on the diagnosis of dementia alone. The International Longevity Centre (ILC) (2011) produced a report called The Last Taboo, which discusses the issues of sexuality and intimacy in older adults. They name the topic of sexuality and persons with dementia “the double jeopardy.” The report says that while sexuality and intimacy are important aspects of a person’s well-being, there are many stigmas associated with this topic and many people
are unwilling to consider that persons with dementia and their care partners have sexual and intimate wants or needs (ILC, 2011). For these reasons, there may be barriers to recruiting participants for a research study of a sensitive nature, which will be discussed further in another section.

As a novice researcher, taking on such a sensitive research topic has been challenging. When I first began to explore potential topics for this research project, while I knew I wanted to focus on dementia caregivers I was not sure which aspect of this lived experience I wanted to focus on. I learned through an initial literature review that men are under-represented in the dementia caregiver research. I felt it was important to focus on men. In reviewing the literature on the health of older adults, I found that older adults who were satisfied with their sexual relationship had better overall health outcomes. I decided to explore husband’s lived experience caregiving because they are often subject to poor health outcomes due to burnout and co-morbid health issues. I wanted to explore caregivers’ perceptions of sexual and intimate relationships to see if there was a link between preserving the sexual and intimate relationship and lower rates of caregiver burden.

**Recruiting Participants**

This section outlines the difficulties I encountered while trying to recruit participants. I originally planned to recruit four to six men to participate in the study. I recruited three participants successfully for this research study. It has been well documented that recruiting men for research studies can often be challenging, especially when it involves qualitative research in which men must share their thoughts and feelings.
about an experience. As Butera (2006) suggests, it is possible that men’s refusal or
disinterest in participating in this research was a way of showing their independence and
control over things in their lives that were no longer in their control since they became a
caregiver. Schwalbe and Wolomir (2001) found that men often find participating in
research a threat and an opportunity. It could be perceived as an opportunity to show their
control of a situation during the interview or as a threat because the interviewer holds a
lot of control during the research interview.

The sensitive nature of my research study is likely to be one reason why I had
difficulty recruiting research participants as it results in increased vulnerability in the
research participant. My research posters explained that the research study explored the
intimate relationship between caregivers and care recipients which may have resulted in
some men not wanting to participate, even if they fell within this population.

There were three men who were referred to the study but declined to participate
because they did not have time to participate in the interview. Having little free time is a
common reason for men to avoid participating in research (Butera 2006). These men had
wives who were still living, one of which lived at home with the potential participant,
while the other two lived in residential care facilities. One man stated:

I have so much on my plate as it is with caring for my wife. Even though she is
living in a nursing home I go three times a day to feed her…at least that often.
When I am not there I need to take time for myself and to keep the house in order
and things like that. I just don’t think I have anything left to give at this point.

The man whose wife still lived at home had a similar reason for declining:
My wife requires one on one care all day, and when the relief care worker comes I have to get groceries, do laundry, banking and all those other every day activities. I just don’t have the time to devout to it right now.

Another man who was interested in participating in this research project did not meet the inclusion criteria. He was the son who cared for his mother with dementia. He was very enthusiastic and asked for me to change the focus of my study so that he could participate. I informed him that I would refer him to other research studies if I heard of any. He called me three different times to inquire about participating. This inquiry showed that caregivers for those with dementia do want to tell their story due to the nature of the experience they had. It is important to consider for future research.

Although I anticipated barriers to recruitment along the way due to the sensitive nature of the subject and the specific population I was targeting, I was perhaps unprepared for how challenging it would be as a novice researcher. Many methods of recruitment were attempted. I did not use paid media as I did not have funding for this research study. I used posters, online advertisements, community organizations, word-of-mouth, and social media.

Posters. I created posters that described the research study and included my contact information for those interested in the study. These posters were distributed in Ontario and New Brunswick. I had both a New Brunswick phone number as well as an Ontario phone number on these posters depending on where they were distributed. These posters were placed in family doctor offices, as well as offices of gerontologists. I obtained ethical approval to advertise within the University Health Network which is a
collection of four hospitals in the greater Toronto area. These posters had many tabs taken off them and resulted in one potential participant. He was not eligible to participate in the study because he is a son who cares for his mother with dementia.

**Online advertisements.** The same information that was listed on the posters was put into Kijiji advertisements that were placed in all major cities across Canada. These advertisements were deleted and reposted to keep them on the first two pages of advertisements. Many views were accumulated on these advertisements, ranging from 20-100 views, depending on the city in which they were posted. These posting resulted in one phone call from a man who was looking for advice on caring for his aging mother who was suffering from memory loss. He asked about resources and doctors that he should take his mother to. I informed him that I was not an expert about dementia and that he should talk to the family doctor for more information. This inquiry also shows that dementia not only affects spousal caregivers but other family caregivers as well. It also shows an interest in telling about the experience and information seeking. I also received a phone call as a result of a Kijij advertisement in which a grandson who had cared for his grandmother wanted to participate.

**Community organizations.** I reached out to community organizations that work with caregivers and requested their assistance in disseminating information about this study to potential participants. I made successful contact with the Caregiver Coalition of Ontario who printed the advertisement in May 2015. This advertisement did not result in recruiting any participants. I also reached out to the Alzheimer Societies in New Brunswick and Ontario for assistance with study recruitment. Unfortunately, I had
difficulty contacting the Society’s managers because they were on vacation or did not return my phone call. (I contacted their social media coordinator who informed me that they do not post advertisements from individuals external to the Society on their social media sites. I was hopeful that I could attend the Society’s “coffee time” session that is a forum for caregivers to come together and talk about their experience. Despite repeated attempts to reach the Society, I was unable to get a response to my request to attend the “coffee time” session. Another community organization who helped me with study recruitment was the Memory Clinic, which is a part of the University Health Network in Toronto. I met with the manager of the program as well as the social workers who work with the participants of the Clinic. They put my posters up in the Clinic and shared information with potential participants, but they were unsuccessful in finding any participants for me. They explained they too have difficulty recruiting participants because there are many research projects underway. I also tried to recruit through the Dotsa Bitove Wellness Academy which is a center of excellence and research in relational dementia care. I did not have success here as the research study did not match their vision and mission.

**Word-of-mouth.** Word-of-mouth (someone I know talking about my study) was the most successful means of recruitment for this research study. I recruited five participants through this method, three of whom agreed to participate and two who declined at the time of consent. The two who declined at the time of consent felt that they did not have enough time to devote to being in the research study as they were still caring full time for their wives. I think this was the most successful means of recruiting as a
word-of-mouth referral gives the researcher credibility with the potential participant and perhaps helps build trust within the research-participant relationship. It has been documented in the literature that when a research participant hears of the research from someone they trust, they see the research as more valid (Seidman, 2013; Truglio-Londrigan, Gallagher, & Sosanya, 2006).

**Social media.** I posted advertisements for this research study regularly on Facebook. I used Facebook to indirectly reach potential participants through their friends and family, who were more likely than the target population to be on social media and who could encourage study participation. I had several shares by friends and family on Facebook as well as questions about the study. One potential participant was recruited through a grandson who passed on the information letter and contact information to his grandfather. This participant then declined to participate in the research study. He did not provide a reason for declining other than he “didn’t want to”. I joined four caregiver support groups on Facebook, but could not find one specific to Canada to join. My posts in these support groups did not result in any participants. I used Facebook as a way to follow-up with two women who attend a presentation I did about my study and who wanted more detailed information about the study to share with a family member. I did not get a response from these women when I reached out to them through Facebook and email.

**Men participating in research studies.** It has been well documented that recruiting men for research studies can often be challenging, especially when it involves qualitative research in which men must open up about an experience. The challenges in
recruiting men for interview based research had been linked to ideals of masculinity, long work hours, and limited flexibility in scheduling extra activities into their day to day routine (Butera 2006, Witty et al., 2014). It has also been reported in the literature that as society historically has represented men as dominant in nature, there is a refusal to accept potential analysis by others. It has also been reported that men may be resistant to this analysis, specifically from women and do not want to appear to have a knowledge deficit in a certain topic (Oliffe and Mroz 2005). Butera (2006) found that men’s refusal or disinterest to participate in interviews is sometimes a means of showing independence and control by saying no. I believe that after learning of the lived experience of these men that this is one explanation. Due to the little perceived control they had within the assumption of the caregiving role and the everyday tasks of caregiving, it is possible that saying no to research studies is the only place they are able to have control.

I also found that men who were actively caring for their partner declined to participate due to the lack of time to do so. Of the interviewed participants, none had told their stories and just worked through the caregiving experience as best as they could with little influence from resources or assistance from others. One participant expressed that being able to tell his story was therapeutic as he felt he could not talk to his friends and family about his experience.

**Reflection on Recruitment Challenges**

Despite not recruiting as many men as I planned, I have reflected on the challenges I encountered with recruiting participants for this study and what I could do differently in doing future research. I learned that many organizations are bombarded
with requests from researchers wanting to partner with them and advertise their research through them. I have learned that it is important to ensure your research matches with the organizations who you are approaching to assist with study recruitment. For example, The Alzheimer’s Society’s mission is to help those who are dealing with the everyday effects of this disease as well as those who care for them, rather than helping researchers find study participants.

It was helpful to hear the reasons for which these participants did not want to participate in the study. It is possible that I did not successfully recruit more participants because the target population is preoccupied with their role as a caregiver. From the men who participated in this study, it was clear that caregiving was their primary focus. This suggests to me that I might have recruited more men if I could offer them caregiving respite services, allowing them to consider participating in the research. Potential participants might be more inclined to participate in the research if their wives were being cared for. Unfortunately, I did not have any money to offer caregiving respite services to the men.

I have also reflected on the importance of gatekeeping when recruiting for a research study. Kawulich (2010) defined gatekeeping as the process in which researchers are given access to a research setting or a group of participants who could be involved in research. Especially when recruiting vulnerable or hard-to-reach subjects, it is important to gain the support of gatekeepers (Berg & Lune, 2011; Witty et al., 2014). Gatekeepers can have an influence at a local level, and add credibility to the research study in the eyes of potential participants (Seidman, 2013). Some gatekeepers who I tried to engage in this
research study were organizations such as the Alzheimer’s Society, the memory clinic at the University Health Network, as well as the Dotsa Bitove Wellness Academy. Unfortunately, my ability to recruit through these organizations was limited to posters placed in the memory clinic. The Board of Directors for the Dotsa Bitove Wellness Academy gave reasons to explain why they did not allow researchers to recruit their members. The Academy’s philosophy is one based in relational care and it focuses on life-enrichment, engagement and quality of life for persons with dementia, their caregivers, and all members involved in their lives. As my research study focused on the experience of the male spousal caregiver only and did not include the spouse, it did not match the Academy’s philosophy. C. Jonas-Simpson, the Director of the Bitove Academy, explained:

*Given that the study is not aligned specifically with Bitove (not inclusive of the spouse and thus not a relational focus), not only conceptually, but through interpretation. I would decline.* (personal communication, February 22, 2017).

Another member of the Board stated:

*If the Bitove is truly about relational caring, which I know it is, then does it make sense to only ask about these things with one person in the relationship? It seems to me that relational caring is about how all in the relationship experiences relationships. Just something that struck me as I read through the interview guide.* (personal communication, February 22, 2017).

And finally,
My feeling is that a justification needs to be made for the sites where recruitment will take place. This would require that students and other researchers align their study with the philosophy at the Bitove. (personal communication, February 22, 2017).

These quotes show the importance of engaging gatekeepers in a collaborative partnership in developing a research project that meets the goals of both the researcher and the gatekeepers. A collaborative partnership has been shown to build relationships between researchers and organizations who are involved in a joint intellectual endeavor. Both parties can benefit from this partnership. Partnerships between academic institutions and clinical practice can enhance research opportunities (Balakas, Bryant, & Jamerson, 2011). Collaborative partnerships help close the gap between education and practice (Balakas et al., 2011; Traynor, Dobbins, DeCorby, 2015). In the future, it would be important to engage these stakeholders and organizations from the conception of a research project so that it is a mutually beneficial process.

Interviewing Participants

Using phenomenology as my research methodology and method, I decided that semi-structured interviews would be the best method to glean the most from the research participants about their lived experience. In preparing for these interviews, I created an interview guide with five questions and prompts for every question (see Appendix C). I did a lot of reading about how to conduct successful interviews. I was nervous about interviewing men and reading this information helped me feel more confident in what I was doing. I felt it was important to display open, relaxed non-verbal communication in
the interviews so as to help the participants feel at ease. Another way I helped participants feel more comfortable in sharing their story with me was by giving them the option of where the interview was held. Two of the three men agreed to meet at their homes, while the third agreed to a telephone interview. I offered to come to his home but he thought that a telephone interview would serve just as well as an in-person interview. Being present in the participant’s home was at first uncomfortable but I believed that being in their own home allowed the participants to be at ease during the interview. I did not feel unsafe in any of the homes, especially since the participants had been referred to me from a mutual acquaintance.

When I did the interview by telephone, I was distracted at the beginning of the telephone interview as I wanted to be sure the conversation was audio recording properly. To protect confidentiality over the phone, the interview was completed at a time when I was home alone in my office. There were a couple of occasions where there were noises in the background that interrupted the conversation (e.g., I dropped a pen on the desk where the phone was on speakerphone). Elmir, Schmied, Jackson, & Wilkes (2011) and Taylor et al. (2011) suggest that face-to-face interviews are the most effective means when interviewing participants about a sensitive subject. Other studies have suggested that telephone interviews limit emotional vulnerability of the participant as they are communicating virtually and may feel protected by that (Trier-Bieniek 2012). The most common methodological issue when engaging in telephone interviews is establishing rapport, and the use of therapeutic non-verbal communication (Mealer & Jones, 2014). While Novick (2008) suggested that the loss of non-verbal visual cues in telephone
interviewing is a disadvantage, it is possible that it does not affect the quality of the interview. Mealer and Jones (2014) explained that with the elimination of visual cues, emotional distance is created and participants may feel less vulnerable and feel there is a lower risk of judgement from researchers, which as previously discussed is often a barrier to men participating in research. The use of silence, tone of voice, and lengths of pauses in conversation are effective non-verbal cues that are not lost in telephone communication (Mealer & Jones, 2014). I used these techniques during the interviews, both those done over the telephone and in-person. These techniques, especially the use of silence, was beneficial in gleaning more about their lived experience. In person, I would simply nod my head to encourage the men to expand more. On the telephone, I would use silence to allow the participant to expand, and if the silence was prolonged, I would add a phrase such as “go on” to encourage the dialogue. Using these methods were effective. The participant reflected that “he hadn’t thought about it before” when I used probing questions during the interview.

I was surprised when the men started to tell their stories unprompted (and sometimes before the demographic form was completed!). It was evident that the men had something to say about their caregiving experiences and wanted to be heard.

I transcribed all the interviews myself. This was my first experience transcribing interviews. Transcription was a lengthy process in which I would have to type the dialogues, rewind the audio, listen again and check what I typed. Each interview took around 10 hours to transcribe. Although it was time consuming to transcribe my own interviews, it provided a lot of time for reflecting on the participants’ lived experience.
learned more about the men each time I listened to their interviews. After transcribing the interviews, I listened to the interviews several more times to allow for more time for reflection. van Manen’s (1997) phenomenological method involves being immersed in the data which allows the researcher to reflect on the experience, and extract phrases or quotes that act as a description or illustration of this theme. By transcribing my own interviews, I was able to be immersed in the data.

In reflecting on the interview process, I was able to identify areas of strength as well as areas for improvement. Mackereth and Milner (2009) said that when conducting research about a sensitive subject that building trust with a participant is even more important than research that is not considered sensitive in nature. My goal was to build some level of trust in the relationship with the participants that I interviewed. Munday, Kynoch & Hines (2015) stated that patients and families not only trust nurses as professionals who care for them (or their loved ones) but also as mediators in helping them navigate the healthcare system. I think that since the participants knew that I was a nurse, they were more at ease with telling me their story as there was a sense of this trust in me as a healthcare professional. Participants were recruited through word-of-mouth from someone they trusted, which made it easier for me to gain their trust. I was professional in how I facilitated the interviews. I arrived at the interview location on time, dressed casually, and took some time to get to know participants before starting the interview. I disclosed some information about myself such as where I am from, where I am living and my current job. This helped me build rapport with the participants, which Mealer and Jones (2014) suggest is important when interviewing participants especially
about sensitive topics. I made sure that participants knew I was not an expert in dementia, but rather a nurse researcher wanting to hear their personal story and experience. I reacted in a gentle and comforting way when participants spoke of sensitive aspects of the caregiving relationship. I responded with such phrases as “that must have been a difficult time for you” and “it sounds like you have tried very hard to be your wife’s caregiver.”

By keeping field notes I was able to reflect on the interview experience. Being a novice researcher, I sometimes felt uneasy asking difficult questions about sexuality and intimacy and perhaps did not glean as much of this area of the lived experience as I could have. With each interview, I become more comfortable in asking questions about sensitive topics. I was able to gauge the participant’s comfort with the topic through their body language and what they were saying. This helped me decide on how to frame the questions and how much to probe for more detailed information.

**The Role of Emotion in the Research Process**

Every experience that we engage in elicits some type of emotional response and shapes how we make sense of the world around us, which is also true of a researcher involved in conducting research (Dickson-Swift, James, Kippen, & Liamputtong, 2007; Hubbard, Backett-Milburn, & Kemmer, 2001; Warr, 2004). With qualitative research, the researcher is simultaneously trying to make sense of the research participants’ lifeworld, and trying to make sense of and cope with the research process itself. This is especially true of a novice researcher (Johnson, 2009).
Many emotions accompanied me along the journey of being a novice researcher, ranging from frustration to excitement to sadness. I felt very frustrated during the recruitment process. I felt that it was important to understand caregiving from men’s perspective and its impact on their intimate relationships. I was frustrated that I was not gleaning more interest about the study and that community organizations were not as able to help me as I originally anticipated. Upon reflection, I have come to an understanding of the barriers I faced during the research process especially in regards to recruitment. I think that these barriers speak to the importance of further research on this topic - an in-depth analysis of their experience is needed to know how support men who care for their wife with dementia. In the future, studies that involve caregivers of those with dementia perhaps need to make the research study more accessible to these caregivers with means such as, monetary incentives, or to offer respite care for their spouse during the interview time.

Despite repeated attempts to recruit participants, I fell short of my target sample size. This resulted in feelings of sadness, disempowerment and disengagement. Combined with pressures to achieve project deadlines, study recruitment proved to be a highly stressful stage of the process for me. At times, these feelings resulted in me putting off analyzing data or writing up the findings. I felt defeated from the lack of success in recruiting participants. I was able to remove myself from the data and take a break when I was feeling this way. With the support of my research supervisor and constructive feedback, I was able to re-immerse myself in the data. I think having an
awareness of my feelings allowed me to grow as a researcher and learn how trying the research process can be.

At times during the research process, I felt excited about the data I was collecting. This excitement about the data I collected helped me feel more engaged with my project. I felt that I had a duty to create something from the stories these men shared with me. I was able to reflect on my own feelings after each interview in my own field notes. By reflecting on my own experiences with this topic and my own feelings I was able to recognize how these reflections can add value to a research study. Importantly, my nursing experience helped me empathize with participants and helped them reflect upon their feeling as they shared their stories. For example, I found it touching to hear Samuel talk about his wife: “…she was mine from the time she was 14 years old. It’s really hard to let your best friend go.”. Samuel was teary when telling this story. Although I found this to be sad, I also found it heart-warming that this man could so fondly remember the love he shared with his wife, as if it was a means to help him carry on in her absence.

Support of a Supervisor for a Novice Researcher

The literature says that it is important to select a supervisor who has experience in the topic of research and of the methodology and methods used for the research project. It is also documented that regular meetings, discussions, and academic agreements are integral of the progression of the research project. The relationship between supervisor and student is one that spans over a long duration in time, which includes formal instruction as well as interpersonal support during the research process. It is important that the supervisor foster independence, provide intellectual guidance and instill
confidence in the student, and necessary for the student to take initiative and develop a sense of autonomy during the process (Thompson et al., 2005).

My thesis supervisor was chosen for her expertise in my research methodology and methods which was a great benefit to me as I navigated learning this new research methodology and methods for the first time. My supervisor and I have had a long relationship, in which we have developed a sense of trust and improved communication over the years of supervisor-student relationship. When I relocated to Ontario, our relationship evolved to include regular meetings via email, Skype, and telephone. With guidance from my supervisor, I was able to maintain a reasonable timeline, and adjust it as needed with the flexibility of my supervisor. In times of frustration and disengagement, I felt safe to explore these feelings with my supervisor to create a plan to stick with my timeline. As our relationship continued, at the end of one meeting we would schedule the next meeting so we were accountable for the work we each needed to complete. Deadlines for submitting draft work motivated me to continue my work and helped me to avoid procrastinating.

**Strengths of This Research Study**

To the best of my knowledge this was the first study that explored the lived experience of sexuality and intimacy for men who cared for their wives with dementia. Much of the research either focuses on women caring for a partner/spouse with dementia or some combination of men and women caregivers. A strength of this study is that it focuses exclusively on men. This is important because historically research studies have focused on the female lived experience of spousal caregiving (Pinquart & Sorenson,
With men being under-represented in the literature, it is difficult for healthcare practitioners to draw conclusions about how to support men caring for their wife with dementia.

van Manen’s (1997) phenomenology was an appropriate methodology to develop the lived experience of the participants. The focus of phenomenology is to develop a meaning of the lifeworld rather than creating a theory. These meanings are created by the way people interact in the world and by the experiences they live. As this research study involved a rather sensitive and specific topic, I wanted to be able to explore their experiences and glean understanding from participants.

Another strength of this study is the qualitative research methodology and methods I used in this study. While the literature suggests that men do not express themselves, researchers are more often turning to qualitative research methodologies and methods to provide context and insight to the experiences of men (Oliffe & Mroz 2005; White et al, 2012). Using interviews in this study has allowed me to hear what men had to say about caregiving.

**Limitations of This Research Study**

One limitation of this research study is the small sample size. Because of the small sample size, the description of the lived experience is limited to these participants. While we are able to deduce that others may experience similarities in their experiences, we cannot generalize to the entire population of male caregivers.
I also moved to a different province during the research process. Being away from my home university was difficult because I did not have immediate, in-person access to the support I needed. Much of the contact I had with my supervisor and other students was through telephone. I also think that being a new nursing graduate when I started this graduate program meant that my focus was on my bedside nursing career. I occasionally disengaged from academia because I was focused on increasing my bedside nursing skills by taking extra courses and critical care nursing programs. When I started the program, I was a full-time student and held a casual nursing position. When I moved to another province, I became a part-time student and obtained a full-time nursing position at the hospital. Balancing the desire to further enhance my bedside skills while also staying engaged in my research study was challenging at times.

**Implications for Nursing Practice**

I will highlight some implications for nursing practice based on the research findings. It is important for nurses to be aware of the challenges encountered by men caring for their wives with dementia. Caregivers need to be supported because they help persons living with dementia to remain living in their own surroundings longer, and in turn reduce the burden on the health care system. It is well documented, however, that caregivers are at risk of adverse health outcomes and burnout in relation to caregiving (CIHI, 2011; Evans & Lee., 2013; Rinaldi et al., 2005; Shim et al., 2012). A study by de Vugt et al., (2006) found that spousal caregivers who are similar in age to their spouse with dementia are at risk of cognitive decline and dementia as they are older adults themselves. In assessing informal spousal caregivers, nurses are able to monitor the
cognitive status of these caregivers. In cognitive screening and assessment of caregivers, health care professionals are able to identify risk to the care giver and care recipient when the caregiver is also experiencing cognitive decline, which could result in safety issues and affect the caregiver’s ability to provide adequate care.

One of the men who was interviewed stated that simply being able to tell his story was very therapeutic for him. It was especially important for the men because they did not feel they could share this with friends and family. There is a need for these caregivers to have someone to talk to as they often feel isolated in the experience which is possible through support groups. For nurses, it is important to recognize how therapeutic talking can be for men caring for their wives with dementia, and for caregivers in general (Balzer-Riley, 2000). East et al., (2010) stated that storytelling is not only a way to gain information for the listener, but in can help build resilience in the storyteller as it allows the storyteller to affirm their experience. In this caregiver population, nurses can establish therapeutic nurse-caregiver relationships as an intervention for this population.

Two men in this study did not access supportive care. They may be at higher risk of burnout because they are often “alone” in their role as caregiver. It is clear that the men in this study developed their caregiving knowledge mostly on their own, with some input from friends and family. Only one participant accessed support from local community support groups/organizations. There is a need for more access and awareness for programs and for these programs to reach these men perhaps in their homes, and also in the rural communities they live in.
The theme of caregiver first highlights how men may be (or become) at risk for poor health outcomes or caregiver burnout. The men were always engaged in the role of being a caregiver, putting the needs of their wife first. The men felt that there was no end in sight in being a caregiver, and felt stuck in the caregiving role. Men could benefit from caregiver support groups and supportive community resources to help reduce the burden of being a caregiver.

The men in this study reported being “stuck” in the role of caregiving and with good community support some of this burden can be alleviated. With supportive community resources such as relief care and personal support worker care, men could have more time to themselves and a break from the duties of caregiving. These resources need to be offered to these men during healthcare appointments as it is crucial to the long-term sustainability of the caregiver role. If these men remain unsupported in the community, they are at risk of adverse health outcomes and they may not be able to remain caregivers for a long period of time. The participants identified not having enough time to access support from community support groups/organizations. Connecting these caregivers with options for relief care primarily could benefit them as they do not feel they have time for other supportive resources such as support groups. By asking questions about the caregiving experience, nurses can aim to tailor their care to these men by developing care plans that best meet their needs.

Stigma about sexuality and intimacy persists among couples when one member has dementia. There is often a misconception that older adults are asexual and do not have intimate needs, but this has been shown to be a myth (Hillman, 2016). Often health
care workers have a negative perception of older adults with cognitive impairment and sexuality and may attempt to deny or conceal the patients right to do so (Hillman, 2016).

Although the participants in this study did not view the changes in their sexual and intimate lives to be of concern, there is much literature that suggests if older adults are able to maintain this part of their lives that their overall health is better. What is clear from the men in this study is that men caring for their wife with dementia need support in exploring what the new form of intimacy can be like after dementia.

**Implications for Future Research**

Future research about the male caregiving experience should including sons and other male caregivers, including men who care for men with dementia. There were three men who contacted me about study participation and who were not deemed eligible to participate in the study. They were not eligible because they were sons/grandsons caring for the mother/grandmother. The experience from children or grandchildren caring for those with dementia would be a valuable dimension to add to research. Do sons and grandsons reach out more to be involved in research studies than husband caregivers? Are these men accessing services and navigating health care more proficiently? Does the intimate and sexual relationship impact the caregiver (e.g., without the sexual/intimate relationship, is the caregiving experience different)? These are questions that I have as a researcher. Perhaps, one group of men copes better with the caregiving experience and their strategies could be applied to groups who do not cope as well.

Future research on caregivers would be more successful if there was early engagement of gatekeepers in the research process. As explained earlier, a lot of the
barriers to recruitment I had were due to the research study not being in line with their values and mission of the gatekeepers. I believe that for research to be beneficial to practice it is important to be aware of the organizations available, their vision and mission, and with this better connect research to practice. Further to this, some of the recruitment barriers may have been eliminated if I had been able to offer caregiving respite services for the time of the interview, as many potential participants declined for this reason.

Chapter Summary

This chapter was a discussion of the research findings. The essence of the lived experience “from loving husband to loving caregiver” was described and illustrated with two themes: 1) caregiver first and 2) a new form of intimacy. These themes were compared to research findings in the literature. This chapter also gave an in-depth reflection of the lived experience of a novice researcher. The chapter concluded with an overview of the strengths and limitations of this study as well as recommendations for future research and implications for practice.
REFERENCES


cr.ca/en/about-dementia/what-is-dementia/dementia-numbers


http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1741-3729


Reiners, G. (2012). Understanding differences between Husserl’s (descriptive) and Heidegger’s (interpretive) phenomenological research. *Journal of Nursing and Care, 1*(5), 1-3. doi:10.4172/2167-1168.1000119


Trier-Bieniek, A. (2012). Framing the telephone interview as a participant-centered tool for qualitative research: a methodological discussion. *Qualitative Research, 12*(6), 630-644. doi: 10.1177/1468794112439005


Youell, J., Callaghan, J., & Buchanan, K. (2016). ‘I don’t know if you want to know this’: carers’ understandings of intimacy in long-term relationships when one partner has dementia. *Ageing & Society, 36*(5), 946-967. doi: https://doi.org/10.1017/S01446866X15000045
Research Volunteers Needed

ARE YOU A MAN WHO IS CARING FOR OR WHO HAS CARED FOR HIS FEMALE PARTNER WITH DEMENTIA?

I am a Registered Nurse and graduate research student at the University of New Brunswick. I would like to interview men about their current or past intimate relationship caring for their female partner who has (or had) dementia. You can take part in the study if you can read and speak English, and live in Canada. To take part in the study or for more information please contact me, Mallory Drost, by phone at 647-925-1915 or by email at m.drost@unb.ca.

Communication via email is not absolutely secure. Please do not disclose personal or sensitive information via email.

This project has been reviewed by the University of New Brunswick Ethics Board.
APPENDIX AA: RESEARCH STUDY POSTER (NEW BRUNSWICK)

Research Volunteers Needed

ARE YOU A MAN WHO IS CARING FOR OR WHO HAS CARED FOR HIS FEMALE PARTNER WITH DEMENTIA?

I am a Registered Nurse and graduate research student at the University of New Brunswick. I would like to interview men about their current or past intimate relationship caring for their female partner who has (or had) dementia. You can take part in the study if you can read and speak English, and live in Canada. To take part in the study or for more information please contact me, Mallory Drost, by phone at 506-221-1880 or by email at m.drost@unb.ca.

This project has been reviewed by the University of New Brunswick Ethics Board and is on file as REB#2014-127.
APPENDIX B: DEMOGRAPHIC FORM

This information is collected to help us get to know you. All information will be kept confidential.

About you:

1. How old are you? (years) _______________

2. How long have you been (were you) married or lived common-law with your spouse? (years) _______________

3. How long have you been (were you) the caregiver for your spouse? (years) _______________

4. What is your current working situation?
   - Working full-time
   - Working part-time
   - Unemployed
   - Retired
   - Student
   - Other (please specify): ________________________________

5. Which of the following best describes your cultural/racial background?
   - White (Caucasian)
   - Black
   - Aboriginal (First Nations, Metis, Inuit)
   - Asian
   - Arab
   - Filipino
   - Latin American
   - Other (please specify): ________________________________

About your spouse:

6. In what year was your spouse diagnosed with dementia? _______________ (year)

7. How old is (was) your spouse at the time of diagnosis? (years) _______________
8. Where did your spouse live after being diagnosed with dementia or where does she live now?

- Home
- Outside the home If so, where? _________________________________
APPENDIX C: INTERVIEWING METHOD AND QUESTIONS

Introduction to Interview: I would like to ask you about your lived experience of caring for your female partner with dementia and how your relationship may have changed while you were her caregiver. These questions will focus on parts of your relationship, including affection, love, intimacy, and sexuality. To help you tell your story, I will ask you questions about your experiences.

1. Tell me what it was like for you when your female partner was diagnosed with dementia.

2. Tell me what it was like for when you became your female partner’s caregiver.
   Probes:
   • What led you to become your spouse’s caregiver?
   • What were your feelings when you decided to become a caregiver?
   • How would you describe yourself before you were a caregiver?
   • How has your description of yourself changed?
   • What has been the most difficult part of being a caregiver?
   • Tell me about some positive experiences of being a caregiver

3. Tell me about your relationship with your spouse before she was diagnosed with dementia.
   Probes:
   • What did you do together as a couple?
   • What was your day-to-day routine like? Can you give me some examples?
• Can you tell me about satisfaction with your intimate relationship including affection, love, intimacy and sexuality?

4. Tell me about your relationship with your spouse after she was diagnosed with dementia.

Probes:
• What has changed in your relationship?
• What has stayed the same in your relationship?

5. Tell me how you and your female partner have expressed affection since she was diagnosed with dementia?

Probes:
• How does where your spouse lives affect how you and her in expressing affection? (e.g., nursing home, hospital, own home)
• How do your relationships with others affect the way you and your spouse express affection? (e.g., healthcare providers, other family members)
• How do you see yourself within your intimate relationship with your female spouse in terms of affection, love, and sexuality?

6. Is there anything else you would like to talk about that you feel is important?
APPENDIX D: LIST OF COMMUNITY RESOURCES

1. Alzheimer’s Association Helpline: 1-800-272-3900

   This agency provides reliable information and support to persons in need of assistance while caring for a loved one with Alzheimer's disease during the day or night.

2. ALZConnected is an online space for patients and caregivers to connect with each other for support, to ask questions and to share community resources.

   https://www.alzconnected.org/?_ga=1.189096622.462698561.1369691725

3. Alzheimer's Navigator develops an action plan for families of the person with dementia based on surveys. It includes step-by-step information as well as information and programs in the local community.

   https://www.alzheimersnavigator.org/?_ga=1.144158384.462698561.1369691725

4. Alzheimer's Society of New Brunswick

   Phone: (506) 459-4280

   Visit http://www.alzheimernb.ca/site/web_links for support and services.

5. Alzheimer's Society of Ontario

   Phone: Tel: 416-967-5900

   Visit http://www.alzheimer.ca/en/on/We-can-help for support and services.
APPENDIX E: INFORMATION LETTER FOR PARTICIPANTS

Research Project Title: *From lover to loving caregiver: The lived experience of intimacy and sexuality in the transition to caregiver for spouses of those with dementia*

Research Team: Mallory Drost, RN, BN, Master’s of Nursing Student, Faculty of Nursing, University of New Brunswick, Fredericton, New Brunswick
506-221-1880 or mdrost@unb.ca

Dr. Krista Wilkins, RN, Assistant Professor, Faculty of Nursing, University of New Brunswick, Fredericton, New Brunswick
506-447-3077 or kwilkins@unb.ca

Purpose: I would like to learn about men’s thoughts and experiences regarding their relationship with their spouse living with dementia. I would like to talk with men who have cared for their spouse. Little is known about men’s experiences in caring for spouses living with dementia. I will use what is learned from this study to inform future research with male caregivers involved in dementia care.

Process: Taking part in this study means that you will speak with me about your relationship with your partner living with dementia. You will be asked questions about intimate parts of the relationship such as affection, love, and sexuality. The interview will take about an hour to complete.

When we meet to discuss your experiences caring for a spouse with dementia, it can be at a location that works best for you. If it is not possible to meet in person, we can use an internet program like Skype or talk by telephone. For this, you would need access to a computer with internet access or a telephone. What you speak with me about will be
recorded and typed, but will be kept confidential and used only for the purposes of this research project.

Benefits: There may not be any direct benefits for you for participating in the study. You may find that you enjoy talking about your relationship with your spouse who has (had) dementia. Your participation will contribute to the knowledge of professional caregivers and healthcare providers in order to improve health and services for other men who care for their partner with dementia.

Risks: There are no known risks for taking part in this study. If you become upset, we will stop talking and we only continue talking, if and when, you feel okay to do so. I will call you within 48 hours of talking with you to see that you are okay. If you wish, we will refer you to local resources like the local chapter of the Alzheimer Society.

Confidentiality: Any documents with your name or contact information will be kept locked and separate from information collected from our talk. Names and places will be removed from typed record of what you have talked about. This recording will be permanently removed from the digital recorder after it has been typed. Information collected from interview will be stored on a computer file for 2 years and will be protected by a password known only to me, as the researcher. Information collected will be identified only by a research number. This number will be assigned to you at the start of the study. Although I will protect your privacy as outlined, if the law requires it due to unforeseen issues (i.e., risks to your spouse), as a nurse I will be required to reveal certain personal information.
Your Rights: Taking part in this study is your choice. You may withdraw from the study for any reason at any time without consequence. You do not have to answer any questions you do not want to answer. You do not have to share anything you do not want to share.

Future Use of Study Information: Your information may be used in future studies, but only with further ethical approval from research authorities at the University of New Brunswick.

Being Informed About the Study’s Results: If you wish, you will receive a written copy of the record of what you said during your interview. You will also be able to request a summary of the overall study results that may include information from the other men who participated in this study. This summary will not contain any names or identifying information. If you wish, this summary will be sent to you by e-mail or Canada Post.

Information collected from you will be used for my master’s thesis, articles in professional journals and public talks. No real names or places will be used.

Additional Contact Information: This project has been reviewed by the University of New Brunswick Ethics Board and is on file as REB2014-127. If you have any concerns about the study or about your rights, you may contact the Research Ethics Office at (506) 453-5189 or ethics@unb.ca
APPENDIX F: INFORMED CONSENT FOR STUDY PARTICIPANTS

Research Project Title: *From lover to loving caregiver: The lived experience of intimacy and sexuality in the transition to caregiver for spouses of those with dementia*

This project has been reviewed by the University of New Brunswick Ethics Board and is on file as REB2014-127.

**Participant Questions**

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<tr>
<td>Has this study been explained to you?</td>
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<td>Have you read the attached information sheet?</td>
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<td>Have you been able to ask any questions you have about the information?</td>
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<td>Do you understand you can withdraw from this study at any point?</td>
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<td>Do you understand you will receive a signed copy of this consent?</td>
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**Participant Statement**

My signature confirms that I hereby give my informed consent to be a participant in this research study.

Printed name

Signature

Date
I wish to receive a written record of my interview. | Yes | No
---|---|---
I wish to receive a summary of the completed research. | Yes | No
I wish to be invited to a presentation about the research findings. | Yes | No

**Please provide your contact information:**

Email: ___________________________________________

Telephone number: _______________________________________

Mailing address: _______________________________________

____________________________________

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**Researcher Statement**

I have explained to the above participant the nature, requirements and the purpose of this study. I have answered any questions that have been raised. It is my belief that the participant understands the implications and the voluntary nature of this study.

Printed name __________________________
CURRICULUM VITAE

Name: Mallory Drost

Universities attended: University of New Brunswick, Bachelor of Nursing (2012)

University of New Brunswick, Masters of Nursing (2017)