

**BEING A MAN WHO CARES: EXPERIENCES OF RURAL MALE
CAREGIVERS WHO CARE FOR SPOUSES WITH DEMENTIA IN SOUTHERN
AND CENTRAL ALBERTA**

RYAN D. WALDORF
Bachelor of Nursing, University of Lethbridge, 2006

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WHO CARE FOR SPOUSES WITH DEMENTIA IN SOUTHERN AND CENTRAL
ALBERTA

RYAN D. WALDORF

Date of Defense: March 26, 2015

Dr. J. Kulig Supervisor	Professor	Ph.D.
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Dr. S. Spenceley Thesis Examination Committee Member	Assistant Professor	Ph.D.
---	---------------------	-------

Dr. L. Fehr Thesis Examination Committee Member	Senior Instructor	Ph.D.
--	-------------------	-------

Dr. K. Penz External Examiner University of Saskatchewan Saskatoon, Saskatchewan	Assistant Professor	Ph.D.
---	---------------------	-------

Dr. C. Witcher Chair, Thesis Examination Committee	Assistant Professor	Ph.D.
---	---------------------	-------

DEDICATION

“A man should look for what is,
and not for what he thinks should be.”

(Albert Einstein, 1879-1955)

This thesis is dedicated to my wife Rhonda, who has steadfastly supported me, even on the darkest of days. I would never have completed this work without your love, support, encouragement, and patience.

To my children Abby and Aspyn, do not be afraid to follow your dreams and never ever give up.

To my past and present instructors and professors, for helping me to realize the potential that I have. Thank-you also for encouraging me to write and recognize the power of the written word.

ABSTRACT

The purpose of this grounded theory study was to understand how male caregivers of spouses with dementia in rural southern and central Alberta perceive their role as a caregiver. Informed by the theoretical framework of masculinity theory, this research describes how rural masculinity is conceptualized and expressed by male spousal caregivers. Themes were created, with all themes and sub-themes being connected to the core category of *separating the wheat from the chaff*. Rural Male Caregiving Theory is a substantive theory that describes the perceptions and experiences of rural male caregivers. The research findings and how they are similar and contribute to the current literature on rural male caregiving is discussed. The findings from this research study will assist health care professionals in understanding what male caregivers are experiencing when in a caregiving role.

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CHAPTER ONE: INTRODUCTION

Male Caregivers of Spouses with Dementia in Rural Settings

I had an experience that profoundly influenced me while I was working as a clinical instructor in a rural hospital. I approached a male spousal caregiver and attempted to engage him in conversation. I wanted to reassure him that the health care team understood the struggles he was experiencing; that we were there to assist him and provide the necessary care for his spouse. He looked at me for a few seconds in the hallway, sighed deeply, and then shook his head. “You will never even begin to understand what I have experienced with my wife. A person that you have loved, raised a family with, has been your constant companion and support. Now, she hardly recognizes me, I have to dress her, feed her, give her crushed pills disguised in pudding, and calm her when she is screaming and frightened in the middle of the night.” He turned, walked into his spouse’s room, and began feeding her. I was left alone in the hallway, with the stark realization that he was correct. How could I have the audacity to claim to understand what he was experiencing? This research is my first attempt to truly understand the human experience of caring for a loved one with dementia.

Caregivers of older persons, individuals aged 65 and over, commonly take on the caregiving role and prefer to provide the majority of care required on their own (Hollander, Liu, & Chappel, 2009), despite the varying physical, emotional, financial, and social strains associated with this role (Shanks-McElroy & Strobino, 2001). Within Western society, there is an underlying assumption that spouses are obligated to provide care to their partner with dementia who may have fluctuating and unpredictable care needs for an indefinite period of time (Åberg, Sidenvall, Hepworth, O’Reilly, & Lithell,

2004; Keefe, 2011). Historically, female caregivers comprise the largest caregiving population, with wives and adult daughters making up an estimated 75% of the caregiving population (Malonebeach & Zarit, 1991; McMurphy, Szebeheley, Eliasson, & Olsson, 1993; Stone, Cafferata, & Sangl, 1987). Husbands are generally willing to take on the role of primary caregiver for their spouse, despite the unknown challenges and difficulties they may encounter. Canadian studies have varied on the estimated percentage of male spousal caregivers, but the proportion of male caregivers has been increasing, ranging from 19% in 1987 to 43% of the total caregiving population in 2008 (Cranswick & Dosman, 2008; Canadian Study of Health and Aging [CSHA], 1994a; 1994b; 2000; Kramer, 2002; Stone, Cafferata, & Sangl, 1987). This trend of males taking on the caregiver role has resulted in females representing a slim majority--54%--of the total caregiving population in the most recent analysis of caregivers in Canada (Sinha, 2013). A report on caregiving conducted in the United States found male caregivers accounted for 34% of the total caregiving population (National Alliance for Caregiving, 2009). In Great Britain, analysis of the General Household Survey [GHS] from 1991 to 1998 found men made up 40% of the population of carers aged sixty-five and older (Fisher, 1994; Hirst, 2001). The 2011 census from England and Wales found caregivers aged 75 – 84 years found the ratio of male to female carers was nearly equal with 50.4% of the carers being male (Slack & Fraser, 2014). However, the gender balance sways for carers over the age of 85, with 59% of carers being male (Slack & Fraser, 2014). As these survey analyses indicate, men are taking on the caregiving role in increasing numbers (Carrière, Keefe, Légaré, Lin, & Rowe, 2007). Despite this, male caregivers garner minimal attention from researchers and policy makers.

The age and stage of life that male caregivers are in when providing care to spouses with dementia must be taken into consideration when conducting research on this population. Spousal caregivers are more likely to be older; a study in the United States revealed 47.4% of caregivers are aged 75 or older (Wolff & Kasper, 2006); with husbands surpassing wives in the caregiving role at this age (Kramer, 2002). In Canada, it has been revealed that a little over half of informal caregivers are aged 60 and over, with an alarming 36% of caregivers being older than 70 years of age (Romonow, 2002). Due to their age, these caregivers are more susceptible to acute and chronic illnesses and disease (Messecar, 2012) and they have to stop or refrain from providing care when their own health deteriorates (Stoller & Miklowski, 2008). Caregivers of elderly people with dementia suffer from ailments that can be directly linked to their caregiving duties (Biegel, Sales, & Schulz, 1991; Schulz & Beach, 1999). Accordingly, spousal caregivers are often referred to as 'secondary' or 'hidden' patients who need protection, guidance, and education about the consequences of caregiving (Fengler & Goodrich, 1979; Reinhard, Given, Petlick, & Bemis, 2008) in relation to their health.

Globally, there are an estimated one million elderly male caregivers who are providing care to their spouses diagnosed with dementia, but minimal research has been conducted to assess their unique needs, experiences and perceptions (Cahill, 2000; Fromme et al. 2005; Kaye & Applegate, 1990; Russell, 2001; 2007). How men perceive their role as caregivers has been sorely neglected, despite the fact that caring for a family member with dementia has been recognized as one of the most devastating and challenging caregiving experiences that one can endure (Butcher, Holkup, & Buckwalter, 2001; Wackerbarth, 1999). The average length of time that husbands can anticipate being

in a primary caregiving role for their spouse diagnosed with dementia is five years (Harris, 2002). This sobering statistic reinforces the need to create a substantive theory to illuminate how men perceive their caregiving role. In this way, health care professionals would be able to understand the experiences that are unique for male caregivers who care for a spouse with a diagnosis of dementia in rural areas.

Dementia and Rural Spousal Caregivers

Dementia

Dementia commonly presents with difficulties in the affected individuals' recent memory and one or more changes in cognition, behaviour, mood, thinking, perception and insight (National Institute for Health and Clinical Excellence, 2006). What is crucial to note is that brain function is affected enough to interfere with an individual's ability to function in everyday activities, to an extent that cannot be explained by another disease process or acute state of illness (Stanton, 2001). Furthermore, there is no known cure for dementia (Rudd, Viney & Preston, 1999; Trigoboff & Wilson, 2004) and it remains the leading cause of dependency and disability among older people worldwide (Alzheimer Disease International, 2009). The progressive nature of dementia, along with functional disability, behavioural problems, and increased dependence on caregivers for routine activities of daily living, place substantial demands on caregivers (Chappell & Penning, 1996; Gwyther, 1998; Herrmann, Gauthier, & Lysy, 2007; Markle-Reid & Browne, 2001; Perel & Hopkins, 1998). Research has found that caring for someone with dementia is more difficult and burdensome than caring for an individual who has other chronic conditions and disabilities (Light, Niederehe, & Lebowitz, 1994) as there is no uniform course and no predictability to the rate of cognitive and physical decline (Tuokko &

Hadjistavropoulos, 1998). The persistent nature of caring for individuals diagnosed with dementia has been termed “the 36-hour day” (Mace & Rabins, 2006, p.1), which speaks to the unrelenting responsibilities placed on the caregiver (Biegel, Sales, & Shulz, 1991). All of these factors related to the disease can overwhelm or distress male caregivers who are attempting to provide care safely while maintaining a high quality of life for their spouse.

Spousal Caregivers in Rural Settings

Spouses play an integral role in caring for individuals in rural communities with a diagnosis of dementia. An estimated 55% of individuals diagnosed with dementia in Canada are residing in their homes, with 98% requiring assistance from a caregiver (Canadian Study of Health & Aging [CSHA], 1994b). A study of Canadian rural communities noted that the elderly can account for 20% to well over 30% of the total population (Hodge, McKay, & Beeckmans, 1993; Bryant & Joseph, 2001). Furthermore, rural populations are aging in place, resulting in an increased proportion of rural individuals having dementia or caring for someone with dementia (Forbes & Hawranik, 2012). Nationally, the population of older adults in rural areas is growing faster than in urban areas and populations living in rural settings experience a higher old age dependency ratio (Bollman & Clemenson, 2008; Hart, Larson, & Lishner, 2005; Statistics Canada, 2007). Alberta has been the only province that has experienced significant population growth from 1981 to 2006 in rural and small towns coupled with an increase in the ratio of seniors and the absolute number of seniors (Bollman & Clemenson, 2008). With these demographic changes occurring in rural areas in Alberta, there will be a significant number of seniors with a diagnosis of dementia requiring care.

Research Question

The research question that guided this study was: How do male caregivers of spouses with dementia in rural southern and central Alberta come to understand their role as a caregiver?

Purpose of Research Study

The purpose of my research was to explore the male caregiving experience and how male caregivers come to understand their caregiving role when providing care for spouses with dementia in a rural environment. Spouses are critical in ensuring people with dementia are able to continue residing in their rural homes (Schneider, Murray, Banerjee, & Mann, 1999), as the person with dementia typically relies on their spouse for constant and consistent support (Walker, Pratt, & Eddy, 1995). The rural setting where the care takes place contributes to the experience and meaning of the home environment (Williams, 2002). Moreover, there has been minimal examination of the experiences of men *as men*, as gendered beings, when in the active role of caregiver (Black, Schwartz, Caruso, & Hannum, 2008; Calasanti & King, 2007; Pretorius, Walker, & Malan Heyns, 2009; Ribeiro, Paúl, & Nogueira, 2007; Ribeiro & Paúl, 2008; Russell, 2007). The significance of male gender and gender relations (Connell, 2005) when taking on a caregiver role will be explored and expanded upon in this study. Despite the acknowledgment that the setting where the caregiving takes place has an effect on the caregiver and care receiver, very little research has examined dementia in a rural context (Blackstock, Innes, Cox, Smith, & Mason, 2006). For the purpose of my research, I will be using the rural and small town [RST] definition which is: “a population living outside the main commuting zone of larger urban centers (urban centers numbering 10,000 or

more)” (du Plessis, Beshiri, Bollman, & Clemenson 2001, p.6). Williams & Kulig (2012) emphasize that an advantage of the RST definition is that it designates small towns and the surrounding community as rural and allows for analysis of issues in these specified geographical areas. Thus, I have been able to analyze the experience of male caregivers and the issues that they encounter in specified geographical areas in southern and central Alberta.

Goals of Research Study

Researchers note that all too often caregiving research compares males to their female caregiver counterparts, and does not take into account the dynamic aspects of care needs, caregiving roles, and care outcomes (Ory, Yee, Tennstedt, & Shulz, 2000). The theoretical framework for this research was guided by masculinity theory (Connell, 2005), which will be expanded upon further in the following chapters. Understanding the social process of caregiving as perceived by men corresponds well with Straussian grounded theory methodology underpinned by symbolic interactionism (Corbin & Strauss, 2008), which is the qualitative method I have chosen for my research.

The processes involved in grounded theory methodology are characterized as inductive, emerging, and shaped by the researcher’s experience and the social lens they utilize in collecting and analyzing the data (Creswell, 2013). Consistent with the tenets of exploratory qualitative research, I have engaged in processes that have helped me recognize my influences on the research process and documented my thoughts and perceptions while engaged in research. Over time and by immersing myself in the data, a theory emerged from the data to explain the process (Corbin & Strauss, 2008) that rural men go through when becoming a caregiver. A further benefit of applying grounded

theory is the ability to examine the limitations and opportunities in the rural setting of everyday life of my research participants (Liamputtong, 2013). I was fortunate in having been born and raised in a rural setting. I found my rural background contributed to establishing rapport with the various male caregivers who agreed to be interviewed. This assisted me to uncover the importance of the rural setting in relation to the everyday life of my research participants.

Background on Research Study

The research question that I proposed has evolved over time from my prior work experience as a community transition team nurse, where one of my responsibilities was to transition elderly patients from an acute care hospital setting to care facilities located throughout southern Alberta. I have been either directly or indirectly involved with cases where male caregivers are physically, mentally, and emotionally exhausted as a result of the constant care required by their spouse with dementia. In my experience, it was not well understood by the nursing staff that nearly 60% of male caregivers spend eighty-four hours per week caregiving (Ducharme et al., 2006). There can be a generalized misperception that husbands are not able to provide adequate care and that men were not made or meant to be caregivers.

My interest in this research study also stems from my role as a male in a highly gendered profession, that gender being mostly female (Kellett, 2010); where men can often be misunderstood. From my experience and perception, male caregivers of spouses with dementia are also marginalized and misunderstood; nursing interventions are typically focused on supporting and educating female caregivers in the acute care hospital

setting and in the surrounding rural communities of southern Alberta. Therefore, my personal and professional situation has compelled me to conduct this research study.

Format of Thesis

In this chapter, the demographic shifts associated with caregivers and where caregiving takes place were both highlighted. This led to an identification of the knowledge gap and the significance of the research question. Rationale was given for the use of the rural and small town definition of rural for my research. Chapter Two provides an overview of the literature in relation to male caregivers for spouses with a diagnosis of dementia. Incorporated into the literature review is the recognition and importance of male gender and rural place and space where the caregiving occurs.

The design and methodology utilized for this study are discussed in Chapter Three. Throughout this third chapter, I examine my personal and professional assumptions before, during, and after entering the field. This chapter describes the rationale for selecting the theoretical framework, methodology, sample and sample size, setting, data collection method(s) and data analysis techniques employed during my research. I will consider the unique ethical considerations in relation to elderly male caregivers, and provide rationale on how I approach this marginalized population. I conclude this chapter by outlining how rigor was established and maintained during this study.

I begin Chapter Four with the demographic data of the twelve interview participants. I will discuss the themes arising from the data: watchful waiting, walking the walk, from breadwinner to bread maker, persevering patience, and crossing over. An

outline of the substantive theory created from the data is described under the core category of separating the wheat from the chaff.

In Chapter Five, I describe the limitations of the study and implications deduced from the findings in interacting with rural elderly male spousal caregivers for professionals and for the public at large. Possible interventions directed towards rural elderly male caregivers are presented, along with future considerations of resource allotment for elderly rural male caregivers.

Summary

My purpose in this research study was to describe how male caregivers residing in rural communities in southern and central Alberta come to understand their caregiving role. I will explore what it means to be a male caregiver of a spouse with dementia. It is my hope that this research study will inform interventions which are unique and provide benefits for male caregivers in rural communities.

CHAPTER TWO: REVIEW OF THE LITERATURE

Rationale for Topic

Male caregivers are growing steadily in numbers both provincially and nationally, but little is known about how they perceive their caregiver role. Dementia is the most significant cause of disability among Canadians over the age of 65, and the predicted surge in dementia cases is set to overwhelm our current health care system (Alzheimer Society of Canada, 2010). Dementia not only impacts people diagnosed with the disease, it also places an enormous long-term burden on those who care for them (Alzheimer Society of Canada, 2010; Armstrong, 2001). Distressingly, despite the amount of care provided to individuals with dementia, dementia is a progressive disease with no known treatment to cure or reverse the process; it remains a fatal disease (Smetanin, Kobak, Briante, Stiff, Sherman, & Ahmad, 2010). As a result of the rapidly changing nature and extent of the family network, spouses increasingly find themselves in the primary caregiver roles for their partners who require care (Carrière, Keefe, Légaré, Lin, & Rowe, 2007; Jansson, Nordberg, & Grafstrom, 2001; Kitwood, 1999). Being the primary caregiver for their spouse with dementia is “not a role typically aspired to, anticipated, or chosen” (Moen, Robinson, & Fields, 1994, p.S176) by male caregivers. The aging of the Canadian population is profound in rural and small towns (Dandy & Bollman, 2008; Petch & Shamian, 2008).

In this chapter, I outline and discuss the findings and implications from the literature in relation to male caregivers and the rural areas where they provide care. I begin by presenting demographic data and detailed information about the population commonly susceptible to dementia, followed by a chronological sequence of literature

published in relation to the phenomenon of male caregivers and how they inform and influence my research. I explore the significance of gender informed by masculinity theory in relation to caregiving. A summary of literature regarding rural male caregivers who provide care to spouses with a diagnosis of dementia is presented.

Demographic Profile

There is a growing number of studies, reports, and statistical data being compiled and released on the prevalence rates and costs associated with caring for individuals diagnosed with dementia. Numerous reports and Statistics Canada data detail the growing elderly population, who the individuals are who care for them, and where they are residing. The World Health Organization [WHO] (2012), in collaboration with Alzheimer's Disease International (2009), dedicated an entire chapter to caregivers for individuals with dementia, examining the issue from a global perspective. A document endorsed by the Alzheimer's Society of Canada entitled *Rising Tide: The Impact of Dementia on Canadian Society* examines the prevalence and impact of dementia at a national level (Smetanin et al., 2010). Provincially, the Alzheimer Society of Alberta brought to the forefront the impact of dementia using simulated projections of the population from 2008 to 2038 (Smetanin, Kobak, Briante, Stiff, Sherman, & Ahmad, 2009). Finally, a large, multicentre, longitudinal study on dementia was produced by the Canadian Study of Health and Aging [CSHA] (1994a; 1994b) that generated numerous studies and allowed for generalization of the data to our national and provincial population(s). What makes the CSHA population-based cohort study unique is the large overall sample of 10,263 people aged 65 or over from across Canada who were contacted in the community and in care facilities to create a better understanding about the

prevalence of dementia (McDowell, Hill, & Lindsay, 2001). The caregivers of individuals with dementia were interviewed during the study, providing rich data about individuals diagnosed with dementia and those who care for them residing in communities and care facilities across Canada (CSHA, 1994b). Unfortunately, the only published study from the caregiving interviews was from the first phase in 1994; hence, the information on caregivers of people with dementia in Canada is dated (CSHA, 1994a; 1994b). Furthermore, the study excluded samples of the elderly population from the Yukon and Northwest Territories, the rationale being that the numbers of elderly people living in those areas were small and the population was widely dispersed (McDowell, et al., 2001).

Prevalence rates of dementia

The CSHA found an estimated eight percent of all Canadians aged sixty-five and over met the criteria for dementia (CSHA, 1994a). A study conducted in the United States showed that nearly 14%, or one out of every seven individuals aged 71 years or older have some form of dementia (Shagam, 2009). It must be noted that dementia is not an expected and normal process of aging, but with aging there is an increased risk of being diagnosed with dementia (Hendry & Douglas, 2003; Smetanin, et al., 2010). Indeed, age is a primary risk factor for dementia, with the incidence of dementia in Canada accelerating as the population ages (Alzheimer Society of Canada, 2010; Hodge, 2008). The CSHA collated data from 22 previous studies from various parts of Canada, and determined that the occurrence of dementia doubled with every 5.1 years of age beginning at age sixty-five (CSHA, 1994a). This translates to an alarming 34.5% of individuals aged eighty-five and over living with some form of diagnosed dementia

(CSHA, 1994a; Hodge, 2008). This estimation is conservative compared with other researchers, who estimate that 47% of the population older than 85 years are affected by dementia (Butcher, Holkup, & Buckwalter, 2001). The cohort aged eighty-five and older is growing four times faster than any other segment of the Canadian population (Statistics Canada, 2006). Wenger (1987, 1990) noted that a higher proportion of people over eighty years of age in the general population results in higher numbers of dependent elderly, with many older caregivers in the population caring for them. An estimated 60,150 new cases of dementia are diagnosed per year in Canada, with 2008 demonstrating the highest rate ever with 103,700 new cases (Alzheimer Society of Canada, 2010; CSHA, 2000). This significant increase of new cases of dementia being diagnosed at a national level underscores the need for acknowledging and supporting caregivers.

Dementia can be undetected and untreated in the community for significant periods of time. Researchers Sternberg, Wolfson, & Baumgarten (2000) randomly selected 252 participants from the CSHA cohort to “estimate the frequency and correlates of undetected dementia in community-dwelling older people” (p.12). Of the 252 subjects, 64% had undetected dementia. The authors concluded that families may deny the degree of cognitive impairment that an individual is experiencing and caregivers may fail to detect dementia because of their misconception that cognitive decline is a normal part of aging (Sternberg et al., 2000). A second reason given for not detecting dementia in the community is that spouses can tend to minimize the extent of cognitive impairment in their partner (Nagatomo, Akasaki, Uchida, Tominaga, Hashiguchi, & Takigawa, 1999). Further survey data analyzed from the CSHA database found a median of 1.6 years elapsing between the caregiver’s first recognition of a dementia symptom and a physician

evaluation and eventual diagnosis of dementia (Sternberg et al., 2000). Internationally, it has been found that there can be a time delay of up to two years before a medical diagnosis of dementia is made (Cahill, 2000). This estimate was conservative, as Speechly, Bridges-Webb, & Passmore (2008) found that it took almost two years for initial contact with a healthcare professional and roughly 2.7 years from the care recipient's first symptom onset to receiving a diagnosis of dementia. These studies highlight the fact that the prevalence of dementia in Canadian communities may be higher than previously determined, with community-dwelling caregivers and care recipients being unidentified for extended periods of time.

From a provincial perspective, population projections estimate that within the next 30 years, 2.2% of the Alberta population is expected to have dementia (Smetanin et al., 2009). When examining the differences in the gender of Albertans diagnosed with dementia, females represent a significantly higher proportion affected by the disease. The graph below compares female and male gender and the projected increases of females and males that will be diagnosed with dementia in the province of Alberta (Smetanin et al., 2009)

Current and Future Dementia Prevalence in Alberta, Males and Females, All Age Groups: 2008-2038

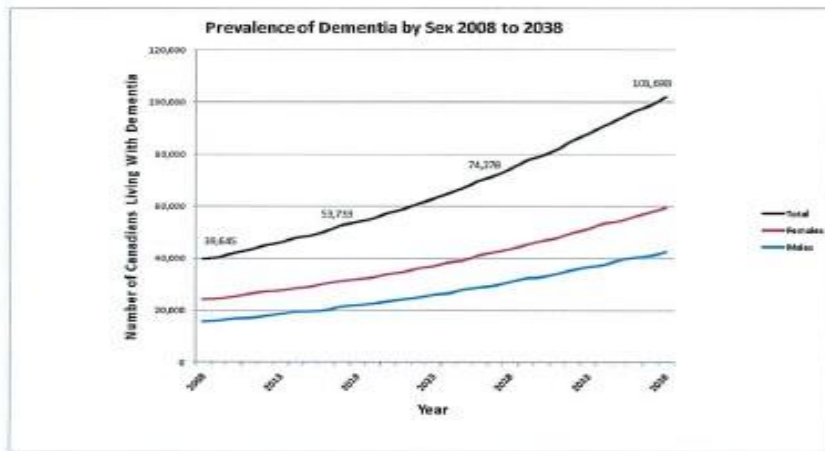


Figure 1.1. Current and Future Dementia Prevalence in Alberta: 2008-2038

These findings coincide with national data that show women are diagnosed with dementia at double the rate when compared to men (CSHA, 2000). This gender gap is increasing even further, with women representing 62% of dementia cases and 70% of new Alzheimer’s cases (Posluns, 2014). Women diagnosed with dementia can expect to live with dementia for 6.7 years, compared to 4.6 years for men until death occurs (CSHA, 2000). The majority of women diagnosed with dementia will require a full-time caregiver as the disease progresses and many of them will rely on the support of a spouse for their care needs in the community.

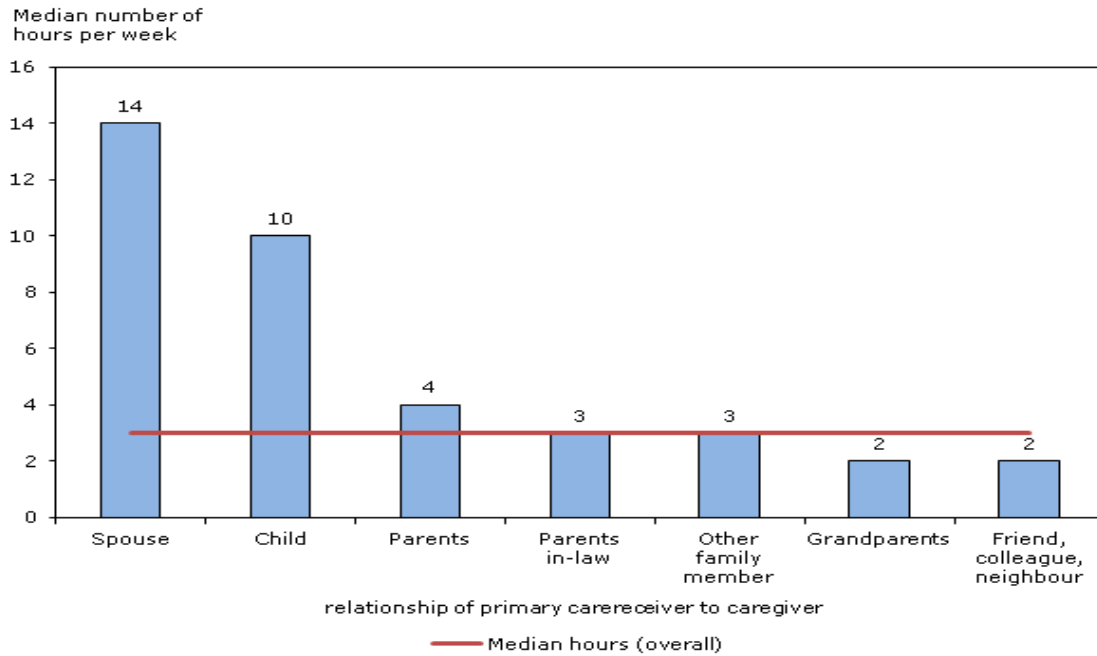
Caregivers of demented individuals

Spousal caregivers comprise the largest proportion of caregivers for individuals diagnosed with dementia (WHO, 2012; Alzheimer Disease International, 2009). Unfortunately, the key role that spouses play in caring for persons with dementia is often not supported or properly acknowledged anywhere in the world (WHO, 2012; Alzheimer’s Disease International, 2009). One of five recommendations made by the

Alzheimer Society (2010) following a two-year intensive study on the impact of dementia was to provide support for family caregivers. A call for the Canadian public and politicians to recognize the role and value of caregivers by supporting caregivers with information and training, meaningful and accessible respite care, and the development of other programs that support caregivers (Alzheimer Society, 2010) was made.

Provincially, it has been reaffirmed that providing caregiver support programs can delay or even negate the need for facility care for individuals with dementia and reduce caregiver burden (Smetanin et al., 2009). Despite these recommendations and the recognition that caregivers who provide care to a demented spouse provide the most hours of care per week (Baker & Robertson, 2008; Statistics Canada, 2013), the development and application of caregiver support programs focused solely on spousal caregivers has not been undertaken at either provincial or federal levels of government. The Canadian Caregiver Coalition (2010) has estimated that 7.4 hours of care is provided on a daily basis to individuals with dementia in the community. The chart below displays the median number of hours per week that a spouse provides is 14 hours, which drops to 10 hours when a child is providing care (Statistics Canada, 2012).

Chart 3
Median weekly caregiving hours longest when caring for a spouse or child



Source: Statistics Canada, General Social Survey, 2012.

Figure 1.2. Median Weekly Caregiving Hours When Caring for a Spouse or Child

An awareness of where individuals with dementia are cared for is required in order to gain a better understanding of the programs needed to service caregivers. A study taken from the CSHA data (1994b) described patterns of caring for individuals aged sixty-five and over with dementia in the community and care facilities across Canada. That study found that 55% of the individuals diagnosed with dementia in Canada were residing in the community, with over 98% of them requiring a caregiver (CSHA, 1994b). The caregivers in 94% of those cases were informal-family members, relatives, or friends (CSHA, 1994b). More recently, research has found that 90% of home care services are provided exclusively by informal family caregivers (Forbes et al., 2008; Keating, Fast, Fredrick, Cranswick, & Perrier, 1999).

Other research found that dementia caregivers were more likely than non-dementia caregivers to be spouses, rather than adult children or friends and neighbours (Ory, Yee, Tennstedt, & Shulz, 2000). Indeed, caregivers for elderly persons with dementia in Canada are most often spouses (36%), followed by daughters (28%) (Cohen, Pringle, & LeDuc, 2001). Furthermore, dementia caregivers were found to be older than other caregivers, to spend significantly more time on caregiving, and to assist with more activities of daily living than other caregivers (Ory, Hoffman, Yee, Tennstedt, & Shulz, 1999). The majority of spouses stopped providing care only when the deterioration of their own health required them to do so (Stoller & Miklowski, 2008). It has been suggested that spousal caregivers are the greatest at-risk group of caregivers, as they are elderly themselves and are therefore subject to negative health consequences (Johnson, 1979; Fengler & Goodrich, 1979; Shanas, 1979). Husband caregivers of individuals with dementia have been found to occupy the role of caregiver for a longer period of time when compared to caregivers of cognitively intact care recipients (Schneider, Murray, Banerjee, Mann, 1999), with the average length of time in the caregiving role being approximately five years (Harris, 2002). Other research has shown that dementia caregivers provide care for more than two years (Keating, Fast, Fredrick, Cranswick, & Perrier, 1999), with one-fifth of dementia caregivers providing care for five years or more (Haley, 1997; Stone et al., 1987).

The male spousal caregiver has several unique attributes. In a qualitative study consisting of thirty husband caregivers of individuals with dementia, the demographic characteristics of husbands ranged from ages 41 to 91, with a mean age of 72 years (Harris, 2002). The spouses providing care are more than likely seniors themselves,

placing them in a role that many had never anticipated when entering the age for retirement (Russell, 2007). A common assumption has been made that male spousal caregivers are not the sole caregivers in the home, that they allow family members to provide the care and they undertake a peripheral caregiving role that is more focused on the maintenance of the home. However, a survey in the United Kingdom of 609 male caregivers showed that 72% of the male caregivers were the only person providing care for the person requiring care in the household (Slack & Fraser, 2014). Men who provide care to their spouse spend 11 to 13 more hours per week on care (Frederick & Fast, 1999) when contrasted with their female counterparts. Kaye & Applegate (1990) found that the average amount of time male caregivers provide informal care is sixty hours per week. However, it is problematic to assess the amount of time husbands are involved in caregiving tasks, as they may not be familiar with them and the tasks were not a part of their previous normal responsibilities in the household (Walker, Pratt, & Eddy, 1995), as women may associate caregiving duties as part of a normal household routine. What is apparent is that husbands are working hard at caregiving, and how they come to understand their role as a caregiver needs to be understood.

Caregiving Literature

The earliest literature examining men as “caretakers” of their spouses (Vinick, 1983) was a report presented at a scientific meeting of the Boston Society for Gerontologic Psychiatry. Dr. Vinick noted “the role of men as caretaker has been relatively unexplored in the social science literature” (1983, p. 61). She explained that little data concerning the meaning of the caretaking role relating to males existed. She presented her findings based on a sample of twenty-five widowers who resided in a

coastal city. The study demonstrated recall bias (Cahill, 2000), as the subjects had all been widowed ranging from 2.5 to 3 years and were asked to recall the months or years they spent as caretakers of their disabled wives (Vinick, 1983). The study found that all but one of the male subjects accepted their role of caretaker as a duty for them to perform and that it would be difficult for elderly males who lack experience to nurse a disabled wife. Vinick (1983) concluded the report by noting that male caretakers may be more prevalent in the community than was perceived and they seldom received support from others in relation to their caretaking duties.

A chapter in a book was dedicated to the experiences of six older men caring for their disabled wives and their use of and knowledge about respite care in their community (Motenko, 1988). Motenko's (1988) focus for his research was threefold. He wanted to discover the meaning of spousal care to male caregivers, the meaning of respite care to male spousal caregivers, and the need for and utilization of respite care by male spousal caregivers. He employed a pilot, exploratory study as the methodology and interviewed six men in their homes. His profession as a social worker with ten years of experience gave him ready access to the elderly male participants for his study. The author credited his comfort in the role of an interviewer and observer to his work experience in the field as a social worker. While only one of the husbands interviewed cared for a spouse with a diagnosis of dementia, the length of time that the husbands had been caring for their wives had dramatic ranges of either 14 to 16 years or 3 to 6 years. Furthermore, he discovered that these men who cared for their wives found it a labor of love, with the desire and motivation to care stemming from their appreciation of the care and support that their wives had provided for them. Caregiving was viewed as more than the tasks of

cooking, cleaning, shopping, and numerous other daily tasks. It was an expression of their appreciation and love for their spouse, “a desire to reciprocate loving care and perpetuate a relationship that continues to hold valuable meaning for him” (Motenko, 1988, p. 111). Caregiving provided the husbands with feelings of affection, approval, esteem, and a sense of security and belonging. Essentially, caregiving had given them a role in society, to be needed by their wives physically, mentally, emotionally, and spiritually. The experience of caregiving was associated with pride and responsibility in these men—not resentment, burden, or stress (Motenko, 1988).

The years following these two publications were devoid of further information on male caregivers, but copious amounts of research pertaining to female caregivers was being published (Cahill, 1999; Ungerson, 1987; Lewis & Meredith, 1988; Brody, 1990; Aronson, 1991; Opie, 1992; Leira, 1994). Caregiving was viewed as a women’s issue, with research “undertaken predominantly by women about women” (Cahill, 1999; Paul, 1999; as cited in Cahill, 2000, p.54). Concerns were expressed by Horowitz (1985) that the burgeoning body of literature about caregiving for the elderly literally “translates into what is known about female caregivers” (p. 614). This research focus on female caregiving left the contributions being made by male caregivers in the shadows (Fisher, 1994; Harris, 1993), despite the desire for health care professionals to gain knowledge of the caring context of men (Lauderdale, D’Andrea, & Coon, 2003).

A study incorporating findings from Vinick (1983) was undertaken and was appropriately titled *Exploring the roles of men caring for demented relatives* (Mathew, Mattocks, & Slatt, 1990). The study consisted of two groups of men. Group 1 was composed of 12 men who provided direct care for an elderly relative at home with a

diagnosis of dementia. Group 2 consisted of 8 men, and were enrolled for a comparison group. These men had placed a relative with a diagnosis of dementia in a nursing home and acknowledged being the primary responsible party for that individual, although they were not involved in the daily care of the relative. All of the participants were required to have been in their caretaking role for a minimum of four months (Mathew et al., 1990). Despite being a primarily qualitative descriptive study consisting of interviews with open-ended questions, scales measuring caregiving burden and a functional dementia scale permitted quantitative statistical analysis to occur. Results from the quantitative data found that despite Group 1 men having to spend an average of 7.2 hours daily on care compared to Group 2 spending 1.7 hours daily on care, the two groups both experienced the same degree of mild to moderate caregiver burden. Qualitative results from the interviews found that the men were primarily motivated to become caregivers out of a feeling of love for the people they cared for, with a few men stating there was no one else available to care for the care recipient. Obstacles identified to providing care were the care recipients' confusion and their loss of the ability to communicate appropriately. A compelling finding was women caregivers preferred the use of support groups, whereas male caregivers asked for housework assistance. The authors noted that the men for the study were difficult to identify in the local population, they all hesitated to give consent, and some responses to questions asked during the interviews were very brief (Mathew et al., 1990). There was an identified need to sample a larger portion of male caregivers to be able to draw conclusions and to develop a database specifically focused on male caregivers.

In response to this need, a landmark study in the United States was undertaken by Kaye & Applegate (1990) with the sole purpose of developing a reservoir of information about the unique experiences and needs of male caregivers. The authors noted that changes were occurring in the ecology of contemporary families that challenged the feminization of caregiving and the assumption that women automatically assume this responsibility. The research project was three-tiered and incorporated a national survey analysis of men engaged in the elder caregiving experience, an intensive local assessment of male caregiver and family care receiver experiences in Pennsylvania and New Jersey's Delaware Valley, and program development. The research project had six main questions that formed the conceptual infrastructure for the study, and were qualitative and quantitative in nature. The quantitative data collected from the national surveys and the local caregivers allowed the development and use of multiple indexes that statistically calculated numerous caregiving tasks and the time taken to provide care. However, the sample of male caregivers selected was not randomized; it was a convenience sample of local caregivers that could not be generalized to the population. Furthermore, the local male caregivers were Caucasian, well educated, middle-class, retired men (Kaye & Applegate, 1990); clearly not a representative sample of the general population.

The qualitative portion of Kaye and Applegate's (1990) study examined and explored the caregivers' subjective experience of caregiver burden and caregiver satisfaction. This is the first instance the term *caregiver burden* (Kaye & Applegate, 1990) was discussed in detail in male caregiving literature. Caregiver burden refers to "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience" (Kasuya, Polgar-Bailey, & Takeuchi,

2000, p. 119). In contrast, the act of caregiving refers to “activities and experiences involved in providing help and assistance to relatives who are unable to provide for themselves” (Pearlin, Mullan, Semple, & Skaff, 1990, p.583). Walker, Pratt, & Eddy (1995) build upon this understanding of caregiving, emphasizing that it should include dependence on another person for any activity essential for daily living, including both instrumental activities of daily living [IADL] and activities of daily living [ADL]. Caregiving, as described in the literature, does not typically include the psychological distress that comes from caring, while caregiver burden is understood as the subjective and objective responses of the caregiver that are connected to the act of caregiving (Kasuya et al., 2000; Pearlin et al., 1990).

Factor analysis performed on male caregiver responses to the national survey data found that men described themselves as self-sufficient, gentle, compassionate, warm, and loving (Kaye & Applegate, 1990). These adjectives have traditionally been associated with the female gender role (Bem, 1974). The male caregivers saw themselves as more affective than instrumental, possessing measurable degrees of affective, expressive, and nurturing personality traits (Kaye & Applegate, 1990). The instrumental adjectives associated with men, which were analytical, yielding, competitive, aggressive, and forceful, all ranked lower on the factor analysis. However, when the local men were questioned in the interviews, they tended to reflect traditional stereotypic conceptions of gender roles and attributes, verbalizing that women are more sensitive and men are more efficient and less tender when providing care. These findings were fascinating as they presented a mixed picture of male caregivers’ gender-related attitudes. Kaye & Applegate

(1990) did stress that the findings were more suggestive than conclusive and more research was needed to confirm or refute their findings.

A study published in 1991 by Chang & White-Means examined the responses given by male caregivers surveyed in the 1982 to 1984 National Long-Term Care Demonstration funded by the U.S. Department of Health and Human Services. Male caregivers made up 27% of the total study population (Chang & White-Means, 1991). On average, husbands performed 65 hours a week of caregiving, and spousal male caregivers were more likely to provide hands-on personal care than a nonspousal caregiving man. A phenomenon that puzzled the researchers was the strong presence of husband caregivers being the sole caregiver of a frail elderly wife, despite the fact that the husbands were older than their wives and men, on average, have a shorter life span than women (Chang & White-Means, 1991). Indeed, Verbrugge & Wingard (1987) found that men tend to die younger and men are more likely than women to suffer from chronic conditions and fatal diseases. Are married men less prone to die younger and enter the role of the primary caregiver? This question was not addressed in this research (Chang & White-Means, 1991). However, recent research has demonstrated that married men live, on average, ten years longer than unmarried men (Waite & Gallagher, 2000).

The research uncovered that male caregivers had equivalent hours of caregiving to their female counterparts and reported to be healthier, more satisfied with life, more active in the labor market, and experienced less financial and physical stress that could be connected to the caregiving role. The authors concluded that these results raise a question for future study--whether gender-role differences are integral in explaining the

gender differences in caregiving behavior and management (Chang & White-Means, 1991).

In a 1993 qualitative study, Dr. Phyllis Harris conducted in-depth interviews with fifteen male caregivers from diverse backgrounds who were caring for wives with Alzheimer's disease. It was emphasized that husbands and wives provided consistent and dependable care for longer periods of time than any other caregiver group (Doty, 1986; Johnson, 1983; Motenko, 1988; Stoller, 1992; Stone, Cafferata, & Sangl, 1987.) The purpose of the study was to garner insight into the complex world of male caregiving and to understand what it is like for a man to take on the role of primary caregiver (Harris, 1993). The mean age of the male caregivers was 73 years (range 68 to 88 years) and the average number of years of marriage was forty-seven. The commitment and the dedication of the male caregiver were highlighted. Indeed, the initial theme identified in the study was commitment to the care recipient and to their caregiving responsibilities; this was a dominant feature throughout all of the interviews (Harris, 1993). Other research noted that caring for a partner with cognitive decline is part of the marriage contract (Miller & Montgomery, 1990), with the act of caring being performed out of a combination of love and duty (Davidson, Arber, & Ginn, 2000). Harris (1993) identified four types of male caregivers: the worker; the labour of love; a sense of duty; and at the crossroads. However, the participants were composed of a convenience sample from a local Alzheimer Society support group chapter (Harris, 1993). The typology of husband caregivers recognized the fact that not all husbands could be categorized into a homogenous group of caregivers, illustrating the need to explore this segment of the caregiving population.

Building on this typology of male caregivers, Harris (1995) took the findings and went one step further by identifying the differences among husbands caring for their wives and how their caregiving experience can have implications for health care professionals who provide counseling to both genders. The introduction notes that as the baby boomers began turning 65 in 2011, they would not remain in their stereotypical gender-role where the men are the primary breadwinners and women the homemakers and caregivers for all in the household. The four typologies are summarized, and counseling implications are made where Harris (1995) gives detailed descriptions of how each type of male caregiver would benefit from different approaches and activities provided by counselors who may interact with them. Assertions are made that male caregivers cannot be best understood by comparing them to female caregivers; they have unique caregiving differences that must be explored and they respond differently to various services and counseling approaches. Harris (1995) concluded by noting that an area of research that required further exploration was whether caregivers were affected by their demographic location, and if this contributed to diversity among male caregivers.

The next study to investigate the male experience of caregiving for a family member with Alzheimer's disease utilized a qualitative phenomenological approach, with the participants being five husbands and three sons (Parsons, 1997). Parsons (1997) pointed out the fact that more women than men are diagnosed with Alzheimer's disease, with the implication that men will be required to take on the role of primary caregiver. The need to examine how men experience the phenomenon of caregiving and to attempt to learn more fully what it means to be a man caring for an individual diagnosed with Alzheimer's disease was the main consideration for this study. Eight themes from the

analysis of the interview data were captured, and demonstrated that Alzheimer's disease shaped the men's feelings towards every aspect of their caregiving role. I appreciated the detailed description of the data analysis that specified how the author identified the themes in the data and discussed how she met with three other researchers to ensure that any areas requiring further investigation were identified to ensure the author's "decision trail" (Sandelowski, 1986) could be followed and the themes could be refined. The participants were interviewed, then contacted for a second interview approximately two months following the initial contact (Parsons, 1997). What the study did not include was the average age of the five spousal caregivers interviewed; in addition, no definition or parameters on the amount and intensity of the care provided was given. Parsons (1997) found that male caregivers enjoyed learning new skills and educating themselves about the health status of the care recipient and their caregiving responsibilities. Furthermore, male caregivers were noted to possess endless perseverance as the care recipient's health declined. Despite the caregivers not being sure of what kept them going, they found that their strength always came from somewhere. The diagnosis of Alzheimer's was also a significant factor with one caregiver noting "it's the worst disease you can possibly have." (Parsons, 1997, p. 404). This is telling of the toll the disease has on the caregivers who bear witness to the decline in cognitive and physical functioning of their spouses.

A study conducted by Kramer (1997a) utilized a cross-sectional study in an attempt to predict strain and gain among husbands caring for wives with dementia. The conceptual framework for the study was the model of caregiver adaptation. Kramer (1997a) recognized and acknowledged that the "tasks of caregiving for a spouse with dementia thrust individuals into a very demanding and distinct new role in which another

is dependent on them” (p. 240). Resources for husband caregivers consisted of physical resources (i.e. health), social resources (i.e. social participation), and coping strategies. What was interesting was that the theory of caregiver adaptation suggested that the way that the male caregiver copes with caregiving would influence their appraisal of the caregiving in terms of strain or gain. Expanding on this, problem-focused coping could promote well-being and the feeling of self-efficacy of the male caregiver when they were able to employ this coping strategy. Kramer (1997a) utilized hierarchical multiple regression analysis to determine the relationships between caregiver appraisal of strain and gain and if it could be attributed to their demographic characteristics, stressors, and resources available to them while in their caregiving role. Husbands with the highest levels of strain were managing spouses with more memory and behavior problems, were less satisfied with their social participation, and were in poorer health. A stated limitation of the study was that the findings could not be generalized to the rural elderly and caregivers who are members of non-traditional family groups. Kramer (1997a) emphasizes that her study is a small step in an attempt to understand husband caregiver appraisal of strain and gain. The assertion that older men are making a significant contribution to caregiving and are the primary source of support for older married women with physical and cognitive impairments was emphasized throughout this study.

A book authored by Harris & Bichler (1997) titled *Men giving care: Reflections of husbands and sons* intertwined Dr. Phyllis Harris’s previous work (1993; 1995) providing new contributions to the field of male caregiving. The assertion that spouses, when compared to all other caregivers, provide the most consistent and dependable care for longer periods of time (Doty, 1986; Johnson, 1983; Stoller, 1992) was reinforced.

What had not been explored was the male gender role and what Harris & Bichler (1997) termed the “masculine mystique” (p. 5). The key elements of the masculine mystique were: 1) control of self, others, and the environment was essential to proving one’s masculinity; 2) the expression of feelings and emotions should be avoided; 3) seeking help and support is a sign of weakness; 4) avoiding a display of vulnerability and intimacy with other men is imperative; and 5) a career is the measure of one’s success (O’Neil, 1982). Fortunately, as men and women age, Harris & Bichler (1997) argue that they experience and demonstrate more relaxed gender roles. This androgyny would entail older men becoming more nurturing and caring as they age; they would also feel freer to take on the caregiving role (Harris & Bichler, 1997). However, more recent biological research on the male brain in various life stages has uncovered that men go through profound hormonal shifts, characterized by a testosterone level at age 85 being less than half of what it was at age twenty (Brizendine, 2010). Brizendine (2010) suggested that the declining testosterone levels make men less aggressive and the concurrent increase in oxytocin and estrogen levels may make men more affectionate, devoted, sentimental, and nurturing. Hormonally, this is the closest ratio of estrogen to testosterone that men experience in their lifetime. Taken literally, it is the closest a man will ever come to being a woman. While the hormonal shifts can partially explain why men may become more nurturing and caring, there is much more to men than their hormones and the societal gender roles imposed upon them.

The goal of the book written by Harris & Bichler (1997) was to develop a framework that focuses on the *meaning* a man finds in his caregiving experience and the *motivations* he has for taking on this uncharacteristic role. The authors made it clear that

they would not compare men to women caregivers, as they wanted the men's voices unobstructed by gender comparison. A qualitative research approach was used to uncover findings about the day-to-day experiences of men in a caregiving role. A total of thirty husband participants were interviewed. The interviewers always prompted the husbands to start at a place that made the most sense to them; the researchers noted that some men had obvious difficulties expressing themselves. Eleven themes were garnered following data analysis, with a chapter devoted to the identification and exploration of the themes. The theme I was most intrigued with was titled "a sense of hope," (Harris & Bichler, 1997, p.20) as Alzheimer's disease has no cure and no definitive treatment exists. The sense of hope was in relation to the men not giving up hope, hope for a cure for dementia being discovered in their lifetime, hope for a better life, and just hope in general. I had assumed that male caregivers, when made aware of the diagnosis of dementia and the terminal result, would automatically lose their sense of hope. Harris & Bichler (1997) also discussed in detail the four typologies of husband caregivers identified in past research completed by Dr. Phyllis Harris (Harris, 1993; 1995). A further chapter was devoted to the service implications for husband caregivers (Harris & Bichler, 1997). The book presented the findings from the research in a clear and concise manner; and I appreciated the chapter dedicated to service implications for husband caregivers that could be employed by professionals who interact with them.

A study examining male caregivers utilized data collected from focus groups. This small focus group research study illuminated how male caregivers' coping skills, unique needs, role development, task provision, utilization of services, and potential service gaps (for the South Central Pennsylvania Alzheimer's Association Chapter

service area) were being met or neglected (McFarland & Sanders, 1999). The focus group met on three separate occasions to provide information about how the group could be more responsive and proactive in meeting the needs of male caregivers who care for individuals with varying degrees of cognitive impairment. The researchers found that men emphasized the instrumental and concrete tasks involved with caregiving, while minimizing their emotional reactions to the experience (McFarland & Sanders, 1999). Each male participant indicated his burden was lessened by continual self-education throughout the disease process; the participants went on to suggest that a support group for men to teach them techniques about caregiving would be beneficial. The more education given to them regarding caregiving, the more perceived control they felt over the disease and the disease process. From a gender viewpoint, the men found their new role as care providers, perceived as a female role, was a difficult hurdle, as it was not a readily accepted role for men. This could have been negated with more education and support from the local Alzheimer's Association chapter (McFarland & Sanders, 1999).

A study from Australia identified a lack of literature available on men as the primary caregiver, despite the increasing number of male caregivers sixty years of age and over caring for their spouses (Cahill, 2000). Using in-depth interviews along with survey instruments, the researchers collected quantitative and qualitative data regarding mens' caregiving experiences. Twenty-six husbands who cared for cognitively impaired wives in their home environments were chosen to participate in the study following referral from an assessment team at a Brisbane hospital. Cahill (2000) proposed that it was the quality of their previous relationship that bonded and held together caregivers with care-receivers. Cahill (2000) drew upon work conducted by Bytheway (1987),

where it was demonstrated that, in older husbands, “caregiving was motivated by a deep sense of reciprocal obligations and a concern to respond to the needs of the care-recipient” (p.56). Cahill (2000) noted that she would have preferred taking a purely qualitative approach to explore the complexities of the personal experiences of the men being studied, but that would have entailed losing the quantitative data that provided valuable insights into service needs and service utilization.

One example was the finding that 50% of the men in the study had the responsibility for urinary incontinence management, while 33% had spouses who were incontinent of both feces and urine (Cahill, 2000). While intimate personal care had been alluded to in previous literature (Kaye & Applegate, 1990; Kramer, 1997b; Parsons, 1997; Russell 2001), no one had quantified the care provided to such an extent. The conclusions that Cahill (2000) reached contradicted earlier research findings about male caregivers that men do not provide ‘hands on’ nursing care to the same extent as their female caregiver counterparts (Kaye & Applegate, 1990). Findings from Cahill’s study and Twigg & Atkin (1995) emphasized that health care professionals need to examine the way in which services to married couples are allocated, as men fail to ask for or receive supports. In an attempt to explain why men do not access services, it was surmised that certain assumptions are held by men about the need for privacy regarding their relationships and family life (Cahill, 2000).

A study exploring how husbands experience their position and themselves as caregivers to their wives with dementia was undertaken by researchers employing a qualitative discourse analytic approach (Kirsi, Hervonen, & Jylha, 2000). The authors state that the findings on male caregivers have been fragmented and contradictory, and

methodologically flawed, which has contributed to the limited amount of systematic knowledge available about men's actions as caregivers. In a response to this need, Kirsi, et al., (2000) asserted that their research was an attempt to respond to the need for research with an appropriate methodology that will produce substantive knowledge in the field of male caregiving. These authors observed the effects of having a population that is aging, improvements in our western living conditions, public health programs, the evolution and treatments available in modern medicine, and the recognition of how to live and promote healthier ways of life as factors that have steadily increased people's average life expectancy. As an unintended consequence, the researchers found that instead of enjoying the easy days of stress-free retirement, increasing numbers of elderly men and women are now spending their time giving care to spouses afflicted with dementia. The researchers analysed 159 stories submitted by Finnish men and women who were giving or who had given care to their demented relatives. The focus for this research was narratives from the fifteen stories written and submitted by the husbands, which was independently analyzed and interpreted by all of the authors. Results uncovered a tension between being a caregiver and being a man and that this tension should be acknowledged by healthcare professionals who provide support for family caregivers (Kirsi et al., 2000). This finding underscores the need for research focused on gender roles in the elderly male caregiver population to uncover the tensions that surround this inherently feminine role.

An observational study was conducted by Jansson, Nordberg, & Grafstrom, (2001) whose aim was to describe caring activities performed when caring for a spouse with dementia. The sample size consisted of eight individuals, with only two husbands

represented in the sample. The researchers reported that during data collection, the observer would stay in the background to observe events without disturbing the routines of the caregiver, and that no changes in the environment or behaviour took place as a result of the visit. Four broad themes were identified: activities of daily living; communication; supervision; and activity/stimulation. The authors noted that all caregivers shared “remarkable similarities in the way that they performed the caring role” (Jansson et al., 2001, p.809), but more importantly the caregivers were caring *for* as well as *about* their partners. To elaborate, caring *for* was about the performance of personal care tasks, while caring *about* referred to the emotional aspects of care; this might also include the relational and affective elements of being caring (Milligan & Wiles, 2010). Jansson et al, (2001) noted that a person afflicted with dementia continuously deteriorates and it may threaten their self-image. The emergence of protecting the care receiver from being aware of their increasing decline while upholding their individual integrity and preserving, as much as possible, their sense of self were important aspects of dementia care. The authors conclude that too often in our modern society, informal care provided by spouses appears to be more or less invisible and performed in silence within the family. The essence of spousal caregiving was brought to the forefront in this study and it was acknowledged that informal spousal caregivers are engaged in demanding and time-consuming care that is not fully appreciated by the population at large. Jansson et al., (2001) contend that spouses, who are willing and able to help their partners, are given the best resources possible, and that the required support is continued throughout the progression of the disease.

A qualitative study examined fourteen elderly men who were the primary caregivers of their wives diagnosed with dementia (Russell, 2001). In this study, Russell provided a clear and precise definition of primary caregivers and detailed descriptions of the care receivers. Furthermore, the author described the two distinct theoretical perspectives that have emerged from the literature relating to male caregivers. The first perspective infers that the work of male caregivers, for the most part, is ineffective and inconsequential. The second perspective suggests “that men are indeed capable caregivers, adaptive and innovative, able to manage as well as nurture in providing competent care” (Russell, 2001, p.353). The findings supported the second theoretical perspective of male caregivers and stressed that research on elderly men should be focused on the experiences of men as *men*, as gendered beings (Russell, 2001). Russell’s findings support Thompson (1997) who suggests that men are forgotten and are invisible as men in a western culture that considers them to not have an active role following retirement from the work force and views aging as decline and disability. Russell (2001) concludes his study by stating that caring for elderly individuals presents an immense societal challenge and the qualitative examinations of experiences as profound as caring for another must be continued. This will benefit both the male caregiver and the care recipient as the world continues to age.

Despite a growing base of caregiving research being created and disseminated in relation to both men and women, a clear and precise definition of what it means to be a caregiver was lacking in family caregiving literature (Walker, Pratt, & Eddy, 1995). This was rectified when Betty Kramer and Edward Thompson (2002) co-edited a book: *Men as Caregivers: Theory, Research, and Service Implications*. In the introductory chapter,

Kramer (2002) articulates what occurs when men embark upon caregiving when she states "...men become caregivers when they are called upon to consider the physical or psychological needs of others, and in so doing experience changes in their expected and accustomed roles, behaviors, social or interpersonal relationships, and perceptions about themselves of others" (p.7). This definition of caregiver is one that takes a holistic approach to caregiving and recognizes that when men enter the role of a caregiver their roles and perceptions about themselves are drastically altered and changed forevermore.

A qualitative narrative approach was used in order to analyze eleven free-form written texts and thirteen focused interviews with Finnish husbands who had provided care to their wives with dementia (Kirsi, Hervonen, & Jylha, 2004). The goal of the study was to find out how husbands qualify their actions as spousal caregivers. The authors acknowledged the need for research that recognizes that dementing illnesses affect the well-being of the patient afflicted as well as their close relatives and primary caregivers. The data obtained for the study were eleven accounts written by husbands describing the care of their spouse, with the average length being 3.5 pages. In the interview process, the authors state that male interviewers conducted ten out of the thirteen interviews; the remaining three were conducted by female interviewers. The transcripts of the interviews conducted by the female interviewers were shorter (7.8 pages) compared to their male counterparts (12.1 pages). This implies that the gender of the interviewer may reflect the amount and depth of the interview data collected. The authors took a social constructionist view of reality (Berger & Luckmann, 1967). It was assumed that male spouses, who have been married for decades to the same individual, would detect minor changes in their spouse with cognitive decline (Kirsi et al., 2004). However, this was not

the case; with several men describing they always felt ‘one step behind’ in relation to their spouses’ cognitive and physical decline. All of the spouses interviewed took on household chores for their wives and with the progression of dementia more personal care was performed. However, while the male caregivers spoke and described taking on household chores as taking charge of the activity, and being proud of the outcome: in regards to personal care the active subject of action disappears, and the caregiver is reacting to the deficient action of his partner. Personal care was not something that caregivers were proud to have learned and accomplished, it was a task that they had to perform in their role as primary caregiver. The findings of the Kirsi et al., (2004) study coincided with Harris’s (1993) four typologies of caregivers. Many topics discussed by the caregivers linked to Parsons (1997) eight themes, but the authors did question the “existence of a uniform essence of men’s care experience” (Kirsi et al., 2004, p.177) as Parsons (1997) asserted that her findings constituted all the caregiving experiences of male caregivers. It was noted that few husbands had participated in or even wanted to participate in support groups for family caregivers, as they felt marginalized in groups dominated by women. This finding is supported by other research: a survey of 339 adult family caregivers of individuals diagnosed with dementia found that only 25% of caregivers had joined or participated in a support group (Shagam, 2009). Finally, Kirsi et al. (2004) noted that the quality and type of outside formal support for traditional domestic caregiving, such as Meals on Wheels for men who were perfectly capable of coping with household chores, was regarded as patronizing. What the men reported appreciating was the support of their existing competencies and the opportunity to learn new ones (Kirsi et al., 2004). These implications are profound, but have not been

disseminated extensively to individuals who interact with male caregivers on a daily basis.

Despite research surmising that men, in comparison to women, do not find caregiving as burdensome or as stressful, men consistently report difficulties in openly expressing their emotions (Fitting, Rabins, Lucas, & Eastham, 1986; Barusch & Spaid, 1989; Pruchno & Resch, 1989; Miller & Cafasso, 1992). Indeed, Lutzky and Knight (1994) propose that the difference in stress levels between males and females could be attributed to the gender bias of the self-reported measurement scales wherein males are reluctant or unable to express their stress level adequately. It is problematic to compare the two genders in a role that is highly correlated with female gender and use measurement tools that are subjective in nature.

A study that employed grounded theory to identify the strategies family caregivers used in the home to care for their relatives diagnosed with dementia was undertaken by Carmen de la Cuesta (2005) in Colombia. Data consisted of eighteen interviews with informal family caregivers and two health care professionals and participant observation in caregivers' support groups and homes. De la Cuesta (2005) purposefully selected care recipients in an advanced stage of dementia as it has been confirmed that they confront caregivers with the greatest physical and emotional demands (Collins, Liken, King, & Kokinakis, 1993). There is no formal public support for dementia patients and their caregivers in Colombia, so caregivers rely upon themselves, relatives, friends, and neighbours for support in the caregiving role (de la Cuesta, 2005). The substantive category that emerged by employing the constant comparison method was eventually termed the *craft of care* (de la Cuesta, 2005). The

researchers found that “caregiving is a craft in the sense that it seeks to respond to needs aiming at restoring health” (de la Cuesta, 2005, p. 885). Caregivers strove on a daily basis to get their relatives to accept being taken care of and to accept them as caregivers. This study had key insights on how care was tailored to meet the needs of severely demented individuals that can be applied by health care practitioners to assist them to assess caregivers’ needs and support them in their creative efforts, especially caregivers who lack the inventiveness of caregivers interviewed in this study (de la Cuesta, 2005).

The vast majority of research undertaken on male caregivers has been conducted internationally. However, a Canadian descriptive study (Ducharme, Levesque, Lachance, Zarit, Vezina, Gangbe, & Caron, 2006) that focused on the context and relational aspects that characterize care provided by older husbands to their wives brought a fresh perspective to male caregiving. The sample size was large, consisting of 323 older husbands caring for their wives with diminished functional or cognitive capacity in Quebec. The authors note that despite older husbands being the largest group of male caregivers, there has been minimal research on this niche segment of caregivers. Ducharme et al., (2006) utilized a theoretical model developed by Pearlin, Mullan, Semple, & Skaff (1990) to examine the “constructs relative to the relational aspects of caregiving involving the caregiver, the cared-for person and family members” (p. 568). What this study added to the field of male caregiving was the recognition of men spending significant amounts of time in a caregiving role. It was found that nearly 60% of the caregivers spent 84 hours per week caregiving (Ducharme et al., 2006). The research also affirmed earlier research that men assist in activities of daily living with bathing being performed by 39% of the husbands and dressing being performed by 54% of the

husband caregivers. Men had a tendency to minimize their needs in regards to accessing formal and informal service utilization of health and social welfare agencies in their community. Since study participants had wives with and without cognitive impairment, comparisons could be made between the two groups. It was found that husbands spent more hours per week providing care to wives with memory problems, with a number of husbands spending up to 21 hours per day caring for wives with cognitive decline. False beliefs that male caregivers are few in number and do not want to provide personal care to their wives abound, despite older husbands being the fastest growing group of caregivers in the western world were refuted through this study's findings. A significant limitation to this study is its lack of comparability to international data, due to universal medical coverage in Canada that provides certain community care and respite care services (Ducharme et al., 2006). Results cannot be generalized to other groups of husband caregivers, as the subjects were based on a convenience sample, despite having a large number of participants.

A close examination of the work of caregiving that elderly men perform in their home was undertaken by Richard Russell (2007), a social worker from the Rochester-Monroe County area of upstate New York. The participants for the study comprised a purposeful sample recruited through human-service agencies in Rochester-Monroe County; ten of the 30 participants were recruited through local churches, hospitals, and key informants via word of mouth. The two main themes that originated from the data were: the work that nobody sees and the joint managerial and nurturing style of caregiving used by men. The first theme related to the visible work that men did in public social locations when employed; that was contrasted with the largely unseen and

unacknowledged work undertaken when they entered their caregiving role in their homes. It was noted that care work seldom elicits formal recognition of accomplishment and achievement; that this work was invisible and unappreciated, even from immediate family members and neighbours who interact with caregivers on a daily basis. However, if something was built and in view, such as planting and maintaining a garden, that work was readily acknowledged, yet the “care work that sustains, maintains, or restores the status quo, remained invisible, unacknowledged, and unappreciated” (Russell, 2007, p. 305). The role that male gender has in relation to caregiving provides some explanation about why this care work is not recognized by our society. The second theme related to the skills for many men in the study when caregiving including being both managerial and nurturing. The skill of managing their caregiving was rolled over from when these retired men were employed in the workforce. This allowed men to seek out and organize outside help as a coping mechanism of managing their own lives, along with the life of the care recipient. Men readily discussed their management or organization of caregiving, but were much more hesitant to discuss and describe the emotional or affective aspects of caring. Russell (2007) issued a call to continue to challenge the long-held assumptions of rigid gender roles and the need to revise the way we conceive the social organization of care work as we move forward in understanding the phenomenon of male caregivers. As a society, we must be willing to expand our preconceived notions of what a caregiver is and the support required for the role to be enacted successfully. However, in Russell’s study, the men did acknowledge that caregiving was a combination of management, nurturing, and emotional commitments that ultimately benefited the care receiver.

A social worker and assistant professor from the University of Iowa, Dr. Sara Sanders conducted a qualitative phenomenological study to examine the experiences of 20 male caregivers with their informal support networks. The average age of the men was 73 years old, and all the care recipients had some form of dementia in addition to another chronic health condition. She specifically looked at two phenomenon: 1) perceptions of the male caregivers about the willingness of their informal support networks to provide caregiving assistance and 2) willingness of the male caregivers to ask their informal support networks for assistance (Sanders, 2007). Despite the assertion that rural male caregivers were targeted for the sample, no definition or parameters in relation to rural were given. The sample consisted of male caregivers who resided in rural communities in a primarily rural state in the Midwestern region of the United States. A precise definition for informal supports was included “a group of family members, relatives, friends, and neighbors who provided assistance” (Li, Edwards, & Morrow-Howell, 2004, p.57).

After the interviews with 20 participants on two separate occasions approximately four months apart, seven themes emerged from the data (Sanders, 2007). The seven themes were divided into two main areas; the first area consisted of four categories associated with how the male caregivers viewed the willingness of the informal support networks to provide caregiving assistance. The four categories were labelled: 1) not involved with care, 2) emergency assistance only, 3) feel free to call if we could be of help, 4) part of the caregiving team. The help that male caregivers desired from the informal support network was more instrumental (i.e., assisting with laundry, transportation, respite, or yard work) than emotional care. The second area explored the degree to which the male caregiver was willing to ask for help. The three categories were

labelled: 1) asked for assistance, 2) felt guilty about asking for help, 3) did not ask for help. The guilt associated with asking for help was related to the fact that their support systems were in a similar age group or were also caregivers. The men verbalized feeling guilt when asking for assistance from others who have numerous responsibilities of their own. A possible factor that contributed to their support systems being in a similar age group was attributed to residing in a rural community where supports could be strained due to younger people leaving the area and being less proximate to neighbors. The two areas and subsequent identified categories are interrelated, but highlight the complexity that occurs when male caregivers seek out caregiving assistance from their informal support networks. Sanders (2007) implores it is imperative that health professionals who work and interact with rural male caregivers have knowledge about issues “specific to men, such as their strategies for accessing help, patterns for problem-solving behavior and coping patterns, as well as the gender roles in the community and the potential obstacles that they may face as caregivers” (p. 113). She concludes that issues male caregivers have may be radically different from the issues that are expressed by female caregivers and health care providers must be willing to explore this with male caregivers.

A systematic literature search was undertaken by Baker & Robertson (2008) to determine what was currently known about men coping with caring for someone with dementia. The vast majority of articles focused on reporting research and interventions with minimal analysis of how gender acted as a mediating variable for coping with caregiving (Baker & Robertson, 2008), despite the acknowledgment that psychological processes related to caregiving may be vastly different for men and women (Miller & Cafasso, 1992). By not focusing on gender as a critical factor in caregiving research, an

unintended consequence is that the gendered nature of caregiving remains essentially unquestioned and uncontested (Hooyman & Gonyea, 1995; Kaye & Applegate, 1990) in the literature. Indeed, I was taken aback when four of the articles in the literature review reported no sex-differences in coping and burden between male and female caregivers (Chiverton & Caine, 1989; McConaghy & Caltabiano, 2005; Saad et al., 1995; Pot, Deeg, & Van Dyck, 2000). The remaining nine articles focused exclusively on male caregivers, and while the general consensus was that men experience caregiving differently from women, the impact of gender was not investigated to any great depth (Cahill, 2000; Davies, Priddy, & Tinklenberg, 1986; Harris, 1993, 1995, 1998; Kramer, 1997; McFarland & Sanders, 1999; Russell, 2001; Siriopoulos, Brown, & Wright, 1999). In their conclusion, Baker & Robertson (2008) make an appeal for better conceptualised and designed research to understand how men cope and experience caregiving for someone with a diagnosis of dementia. Despite the awareness of gender differences persistently being raised in many areas of research, it is rarely investigated to any great depth. The authors contend that if we were to focus on deepening our knowledge with how men cope with the challenges of dementia caregiving, it would not only enrich our understanding of the caring role, but it would also contribute to the development of appropriate interventions for male caregivers.

How we understand the ways that men experience and manage the strain of caregiving was the focus of a Norwegian study (Knutsen & Råholm, 2009). The author contends that male caregivers are hidden caregivers and if we do not identify and support them, the informal family care system may collapse. This phenomenological study utilized Giorgi's method of analysis to describe the experiences of men taking care of

their wives with dementia. Knutsen & Råholm, (2009) found that the nine men in the study expressed a wish to be able to speak to other men in the same caregiving situation. The male caregivers felt it was their duty to carry on with home-based care, and mastering caregiving skills gave them a sense of satisfaction and joy. If the men became exhausted in their caregiving role and had to seek augmented formal or informal support, they reported intense feelings of guilt. The finding that caring for a relative with dementia can lead to emotional distress and physical exhaustion (Alfonso, Krishnamoorthy, & Gomez, 2010) is not unique, but the feelings of guilt associated with asking for help was a new and compelling finding.

The negative aspects and stressors associated with caregiving has been the primary focus of caregiving research on male and female caregivers. Researchers have attempted to compare and contrast how male and female caregivers who care for demented and cognitively intact individuals identify and respond to caregiver burden (Akpınar, Kucukguclu, & Yener, 2011; Allen, 1994; Almborg, Jansson, Grafstrom, & Winblad, 1998; Eters & Harrison, 2008; Fitting et al., 1986; Kim, Chang, Rose, & Kim, 2011). This focus on the negative results in minimal attention given to the positive and rewarding aspects of caregiving, creating a skewed perception of caregiving that limits our ability to fully understand caregivers (Kramer, 1997b; Louderback, 2000).

To rectify this growing disparity, Pretorius, Walker, & Malan Heyns (2009) incorporated a salutogenic model that specifically focused on successful coping, and represents a new way of thinking about caregiving stressors. The concept of salutogenesis is focused on locating and examining factors which are responsible for the formation and maintenance of health (Buch, 2006). The purpose of the study was to explore the

experiences of ten men caring for spouses living with dementia in South Africa (Pretorius et al., 2009). Qualitative methodology was primarily used in the study, with limited quantitative measurement to “extend the framework for the interpretation of the qualitative data” (Pretorius et al., 2009, p. 83). Male caregivers preferred to engage in problem-focused coping strategies rather than apply emotional coping strategies in attempting to manage caregiving situations. The utilization of problem-solving processes in relation to caregiving activities has been identified by other researchers (Cahill, 2000; Parsons, 1997; Siriopoulos, Brown, & Wright, 1999). In the Pretorius et al. (2009), study, individuals reported high levels of caregiver burden on the Carer Burden Inventory survey, but did not verbally report any difficulties in relation to experiencing caregiver burden during the interviews. The male caregivers were found to be effective caregivers and experienced their role as a caregiver as comprehensible, manageable, and meaningful. Key desires for male caregivers were greater access to time for recreation and regeneration. Results of the quantitative data gathered that indicated two of the caregivers were in poor general health and 22% of the caregivers were at risk for the development of mental disorders (Pretorius et al., 2009). The combination of qualitative and quantitative methodologies allowed the researchers to compare interview findings to instrument findings on the subjects being studied, which formed some new conclusions that were not readily apparent in past research.

Research completed by social workers gave a different perspective on 17 husband caregivers of care recipients with various forms of progressive dementia coupled with a minimum of one chronic disease (Sanders & Power, 2009). The main research question was “What are the changes in the roles, responsibilities, and relationships that husbands

experience as they provide care for chronically ill wives?" (Sanders & Power, 2009, p. 42). Phenomenology was the qualitative methodology employed, and the participants were interviewed twice over the span of four months to allow for changes in the caregiving situation and to confirm reliability of the husbands' quotes from the first interview. The two themes, with each theme compiled of four supporting sub-themes were 1) adaptation of old roles within the marital system to new roles that are associated with the responsibilities of caregiving; and, 2) changes within the relationship between the caregiver and the care recipient as a result of the onset and progression of memory loss and other chronic health condition. The authors noted that the most common coping method reported by the men was the clear designation of some form of personal time each day. The men in the study also found it difficult to express their emotions. Sanders and Power (2009) attributed this to male caregivers being socialized to withhold emotions and to process the emotional and psychological effects of caregiving individually. The authors also called for future research on male caregivers to include both rural and urban settings to determine if there are differences in their experiences based on where they provide care. Thus, a call was made for future work to examine and contrast rural and urban male caregivers to examine if place and space (Williams, 2002) have a significant effect on the experience of caregiving.

A review and commentary was undertaken by McDonnell and Ryan (2013) on male caregiving for individuals diagnosed with dementia. In the introduction, they speak about the aging demographic as a worldwide phenomenon, with the risk of developing dementia increasing to one in five individuals aged 80 years and older (Howcraft, 2004). Men are noted for the role they play in providing care for cognitively impaired older

adults in the communities in which they have chosen to reside (Houde, 2001). The total number of manuscripts included in the review was fifty-six, with husbands, sons, and other male relations and non-relations included in the criteria (McDonnell & Ryan, 2013). The findings reaffirmed that in our society caregiving is gendered, with women providing more care than men (Martin, 2000; Pretorius, Walker, & Malan Heyns, 2009; Shanks-McElroy & Strobino, 2001). Male spousal caregivers account for 41% of total spousal caregivers in the United States (Brown, Chen, Mitchell, & Province, 2007). McDonnell and Ryan (2013) note that a large amount of research conducted about male caregivers involves qualitative methodologies, and while valuable insights are generated on the role of the male caregiver, they are limited in relation to the ethnicity of the caregiver and lack of differentiation by relationship to the carer that limits the ability to generalize findings. They call for the findings from these studies be used to inform a quantitative study that would include a vast representative sample utilizing national or even international databases (McDonnell & Ryan, 2013). To be a part of a national Canadian endeavour to create and manage a data base that is a representative sample of male caregivers that could influence and inform policy makers at every level of government is a goal that I have for my career.

A scoping review of men caring for a person with dementia was undertaken by Robinson, Bottorff, Pesut, Oliffe, & Tomlinson (2014). The review only included peer-reviewed articles from 2007 – 2013. Book chapters, conference proceedings, dissertations, and articles without an abstract or title that did not refer to the topic of caregiving in the title were excluded from the review process. In total, 30 studies were retained for review representing, qualitative ($n = 14$), qualitative ($n = 14$), and mixed ($n =$

2) methods of inquiry. It is critical to note that the majority of studies ($n = 17$) compared male and female family caregivers of persons with dementia and therefore, do not apply to my research topic. Three major themes were identified from the studies that add to my thesis background: men's experiences of caregiving, relational factors in caregiving, and stress-related outcomes of caregiving (Robinson et al., 2014).

This scoping review (Robinson et al., 2014) affirmed that men are taking on caregiving roles at an increasing rate, accounting for 40% of caregivers in Canada (Baker, Robertson, & Connelly, 2010; Frederick & Fast, 1999) and 41% of spousal caregivers in the United States (Brown, Chen, Mitchell, & Province, 2007). This has been attributed to rapid population aging coupled with a higher percentage of women being affected by dementia, resulting in the increasing need for male family caregivers of persons with a diagnosis of dementia (Baker et al., 2014). One conclusion is that our current understanding of the influence of gender-related factors on dementia caregiving is at an emerging stage (Baker et al., 2010) of development. However, there is also a realization that male caregivers favor a more independent approach to caregiving resulting in men accessing less formal services and supports than their female counterparts (Baker & Robertson, 2008; Cahill, 2000; Zodikoff, 2007).

The identification that none of the studies in the scoping review employed gender frameworks or masculinities to inform their study design or analysis (Connell, 1987, 2005; Howson, 2006) was compelling; the articles that were included lacked depictions of male caregiving that acknowledged the diversity and differences within and across men's lives (Robinson et al., 2014). The absence of a unifying masculinity theoretical framework continues to be a significant gap in the research literature, particularly as

health care professionals want to apply descriptive work collected in the field toward effective interventions for male caregivers (Robinson et al., 2014). Indeed, the need for more knowledge to be created and disseminated in relation to male caregivers is necessary and vital for health care providers working alongside male caregivers in rural communities.

Summary of Caregiving Literature

The recognition and development of knowledge in relation to male caregiving is a relatively recent phenomenon being explored in the literature. It was enlightening to review studies that incorporated a variety of exploratory qualitative methodologies that created new ways of understanding male caregivers (Harris, 1993; Kirsi et al., 2000; 2004; Knutsen, 2009; Parsons, 1997; Pretorius et al., 2009; Russell, 2001; 2007). Three studies employed both quantitative and qualitative methodological approaches (Cahill, 2000; Ducharme et al., 2006; Kaye & Applegate, 1990), while other studies utilized quantitative statistical analysis to contribute to the qualitative data collected (Jansson et al., 2001; Mathew et al., 1990; Pretorius, et al., 2009). However, the vast majority of the current research has been conducted in urban settings. It is apparent that more research is needed that specifically addresses male caregiving experiences with spouses who have dementia in rural settings. It has been recognized by Houde (2002) that there are many “gaps in the scientific base of knowledge related to male caregivers” (p.634). My research attempts to close a gap in the literature, by utilizing a masculinity theory framework and integrating the importance of rural place when providing care.

Theoretical Framework

Male Gender

In the next section, I examine the literature in relation to male gender and our society, and introduce the theoretical framework of masculinity theory and how it informs my research. Caregiving has been associated with female gender in western society, as traditionally women have provided the bulk of care and assumed the caregiving role more often than their male counterparts (Calasanti & Bowen, 2006; Campbell & Carroll, 2007; Martin, 2000; Pretorius, Walker, & Malan Heyns, 2009; Shanks-McElroy & Strobino, 2001). There has been a corresponding belief that women are naturally better at giving care (Walker, 1992). However, the act of caregiving and being cared for does not discriminate between genders; men and women are equally capable of caregiving (Coston & Kimmel, 2013). Despite this assertion, interviews conducted with a sample of 53 older men regarding their caregiving experiences when caring for their unwell wives found “the gendered nature of caregiving as a feminine role was present in all interviews without exception” (Ribeiro, Paúl, & Nogueira, 2007, p. 305). Thompson (1997) asserted that male caregivers are often compared against a ‘feminine yardstick,’ where males are portrayed as less capable than their feminine counterparts in their role as caregiver (Kaye & Applegate, 1994; Stoller, 1990; Young & Kahana, 1989). Moreover, Russell (2001) portrayed caregiving as being a double threat to males, as “they are judged to be deviant as caregivers if they offer types and amount of care that differ from women, [and] are judged to be deviant as men if they care in the same manner as women” (p. 354). Indeed, all too often men are ridiculed and diminished when partaking in various roles such as doing the dishes, sewing, or wearing an apron in

a kitchen (McLean, 1996). Personally, I can vividly recall my anger when my step-grandfather jeered that I would “make someone a good wife, someday,” whenever I assisted my grandmother with dishes, or when I took interest in the crafts my grandmother was engaged in. There is undeniable contempt and hostility directed towards men when referring to men as having feminine traits (McLean, 1996). Men are socialized in our western culture to accept these traditional caregiver role stereotypes (Chang & White-Means, 1991; Harris, 1993) and often equate caregiving as being in a realm that endangers their sense of masculinity and self-conceptualization of what it is to be a man (Kaye & Applegate, 1990b; Ribeiro et al., 2007). It is not an understatement when Coston & Kimmel (2013) assert that caregiving is “among the most gendered activities in which we engage today” (p. 193). To gain a sense of what men may be experiencing when caregiving, it is necessary to understand how gender is acquired and demonstrated in our western society.

Gender and Society

Prior to conducting my research, I did not appreciate the role that gender has in relation to caregiving. Gender is a concept that has the potential to be defined in various ways depending on an individual’s philosophical, social, cultural, historical, political, and intellectual perspective (Kellett, 2010). Chafetz (1990) contends that “along with age, gender is and probably always has been the most salient marker of human beings in virtually all societies” (p. 14). Age and gender are key in relation to speaking about elderly male caregivers, as gender permeates all aspects of sociocultural and individual life (Chafetz, 1990). Bradley (2007) contends that gender is a social construct used by individuals as a way of dividing up the world they perceive around them and making

sense of it. Moreover, Lorber (1994) views gender as a social institution. It represents the social order constructs that holds individuals to strongly gendered norms for their behavior (Kilmartin, 2000; Lorber, 1994). Gender is therefore not fixed, but can vary according to time, place, and culture and is politically bound up with power relations between women and men (Bradley, 2007). Furthermore, Bradley (2007) emphasizes that gender must be viewed as a lived experience as it “refers to aspects of our lives that are all too real” (p. 4). Adding to this, Harding’s (1986) perspective is that the role of gender in social organizations is necessary as “gender difference is a pivotal way in which humans identify themselves as persons, organize social relations, and symbolize meaningful natural and social events and processes” (p. 18). The concept of gender *symbolizes* social events and is a *process* that is continually being produced and reproduced (Wharton, 2012) in context. Therefore, it stands to reason that in the current study, I need to capture representations of gender in the setting where the research takes place, if I am to understand the impact that gender has in relation to the experiences of rural male caregivers.

The process of gender acquisition entails that “the social practices of a society preprogram individuals’ daily experiences to fit the ‘default options’ of that society’s culture for that particular time and place” (Renzetti & Curran, 2003, p. 81). Concurrently, individuals are constantly bombarded with implicit lessons about what is valued, and what differences between people are significant in that culture (Connell, 2000, 2005; Renzetti & Curran, 2003). In regards to published male caregiving literature, gender has been examined conceptually only in reference to sex-roles (Carpenter & Miller, 2002; Connell, 2000, 2005). However, the sex-role approach to gender has the tendency to treat

gender as a variable rather than a theoretical construct; this has the effect of reinforcing an approach to gender that is dichotomous and static (Stacy & Thorne, 1985). Moreover, sex-role theory “explains gender patterns by appealing to the social expectations that define proper behaviour for women and for men” (Connell, 2000, p. 18). From these points, it is apparent that sex-role theory has limitations and is not an ideal theoretical framework for caregivers. Connell (1987) argues that the sex-role theory as a framework for analyzing gender must be abandoned for a number of reasons, as follows: it is unable to theorize power and social interest, it is dependent on biological dichotomy, it is dependent on a normal standard case, and it does not address a way to theorize gender (Connell, 1987). To overcome this, a novel approach proposed by Campbell & Carroll (2007) views gender as a performative act; “something that males and females *do* in particular contexts by adopting behaviors that establish themselves as ‘male’ or ‘female’ in the eyes of others” (p. 492). The main tenet of ‘doing gender’ is the belief that “*doing gender* can vary-not just across cultures or across historic periods, but also from situation to situation within the same culture” (Campbell & Carroll, 2007, p. 492). For example, it was a family tradition that my father prepared the turkey and stuffing every holiday season. Friends and family found this practice quite unusual, as the accepted social norm at that time was that the mother prepared the turkey and stuffing every holiday season.

This section expands upon the importance and impact of what one perceives as a social norm relating to your culture, society, and historic period. Cialdini & Trost (1999) define social norms as the rules and standards that guide and constrain one’s behavior. Due to the establishment of these social norms, individuals learn what is expected of them in their day-to-day social interactions (Mahalik, Locke, Ludlow, Diemer, Gottfried,

Scott, & Freitas, 2003). In the way that these social norms influence people to engage in behavior, gender role norms come into effect when individuals observe what most men or women do in social situations and are told what is acceptable or unacceptable behavior for men or women (Mahalik et al., 2003). When approaching adulthood, the majority of men have learned to behave in a gender-appropriate manner (Brizedine, 2010) and what standards or expectations are associated with being masculine (Mahalik et al., 2003). They are then able to ‘do gender’ in a socially acceptable manner and learn what is expected of them in their gendered lives and relations. ‘Doing gender’ for a man is influenced by multiple masculinities and how he chooses to display and enact them.

Development of Masculinity Theory

Research on men is pervasive in social science literature, but a focus on men as gendered individuals and their masculinity has been a relatively recent undertaking (Morgan, 1981; Connell, 1987). Psychologists created a masculinity scale in the mid-1970’s to code the four basic ‘rules’ or traits of manhood (Brannon & David, 1976; O’Neil 1981). The identified traits of manhood were:

1. ‘No Sissy Stuff’: Manhood is defined by the distance from what was perceived as feminine.
2. ‘Be a Big Wheel’: Manhood is measured by the size of one’s paycheque; wealth, power status, and success are its defining features.
3. ‘Be a Sturdy Oak’: Manly stoicism is what makes men reliable in a crisis.
4. ‘Give ‘em Hell’: Men are adventuresome, exhibiting risk-taking and aggression (Brannon & David; 1976, p. 1-48).

Suggesting the “traits of the manhood” (Brannon & David, 1976) scale was an initial attempt at examining men and grouping them by how they expressed and displayed themselves in society. However, the scale did not acknowledge or make allowances for men who had traits and exhibited behaviors not touched upon in this scale.

During the 1980s, studies involving men were becoming more sophisticated and concepts were being developed to capture the multidimensional and socially constructed aspect of male dominance in Western society (Connell, 1987). Specifically, the concept of 'hegemonic masculinity' was beginning to appear in the academic masculinity literature (Connell, 1987). The definition of hegemony can be traced back to the ancient Greek term 'hegemonia.' When translated, the term effectively means 'to lead' (Wickersham, 1994). In relation to masculinity theory, hegemonic masculinity involves a specific strategy for the subordination of women and dominance of men (Donaldson, 1993). Connell (1987) contends that hegemonic masculinity represents "a largely symbolic, though legitimate, ideal type of masculinity that imposes upon all other masculinities (and femininities) coherence and meaning about what their own identities and positions within the gender order should be" (p. 98 - 99). The concept of hegemony was introduced into masculinity theory to deal with relational issues (Connell, 1983; Kimmel, 1987). Specifically, the connections between the differences among men, and the relations between men and women (Connell, 1983; Kimmel, 1987). This ideal type of masculinity emerges from the social-cultural milieu, and it becomes the benchmark against which all men must gauge their success in the gender order (Connell, 1987). In the Western hemisphere, the dominant image of masculinity that emerged in the mid-1990s was that of 'the self-made man' (Kimmel, 1996). The ideal traits that these men displayed were stoicism, having unwavering and fierce resolve, being emotionally impenetrable, and being viewed as an armour-plated machine with no apparent weakness (Kimmel, 1996). For many men, this entailed working hard, providing for their family, and remaining tough through the hard times (Howson, 2006) to obtain the hegemonic

masculinity ideal. 'The self-made man' (Kimmel, 1996) was the form of masculinity that occupied the hegemonic position and contributed to the pattern of gender relations (Connell, 1995) during the 1990s. It also perpetuated the core principle inherent in hegemonic masculinity; for man's dominance over women to continue (Connell & Messerschmidt, 2005), as men were in the position of being the primary breadwinner for their family.

The following decade saw a dramatic increase in published material related to men and masculinity theory (Connell, 2005; Kilmartin, 2000). Specifically, Kilmartin (2000) identified 12 distinctive personality traits that men exhibit. The traits were: strength, independence, achievement, hard work, dominance, heterosexuality, toughness, aggressiveness, unemotional, physicality, competitiveness, and forcefulness. These identified traits did not include any traits that could positively influence caregiving or care-receiving and did not allow men to obtain adequate caregiving skills (Coston & Kimmel, 2013). Indeed, these identified traits only compelled men to suppress their feelings: contributing to a variety of psychological, physical, and social problems (Real, 1997). Unfortunately, the description of prohibited activities that the stereotypical man could not engage in were: crying, expressing feelings other than anger, performing 'women's work' (i.e., washing dishes, changing diapers), backing down from a confrontation, getting emotionally close to other men, asking for help, and behaving in a 'feminine' way (Kilmartin, 2000). The majority of these prohibited activities, performing 'women's work,' asking for help, expressing emotions, and behaving in a 'feminine' way (Kilmartin, 2000) can be encountered when entering into and engaging in a caregiving role. These personality traits of what constituted masculinity had a powerful influence

over what both men and women believed men should be, setting men up for difficult late-life experiences (Coston & Kimmel, 2013) when they were called upon to be a caregiver.

To overcome the limitations in examining men in relation to their personality traits (Kilmartin, 2000) and their role as a caregiver, a relational account of gender can be used to theoretically understand the different dimensions or structures of gender (Connell, 2000). By applying the relational account of gender that views gender as a way in which social practice is organized, Connell (2000) created a four-fold model that could be used to describe the structure of gender relations: power relations, production relations, cathexis, and symbolism. I will discuss each of these pillars of gender relations and how they relate to the male caregivers I interviewed.

Power relations. Power relations refers to the main axis of power in Western society, with the gender order consisting of the overall subordination of women and dominance of men (Connell, 2000). Women's liberation terms this 'patriarchy,' and this general structure exists despite attempts at local reversals (i.e. woman-headed households) (Connell, 2000). Coltrane (1994) argues that "authoritative males and nurturing females from ancient times come to stand for some underlying masculinity or femininity that supposedly resides deep within humans. Unfortunately, this imagery resonates so closely with Western culture's gender ideology that most people accept the tribal portrayals as evidence of the inevitability of patriarchal power and feminine frailty" (p. 46). I find it fascinating that our Western culture has embraced the inevitability of patriarchal power, and that attempts to reverse patriarchy have been met with steadfast resistance. I contend that male caregivers unconsciously practice the overall subordination of their spouses with a diagnosis of dementia, related to the cognitive

impairment that accompanies the disease process. Men then take a position of power in the relationship and must make the decisions and choices in relation to the functioning of the household.

Production relations. This refers to the gender divisions of labour in the form of task allocation (Connell, 2000). Attention is paid to the economic consequences of gender divisions of labor, specifically the benefits accruing to men from unequal shares of the products of social labor, termed the “patriarchal dividend” (Connell, 2000, p. 25). This patriarchal dividend is evident in our western capitalist economy that operates through a gender division of labour. The social construction of masculinity contributes to men controlling the majority of corporations and extensive private fortunes. Connell (2000) asserts that the accumulation of wealth is firmly linked to the reproductive arena, through the social relations of gender. The men I interviewed were the primary wage earners in their household, and all but one of the men had wives who left the workforce following their marriage.

Cathexis. Cathexis is considered the desire, or emotional energy, being attached to an object (Connell, 2000). Desire is often viewed as being natural, so it is commonly overlooked and excluded from social theory. However, Barbalet (1998) emphasizes that emotions such as desire, are integral in relation to social theory development. Therefore, “the practices that shape and realize desire are thus an aspect of the gender order” (Connell, 2000, p. 25). Connell (2000) asserts that this is true for both heterosexual and homosexual desire. In relation to my research study, it is the past and present desire that men, in their role as husband, experience toward their spouse.

Symbolism. The final pillar in Connell's (2000) model recognizes the process of communication as being a vital element of social process. Symbolic structures are called into play when communicating that include grammatical and syntactic rules, as well as visual and sound vocabularies. These are crucial instances of gender practice and reinforce a belief in gender dichotomy. An example of this is addressing women by titles that define them through their marital relationships to men. Connell (2000) also notes the symbolic presentation of gender (through dress, makeup, gesture, even the tone of voice) used in conversation is an important part of the everyday experience of gender. I noted that one particular caregiver placed great emphasis on his spouse no longer having the initiative to apply make-up. The application of make-up symbolized beauty and the female gender from his perspective.

Following the new direction that Connell (2000) proposed to examine gender and masculinities, a period of intense debate on masculinities ensued. Attempting to define masculinity or what masculinity means to rural male caregivers is an arduous task, as being masculine is a fluid state of being and under constant revision by individuals. Attempts at locating the origin of masculinity have proven fruitless. Indeed, Reeser (2010) has concluded "that there is no single or simple origin to masculinity, and that it cannot be isolated as beginning in a single place or at a single point. Rather, it is constantly created and challenged in numerous ways" (p. 18). Even more telling was Reeser's (2010) assertion that "there is no single model that everyone turns to in order to define masculinity and to imitate it when they want to be or to act masculine" (p. 18). In an effort to elucidate the concept of masculinity, Raewyn Connell (2005), a pioneer in the development of masculinity theory, contends that "we need to focus on the processes and

relationships through which men and women conduct gendered lives” (p. 71). The process that I will be exploring is the experience of male caregivers, and how their relationships with their spouses change over a period of time. Following the rationale of focusing on the processes and relationships that men and women are engaged in at the time, Connell (2005) writes:

‘Masculinity’, to the extent the term can be briefly defined at all, is simultaneously a place in gender relations, the practices through which men and women engage that place in gender, and the effects of these practices in bodily experience, personality and culture (p. 71)

Thus, being masculine or having masculinity is having a ‘place’ in gender relations, the ‘practices’ that men and women engage, and the ‘effects of these practices’ that are simultaneously occurring. Moreover, Connell (2005) rationalizes “that one’s behaviour results from the type of person one is” (p. 67). Demonstrating, or acting out masculinity, is displayed by and reflected in an individual’s behavior.

Rural health status. My contention is that a large number of rural males engage in behaviors that are not beneficial to their health status. Indeed, multiple studies have demonstrated that among rural population(s), men are less likely than women to be receptive to help, to seek support, or to visit a physician (Cook & Tyler, 1989; Dansky, Brannon, Shea, Vasey, & Dirani, 1998; Hoyt, Conger, Valde, & Weihs, 1997; Sorensen, 1994). Rural male farmers are even less inclined than other rural men to seek medical assistance for any urgent or chronic medical issue or concern (Courtenay, 2011).

Campbell, Bell, & Finney (2006) suggest that rural men delay or neglect seeking medical assistance related to the ‘hypermasculine swagger of rural masculinity’ that they display. Courtney (2006) discovered that rural farming men commonly remain stoic, even in the face of extraordinary circumstances. Unfortunately, this behavior, considered normal for

rural men, can have significant detrimental health consequences as it severely impedes their ability or motivation to seek help (Alston & Kent, 2008) and address their own health needs during times of heightened or prolonged stress (Courtney, 2006). I contend that this stoicism connected to rural masculinity also influences men in the role of a caregiver. They are often unable or unwilling to ask for help, despite the unanticipated consequences for them and their spouse with dementia.

Caring men. The recognition of gender and masculinity and the influence they have on male caregiving must be taken into account and applied to theory development. In previous decades, spanning from the 1960s to the 1990s, women had the responsibility for the work of child rearing, food preparation, and care of the household. Men's participation in such tasks ranged from none at all to substantial, while women's participation remained uniformly high in our Western society (Chafetz, 1990). The responsibility for the household places women in a relationship of inequality, where they end up fulfilling the nurturing imperative (Gilligan, 1982). In other words, a woman cares for others, often silencing her own negative feelings in order to serve and nurture selflessly (Gilligan, 1982). Meanwhile, the men dominate the household by patriarchal control and experience patriarchal dividends in the workforce (Connell, 2000). However, a small segment of men are finding increased cultural permission to be nurturing and affective -- and to express these attributes through caring for others (Kaye & Applegate, 1990). Indeed, Connell (1990) has recognized a change in heterosexual men learning about and becoming engaged in domestic labour that involves "giving to people and looking after people" (p.463). For some men, it is considered normal to care about the

interior as well as the exterior of one's home (Donaldson, 1993) and to engage as an equal partner in household work (Johansson & Klinth, 2008).

Despite there being a portrayal of how rural masculinity is manifested in popular literature and films, academic research on masculinity in rural communities has been limited (O'Lynn, 2010). Rural men are characterized as being 'real men,' as they hunt in the wilderness, operate large and dangerous machinery, and are not afraid to get dirty (Sachs, 2006). Levant & Habben (2003), while recognizing the complexity of gender and multiple masculinities within men, propose that rural men are more traditional in their masculine ideology when compared to their urban counterparts. Masculinity as an ideology refers to "a series of beliefs that a group of people buy into and that influences how they go about their lives" (Reeser, 2010, p. 20). The dominant ideologies displayed by the rural men that Levant & Habben (2003) observed were toughness, self-reliance, homophobia, avoidance of feminine behaviors and emotionality, and a high value placed on accomplishment and work. Furthermore, the reputations of rural men were highly visible and carried a lot of weight (Levant & Habben, 2003). This contributed to men keeping their problems very private and compelled them to avoid seeking assistance from others, especially health and human service assistance (Levant & Habben, 2003). Thus, rural men aspire to achieve a hegemonic ideal on their standing "as a man among other men" (Nadler, 2014, p. 32). Unfortunately, this aspiration to achieve the hegemonic ideal places male caregivers in a position of self-imposed isolation from health and human service assistance that could benefit both them as a caregiver and their care recipient.

Rural icon. A prevalent icon of the rural masculine individual in southern and central Alberta is that of the farmer and rancher. These men struggle "to survive against

all odds, heroically staving off the bankers and weather through plowing, planting and harvesting for days on end without sleep” (Campbell, Bell, & Finney, 2006, p. 5). They display characteristics such as ruggedness, tenacity, perseverance, and strength (Miller, 2004). Rural life is commonly patriarchal, even more patriarchal than urban life, although this has not been objectively measured (Campbell, et al., 2006). With Alberta’s vast expanse of fertile land and rolling pasture for cattle in the foothills, rural farmers and ranchers exert their physical strength to conquer the natural elements, while concurrently maintaining and operating the farm machinery required to work the land (Ward, 2013). Similar attributes can be seen among Alberta rural men who are engaged in other kinds of natural resource extraction including logging, mining and the oil industry although these rural men have not been studied to a great extent. The Alberta rural man and the study of how he displays his masculinities is significant because the Alberta rural man is a product of his environment (Ward, 2013). Typically, the Albertan approach to gender remains uncritical as it fails to consider the manner in which gender is constructed and created (Ward, 2013). Indeed, Connell & Messerschmidt (2005) emphasize the need to recognize the geography of masculinities and to take this into account when applying masculinity theory to selected groups of men. My research will incorporate how gender and masculinities were displayed by the Alberta rural men I interviewed.

The Importance of Rural Place

I have chosen to examine the experiences of male caregivers of spouses with dementia in rural southern and central Alberta. Older adults are overrepresented in most rural places and their proportion of the population is growing faster than in urban areas (Hart, Larson, & Lishner, 2005; Statistics Canada, 2007). Internationally, rural areas are

aging faster than urban areas, leading to higher proportions of older people in rural communities (Innes, Morgan, & Kostineuk, 2011; Dandy & Bollman, 2008). There are several reasons that rural small towns are experiencing rapid growth of the elderly population in Canada. These include that small town seniors tend to age in place (Hodge, McKay, & Beeckmanns, 1993); the out-migration of youth to larger urban centres (Bryant & Joseph, 2001); the attractiveness of some rural communities for people retiring from the workforce (Jauhiainen, 2009; Ministerial Advisory Council on Rural Health, 2002); and that retiring elderly farming populations are more likely to move to a nearby town than to move away (Hodge, et al., 1993).

In relation to individuals with dementia and their caregivers, it has been shown that 55% percent of individuals diagnosed with dementia are residing at home in their communities (CSHA, 1994a; Smetanin et al., 2010). The goal of aging in place is that persons living with dementia and their family caregivers are living as well as possible in a place they call home (Forbes & Neufeld, 2008) and are able to continue living in one's own home while adapting to each other's changing needs and conditions (Fänge, Oswald, & Clemson, 2012). For the elderly, the home environment and personal space are the most significant variables facilitating their independence, as a familiar home can compensate for reductions in physical functioning and cognitive abilities (Beard, Sakhtah, Imse, & Galvin, 2012). Spouses are crucial in enabling persons with cognitive impairments to remain at home, as memories of place play an important role in shaping and sustaining our sense of self (Beard, et al., 2012). For example, spouses can prompt pleasant past experiences and reminisce, allowing these memories to surface while maintaining and preserving the self-identity of their spouse with memory loss (Beard, et

al., 2012). Eliciting memories is enhanced when the place (i.e. swing on front porch with flower bed nearby) can interact with all the senses available to the person with dementia and the spouse attempting to elicit the memory. In this way, rural places are capable of having powerful influences on those who live in them (Keating, Eales, & Phillips, 2013) and provide therapeutic benefits.

It is suggested that over one third of rural men will assume a caregiving role at some point in time (Sanders, 2007). In the United States, it has been shown that rural caregivers are older than their urban counterparts and spousal caregivers of rural elders may be physically frail or cognitively impaired themselves (Buckwalter & Davis, 2011). In Canada, rural-dwelling older adults with dementia are in a similar predicament, as rural residents are less likely to have an adult child to help them and must rely heavily upon their spouses and friends, who are also elderly (Forbes & Hawranik, 2012). Very little research has examined dementia in a rural context, this identified research gap being all the more critical with rural aging populations and aging informal caregivers (Blackstock, Innes, Cox, Smith, & Mason, 2006).

A systematic review of the scientific literature related to informal dementia care in rural and remote settings was completed by Innes, Morgan, and Kostineuk (2011) in order to assess the current state of knowledge, identify support implications, and make recommendations for future research. The literature from numerous multidisciplinary databases was accessed, spanning a time period of twenty years, and it revealed a total lack of consideration about the impact of rurality on informal caregiving experiences (Innes et al., 2011). One explanation given for the lack of consideration about the impact of rurality on informal caregiving experiences is the viewpoint of rural older adults as

being “predominantly male, white, middle class, middle-aged, straight and able-bodied” (Cloke, Milbourne, & Thomas, 1997, p. 212), which is not always the case. Family caregivers of demented individuals in rural areas report that they feel isolated from family and friends; thus, they rely more heavily on their spouses (Brown & Alligood, 2004; Forbes & Hawranik, 2012) for support and friendship. Barriers to the provision of care were discussed in great detail; they were identified as: distance and isolation; geographic and professional boundaries; gaps in health care provider and caregiver knowledge about dementia; and available services (Hansen, Robinson, Mudge, & Crack, 2005). Moreover, Innes et al., (2011) note that there is a decline of family caregivers in rural areas with a parallel projected increase of dementia occurrence. The review noted that limited work examined the experiences of rural caregivers; rather, the focus was on the use of and barriers related to informal service provision (Innes et al., 2011).

Following the publication of the systematic review, Forbes & Hawranik (2012) sought to uncover what aspects of care were viewed as important by rural caregivers. They identified the need for a comprehensive assessment of their family that includes and incorporates the caregivers’ perspective, individualized, respectful, and sensitive care from healthcare providers knowledgeable in dementia care (Forbes et al., 2008; Hawranik & Strain, 2007; Morgan, Semchuk, Stewart, & D’Arcy, 2002). The need for a “coach to facilitate the whole caregiving experience by informing them of resources and supports, helping them to navigate the health-care system, and being their advocate” (Neufeld, Kushner & Rempel, 2007, p. 8) was identified in order to reduce the need for premature admissions to facility care that could necessitate moving from one’s community (Forbes & Hawranik, 2012). Rationales for the poor utilization of current rural health-care

services offered were given, and best practices for current and proposed future rural dementia care were outlined. Although discussion of what aspects of care were deemed to be the most important for rural caregivers was included (Forbes & Hawranik, 2012), the effect and role that gender plays in being a caregiver in rural areas is lacking.

Conclusion

I have presented demographic information pertaining to caregivers, specifically male spousal caregivers and their unique attributes in relation to the care that they provide for their spouses. A chronological sequence of the literature relating to male spousal caregivers who provide care for spouses with dementia was presented. A number of gaps in the literature were identified. Although there has been research done in relation to the four types of male caregivers (Harris, 1993) and the meaning and motivation that men had to their roles as caregivers (Harris & Bichler, 1997), there has been no research on the experiences of male caregivers and how they perceive their role as a caregiver. McDonnell and Ryan (2013) reviewed fifty-six manuscripts that related to male caregiving. It was reaffirmed that in our western society, caregiving is highly gendered, with the public perception that women are providing substantially more care than men (Martin, 2000; Pretorius, Walker, & Malan Heys, 2009; Shanks-McElroy & Strobino, 2001). An introduction to the theoretical framework used to inform my research, coupled with the significance of gender and applying masculinity theory (Connell, 2005) to my research question was discussed. Alberta rural men and how they express their masculinities, and the detrimental effects it can have on their health status (Courtenay, 2011) were articulated. The effect that rural place and space have on the male caregiver and how they impact his ability to provide care will be examined in my research. It has

been established that caregivers of demented individuals in rural areas feel isolated from family and friends (Brown & Alligood, 2004; Forbes & Hawranik, 2012). I will provide rationale on the development and implementation of a community intervention that will decrease the feeling of isolation that male spousal caregivers have in southern and central Alberta in a subsequent chapter but now I turn to a discussion of the research design and method that were employed for my study.

CHAPTER THREE: RESEARCH DESIGN AND METHODOLOGY

This chapter identifies and provides the rationale for my choice of research design and the methodology employed when conducting my research on rural male caregivers. A description of grounded theory methodology will be provided, combined with the philosophical stance inherent in grounded theory. The theoretical framework that underpins this research will be identified. I will outline the geographical setting and recruitment strategies employed when seeking participants for my study. Furthermore, justification for the number of subjects proposed for answering my research question along with rationale for inclusion and exclusion criteria for study participants will be outlined. The sampling approaches that I employed during my research will be discussed. Ethical issues pertaining to the difficulties in obtaining and maintaining informed consent while ensuring participant confidentiality throughout the research process will also be addressed. Practical plans for how data collection and data analysis occurred simultaneously while ensuring the trustworthiness and rigour of my research will be demonstrated.

Grounded Theory Method

When I began learning about the various methods and methodologies associated with qualitative data, it became apparent that grounded theory was a natural choice for my thesis topic. Grounded theory aims to discover the basic social process(es) enacted by people in context that can be conceptually ‘captured’ and further understood through the construction of social process theories (Glaser, 1978). Creswell (2013) asserts that the purpose of grounded theory is to provide a general explanation (theory) of a process, an action, or an interaction, shaped by the views of participants who have experienced the

phenomenon. It is vital to note that grounded theory does not test existing hypotheses or theories, but seeks to inductively generate theories from the research situation in the field as it is (Burden & Roodt, 2007; McGhee, Marland, & Atkinson, 2007). Grounded theory is designed to be used when there is no identified or appropriate theory that can be used as a general framework (Creswell, 2013). Furthermore, Corbin & Strauss (1990) emphasize that a grounded theory should explain as well as describe the phenomenon being studied. Generating a theory of rural male caregiving for spouses with a diagnosis of dementia has not been undertaken; thus, my chosen topic will generate a theory that can be used as a general framework for rural male spousal caregiving from the data that I collected in the field. In addition, my research will help to fill the gap because the only available theory on rural male caregivers focuses on how they negotiate being a caregiver in relation to their male gender, but it took into account all male caregivers and did not separate out and examine spousal caregivers of individuals with dementia (O'Lynn, 2010). Finally, grounded theory can also help explain practice or provide a framework for further research (Strauss & Corbin, 1998). By utilizing grounded theory, my intent is to develop a well-integrated set of concepts that provide a thorough theoretical explanation (Corbin & Strauss, 1990) regarding the experiences of elderly male spousal caregivers in rural settings that could be validated or revised in future research with rural male caregivers of spouses with dementia in rural areas of other provinces, or rural areas internationally.

Since its inception, grounded theory has grown and diversified into three distinct types (Hunter, Murphy, Grealish, Casey, & Keady, 2011). I have chosen the “Straussian” approach to grounded theory (Hunter et al., 2011; see Appendix A). It is necessary to

stipulate the differences in grounded theory methodology and applying grounded theory methods. Corbin & Strauss (2008) define methodology as “a way of thinking about and studying social phenomenon” (p. 1). As there are no simple explanations for experiences, it stands to reason that any methodology that “attempts to understand experience and explain situations will have to be complex” (Corbin & Strauss, p. 8). The methods involved in grounded theory refer to the “techniques and procedures for gathering and analyzing data” (Corbin & Strauss, 2008, p. 1). Grounded theory is therefore a specific methodology originally created by Glaser & Strauss (1967) for the primary purpose of building theory from data. When I use the term *grounded theory method* it is in reference only to how I used grounded theory to gather and analyze data that I collected from the field. I will now explore the philosophical underpinning of grounded theory methodology, which is based upon an interpretative framework that is informed by a pragmatic philosophy and symbolic interactionism.

Pragmatism

There are no simple explanations for social phenomena that occur in specific environments over certain time periods. A phenomenon, such as male caregiving for spouses living with dementia, is the result of multiple factors coming together and interacting in complex and often unanticipated ways (Corbin & Strauss, 2008).

Interpretive frameworks influenced by pragmatism focus on the outcomes of the research, the actions, situations, and consequences of social inquiry, with a clear focus placed upon the ‘what’ and ‘how’ of research (Creswell, 2013). Pragmatists assert that a benefit of utilizing grounded theory is being able to develop and refine abstract concepts that capture the essence of the phenomenon being investigated over the course of inquiry

(Jupp, 2006). Furthermore, the concepts developed when applying grounded theory provide ways of talking about the concepts among professionals (Corbin & Strauss, 2008). Blumer (1969), the founder of symbolic interactionism, stated that professionals use language to talk “and if you can’t talk, you can’t do, and the basis of many professions is still doing” (p. 8). The goal of my research is to enable multidisciplinary health care professionals to discuss and appreciate the unique experiences of rural male caregivers, and to develop and implement appropriate interventions that give them the support that they identify in the rural communities in which they reside. It is vital to understand the varieties of human actions, interactions, and emotional responses experienced by male caregivers in response to the events and problems they encounter while in their caregiving role(s); these will be addressed by adopting an interpretive framework informed by a pragmatic philosophy.

Symbolic interactionism

The sociological foundation of Straussian grounded theory is symbolic interactionism (Goulding, 2002). The emphasis of both Straussian grounded theory and symbolic interactionism is the significance of studying processes, building abstract theory from empirical observations, and creating conditional theories that address specific realities (Bryant & Charmaz, 2007). Symbolic interactionism is based upon the assumption that all interactions have different meanings to different caregivers in different situations (Hamel, 2001). Accordingly, a caregiver can be understood only by uncovering past and present experiences and the meaning that the caregivers place on former and current situations they encounter (Hamel, 2001). Moreover, two principles drawn from pragmatism and symbolic interactionism are built into grounded theory. The

first principle pertains to change (Corbin & Strauss, 1990). Phenomena are not static, but change in response to evolving conditions encountered in the environment. Therefore, a vital component of grounded theory method is “to build change, through process, into the method” (Corbin & Strauss, 1990, p. 5). The second principle that grounded theory shares with pragmatism and symbolic interactionism is in relation to determinism (Corbin & Strauss, 1990). Participants in research are perceived as “having, though not always utilizing, the means of controlling their destinies by their responses to conditions” (Corbin & Strauss, 1990, p. 5). Hence, grounded theory aims to uncover the *relevant* conditions and to determine how informants *respond* to the changing conditions and to the consequences of actions they have taken (Corbin & Strauss, 1990) in relation to the phenomenon being examined. In the next section I will explore the ontology, epistemology, and axiological assumptions (King & Horrocks, 2011) that inform grounded theory and symbolic interactionism.

Ontology and epistemology

From an ontological perspective, realities are considered to exist for human beings in a world of shared meaning (Aldiabat & Le Navenec, 2011; Hallberg, 2006). Accordingly, I sought to frame the subjective caregivers’ views of reality by identifying the concepts and labels they use to structure their reality (Burrell & Morgan, 1979). My intent was to understand the multiple realities of research participants demonstrated by themes that quote the words used by different individuals and presenting their various perspectives (Creswell, 2013). As I engaged in their lived social world, I created shared meaning and came to an understanding of what I think it means to be a male spousal caregiver living in a rural setting.

Using an interpretive epistemological lens, I will seek to understand caregivers, their inner minds and their feelings, and the way these are expressed in their outward actions (Burrell & Morgan, 1979). I wanted to get as close as possible to the participants being studied; therefore, I conducted my research interviews where the participants lived (Creswell, 2013) and cared for their spouse diagnosed with dementia. A call for an epistemological approach that “emphasizes contextual, personalized procedures for establishing truth” (Belenky, Clinchy, Goldberger, & Tarule, 1986, p. 35) has been noted as being necessary for researching male caregivers. Indeed, Kaye & Applegate (1990b) identified a significant void in the understanding of elderly male caregivers and the intimate arena where their caregiving relationships find expression. For a number of male caregivers, they remain stoic in their role as caregivers, are hesitant to divulge their inner feelings (Courtney, 2006), and warily invite researchers into their homes (Sachs, 2006). Symbolic interactionism and grounded theory addresses the contextual and personalized procedure (Belenky et al., 1986) as the researcher and participants are interactively linked in a mutual relationship in the natural rural setting to investigate their behaviour (Aldiabat et al., 2011). Furthermore, studies of meaning and relationship require an idiographic and holistic approach (Burden & Roodt, 2007; Kaye & Applegate, 1990b) that grounded theory and symbolic interactionism fulfill. When interviewing my participants, my intent was to understand their specific and unique rural male caregiver experiences. I approached male caregivers, taking a holistic approach that recognizes the interaction between the whole person and his environment, emphasizing the harmony with oneself, with nature, and with the world (Flynn, 1980). I was aware that I needed to consider the physical, social, spiritual, and emotional holistic functioning of an individual

and how they interact with their environment (Du Gas, Esson, Ronaldson, 1999).

However, holistic health emphasizes that you cannot separate these components; they are interrelated and interact with one another (Du Gas et al., 1999). I have therefore applied an idiographic and holistic approach when interacting with interviewing and writing about rural male caregivers.

Axiological assumptions

The personal values and biases that I bring to this grounded theory research study are my childhood experiences of being raised in a rural and remote environment in northern British Columbia. I value a strong work ethic and admire determined individuals who display resilience in overcoming the numerous challenges faced when residing in a rural setting. I am currently a registered nurse and am financially compensated for caring for individuals in various stages of illness and healing in acute care hospital environments. I am also employed as a clinical nursing instructor at the University of Lethbridge; I supervise and assess third-and fourth year-nursing students in a variety of rural clinical settings. I value caring and consistently display compassion and empathy for patients. Furthermore, I am a husband and father of two daughters, aged eight and four, and am able to provide a safe and stable home environment that I value because it is a place where individuals can be respected and cared for.

My values may not be congruent with male caregivers in rural southern Alberta; there is risk in assuming that rural male caregivers will consistently display the values to which I personally ascribe. I also make a broad general assumption that male caregivers have *chosen* and are willing and able to provide all the necessary care requirements demanded by their spouse. Indeed, caregiving for family members is not necessarily a

role aspired to, anticipated, or chosen (Moen, Robinson, & Fields, 1994). I am also cognizant that while I am in my active role as observer and interviewer, I ultimately decide what is seen or heard in the research context (Johnson & Rowlands, 2012; Mauk, 2012). Grounded theory compels researchers to be reflective, to question and be aware of personal assumptions, and to be able to set aside presuppositions to focus on the data collected in the field (Charmaz & Belgrave, 2012). This research context reflects my own standpoint and place in the community as well as my own self-understanding, reflexivity, honesty, and the integrity of my position as a researcher (Charmaz & Belgrave, 2012; Johnson & Rowlands, 2012).

Reflexivity

I have struggled and continue to struggle with being honest and true to myself as a novice researcher. The research process and engaging in field work are exhausting and time consuming. I was plagued with doubt, anxiety, and uncertainty about my capabilities of communicating the raw emotion and struggles that male caregivers have in the various rural settings where they provide care to their spouse with dementia. These emotions were starkly contrasted with the excitement and joy I experienced whenever another male caregiver agreed to be interviewed, and when I began identifying themes and abstract concepts from the data that I had collected in the field. What I did not fully understand at the time was that I was engaging in the reflexive process when I was focusing on my role as a novice researcher. Indeed, Guba & Lincoln (1981) contend that reflexivity is the process of reflecting critically on the self as researcher, as coming to know the self within the process of research.

It was very difficult to separate my role as a registered nurse from the role of researcher when interviewing male caregivers. When reviewing my audio recordings and transcripts, there were times when I began offering my opinion on the significance of their spouses' declining ability to engage in activities of daily living and their inability to follow a three-stage command. I also recognize my background of being raised on a rural and remote farm and working in the field of agriculture. This allowed me to engage the male caregiver in conversation related to the rural setting in which they reside. I was consciously aware that I was using my role as a registered nurse to teach male caregivers regarding dementia and depression (Alcoff & Potter, 1993). My rural upbringing and previous work experience on a dairy farm and at a grain elevator allowed me to contribute and explore how rural place and being part of a rural community assisted or impeded male caregivers from providing care to their spouses with dementia. For example, I was aware of the necessity of feeding and watering cattle daily in the winter, and inquired of the men I interviewed as to how they managed to care for their spouse and complete these daily chores consistently. My multiple identities of novice researcher, registered nurse, and rural farm boy represented the multiple identities of self in the research setting (Alcoff & Potter, 1993). I contend that I do not have to separate these identities, that they complement one another and contributed to the rich data that I was able to collect in the field.

I am passionate about working with the elderly population living with dementia and am fortunate enough to have worked on an acute care locked dementia unit, where I learned a tremendous amount about caring for those diagnosed and living with moderate to severe dementia. What I must remain cognizant of is that my caregiving experiences

and perceptions are very different from the experiences and perceptions of spousal caregivers. Indeed, critical knowledge of the dementia illness experience does not reside in the health professions; it belongs to the spouses, children, friends, and companions who perform the actual caregiving on a daily basis and over the long term (Alterra, 2007). I was intrigued and impressed by how a number of the men that I interviewed sought out and researched material in relation to dementia and how to care for someone with dementia. What humbled me immensely was when several of the male caregivers asked me during the interview if they had done enough for their spouse; if they had cared for her properly. Who was I to judge what they had done and what decisions they had made? I made a concerted and careful effort to reassure these male caregivers that they had acted in the best interest of their spouses. I did not want to appear to be judgmental or ignorant in regard to the care they had provided and the choices they had to make to ensure their spouses were cared for appropriately and safely.

Another unanticipated challenge was how my Lutheran faith and Christian upbringing would influence my role as a novice researcher. Four of my male participants self-identified as Latter-Day Saints [LDS] and were actively involved in their local congregation. At the conclusion of one interview, an interview participant encouraged me to think about converting to the LDS faith. My immediate concern was whether this crossed or violated any ethical boundaries of my research. The second concern I had was not to engage in a debate on my choice of faith, as a possible negative repercussion was that the participant would decline to have his interview and data that I had just collected be included with the sample. The participant's LDS religious beliefs and practices had a large influence on how he cared for his spouse with dementia, as well as his choice of

rural setting to raise his family. As I had my contact information documented on the informed consent form, I received several unsolicited telephone calls from the gentleman inviting me to events or his home to discuss the LDS faith further. However, the participant also approached other male caregivers independently, and gave me some information on how to contact them to discuss the possibility of interviewing them for my research study. I was deeply troubled, and sought advice from my supervisor to ensure that the ethical guidelines for research were being adhered to. When I was certain that no breach pertaining to my ethical approval of researching human subjects was made, it then became a moral need for me to defend my Christian faith. I approached a number of ministers of Christian faith and acquired their viewpoints. One minister made several suggestions on how to engage in discussion of my faith and beliefs when interacting with LDS. A book was recommended for me to read, which was titled *Reasoning from the scriptures with the Mormons* (Rhodes & Bodine, 1995). Suggestions are made throughout the book on how to approach members of the LDS faith respectfully and engage them in conversation about your faith and Christian beliefs. I did engage the interview participant in person, as he had agreed to review the typed transcript of our interview for a member check. I was relieved when he acknowledged and accepted my unwavering Christian faith and commended me on the research that I was doing.

Several incidents involving my Christian faith and beliefs occurred in further interviews, where it was necessary for me to acknowledge myself as a Christian. I believe that acknowledging my Lutheran faith in future interviews assisted me in building rapport, and allowing men of similar religious backgrounds to divulge personal details; as well as how religion influenced them as men and male caregivers and how they interacted

with individuals in the rural communities where they resided. I never suspected that my Christian upbringing and practices would have any bearing on, or need to be defended, when conducting research in rural communities in southern and central Alberta. What I did anticipate was the impact of male gender in relation to caregiving.

Theoretical Framework

The role that gender plays in relation to caregiving, and the applicability of masculinity theory (Coltrane, 1994; Connell 1987, 2000, 2005; Connell & Messerschmidt, 2005) to rural male caregiving served as the primary theoretical framework that informed this research study and was described in Chapter 2. The overt and sometimes covert display of ‘doing gender’ and acting out their multiple masculinities (Connell, 2005) was observed, and it influenced the way men provided care and approached their caregiving role. Thus, masculinity theory (Coltrane, 1994; Connell 1987, 2000, 2005; Connell & Messerschmidt, 2005) provides a backdrop to explain and adequately describe the performance of masculinity that rural male caregivers exhibit, while simultaneously acknowledging the conceptual complexity that exists when exploring male gender and masculinities.

Setting

For my research study, rural place has significance in relation to the experiences male caregivers have as they provide care. The importance of both space and place, and their relationship to positive and negative health outcomes, has been a focus of human geography researchers. Kearns (1993) elaborates on the importance of place by stating that “places have been understood beyond being locations and points, as possessing meaning, attachments and identity, and hosting and representing human agency,

interactions and cultures” (p. 464). I contend that the rural setting contributes to the experience and meaning of the home environment (Williams, 2002) and can contribute to positive male caregiver experiences. Rural place matters in relation to care and caring (Parr, 2003) and can directly and indirectly influence the caregivers’ and care recipients’ understanding of their culture and their perception of gender (Kearns, 1995; Kearns & Moon, 2002).

The geographical area from which I drew was rural southern and central Alberta. This incorporates rural areas from the western provincial border with British Columbia, spanning to the eastern provincial border with Saskatchewan. The southern Alberta border with the United States is the southern boundary, and it spans to the northern boundary of 54 degrees latitude. For the purpose of my research, I applied the rural and small town [RST] definition which is: “a population living outside the main commuting zone of larger urban centres (urban centres numbering 10,000 or more)” (du Plessis, Beshiri, Bollman, & Clemenson 2001, p.6). To determine what “the main commuting zone” (du Plessis, et al., 2001) referred to in distance, I sent a query to Statistics Canada. The response was that the definition of ‘commuting zone’ does not follow any criteria of kilometric distance (Ng, December 10, 2013). Therefore, I sought out the opinion of my supervisor, and we choose a kilometric distance of a 50 km circular radius extending from urban centres numbering 10,000 or more in population (du Plessis, et al., 2001) for my research study. That is displayed visually below.

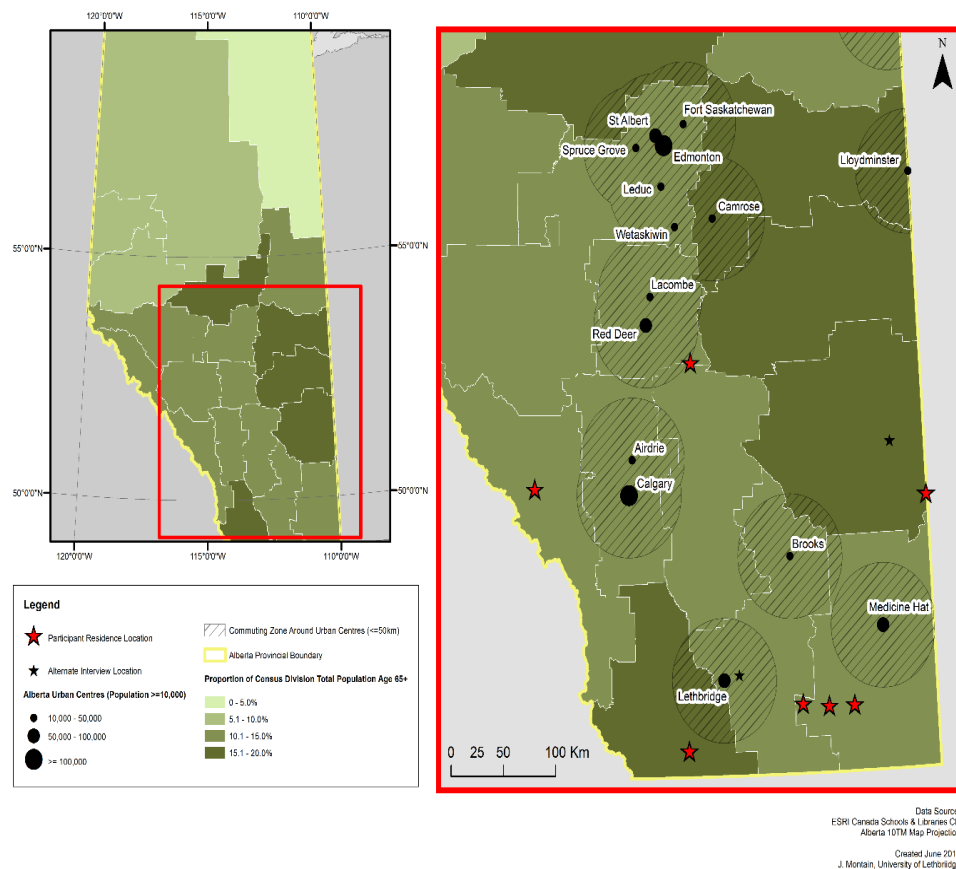


Figure 3.1. Geographical Representation of 50 km Radius

The provincial map to the left shows the province of Alberta, with the inset geographical area outlined in solid red that was the selected geographical setting of my research. The map on the right includes circles with a black border and solid black lines through them illustrating the 50 km radius surrounding urban centres. The red stars signify participant residents' locations when they were in the active role of a caregiver. The smaller black stars display where I conducted the interview, as two interview participants had recently relocated. The varying shades of green represent the proportion of the total population aged 65 and over.

Caregiving literature has demonstrated that the setting where the caregiving takes place has a direct impact on both the caregiver and the care receiver (Butcher, Holkup, & Buckwalter, 2001). A comprehensive systematic review conducted by Innes, Morgan, & Kostineuk (2011) revealed a lack of consideration of the impact of residing in a rural setting on informal caregiving. This is disheartening, as there is a global prediction of a decrease of family caregivers in rural areas with a parallel projected increase of dementia occurrence (Innes et al., 2011). Furthermore, caregivers of individuals with dementia in rural areas report that they feel isolated from family and friends; thus, they rely heavily on their spouses (Brown & Alligood, 2004; Forbes & Hawranik, 2012) for support. My goal was to interview male caregivers in their rural home environments, when feasible. All of the male participants were interviewed in their primary homes in rural settings; the exception was one participant who had moved to a town adjacent to a large urban centre following the placement of his spouse in a full-time care facility.

Recruitment strategies

Recruitment of informants can be the most challenging part of a research study (Patel, Doku, & Tennakoon, 2003). My intent was to seek out male caregivers who had minimal or no contact with health and social service support(s), as this would contribute to having the broadest representation of the rural male caregiving population (Houde, 2002). This recruitment strategy was influenced by my awareness that male caregivers are often hesitant to seek out assistance from health care professionals or to participate in community support groups (Kramer, 1997b) and often lack the appropriate social support(s) while in their caregiving role (Brown & Alligood, 2004). I entered the recruitment phase of my research recognizing the need to use creative means for

recruiting a diverse sample of informants for studies involving husband and son caregivers (Houde, 2002). I focused on being open to any ideas or suggestions made by my thesis committee members in relation to recruitment suggestions.

Initially, a promising prominent physical location where I wanted to display my recruitment posters was rural post offices, as a large number of rural individuals in central and southern Alberta require post office boxes because of centralized mail drop-off. However, Canada Post is federally regulated and post offices are not able to post advertisements in the immediate vicinity of post office boxes. I made several telephone inquiries to local urban and rural postmasters, who empathized with me but could not accommodate my request to post recruitment ads for male participants. Fortunately, when I was brainstorming other avenues of recruitment, it was suggested in a conversation with a local community care case coordinator that all rural small towns, villages, and hamlets had established Family and Community Support Service [FCSS] personnel who were responsible for community programs and development (Austin, 1996; Porter-O'Grady, 1996). My first wave of recruitment required me to personally telephone and email requests to the identified FCSS personnel for 33 rural towns and 28 villages within my established geographical boundaries, utilizing the Municipal Affairs Population List (2012) that identified the names of the towns and villages (Government of Alberta, 2012). This effort resulted in a significant volume of telephone calls and emails- not only from male caregivers, but also from female caregivers and children of parents with failing health and cognitive issues. From the first round of recruitment, five male caregiver participants came forward and were interviewed.

My second round of recruitment was aided by my supervisor, who contacted a reporter who agreed to interview and publish an article on my research study in *The Western Producer* newspaper. One result of the interview was a forum became available to me to make an appeal for more male caregivers to come forward and be interviewed. Due to the extensive distribution and targeted readership of farmers and ranchers across western Canada who subscribe to the *Western Producer*, four more men contacted me and agreed to be interviewed. With the broad distribution, I had caregivers from rural areas in British Columbia, northern Alberta, Saskatchewan, and the Yukon contacting me for more details regarding my proposed research study, or for advice related to someone they knew who was exhibiting signs and symptoms of dementia. I directed all of these inquiries to health care professionals who could assess individuals in their local area.

My third recruitment wave consisted of emailing organizations that may have direct or indirect contact with male caregivers and were willing to have my recruitment ad posted on their website or via their internal listserve. Numerous organizations such as the Alzheimer Society, Social Workers of Alberta, Alberta Rural Development Network, and the Royal Canadian Legion were contacted and given the background on my research along with my recruitment ad attached in pdf and jpeg format for them to distribute (see Appendix B). During all waves of recruitment, I was simultaneously identifying rural newspapers with distributions located in central and southern Alberta and paying for color and black-and-white ads of my recruitment poster to be printed in a rotating pattern across the province. Because of budget constraints, I opted for brief runs of my recruitment ad (for example, one to two week duration). The third wave of recruitment, combined with the simultaneous ads running in rural newspapers (see Appendix B),

contributed to the remaining four male participants coming forward and agreeing to be interviewed.

Due to prominent Latter-Day Saint and Catholic population(s) in rural southern Alberta, I had planned to approach numerous rural churches and ask if my recruitment poster could be included as an insert in their weekly church bulletin. This idea came to the forefront after I read an exploratory study of male caregivers that uncovered many of the men sought out their clergy for social support (Harris, 1993). The possibility of accessing rural churches could prove to be beneficial for recruitment purposes for future research involving male caregivers in rural areas. I had also taken steps to contact the Good Samaritans Society and was in the process of obtaining ethical clearance to post my recruitment ads in rural designated assisted living facilities in central and southern Alberta. Ultimately, these further waves of recruitment were not necessary, as I had sufficient participants for my research.

Depending on the recruitment strategies applied, the sampling process for research studies can suffer from problems of non-response and resultant selection bias which negatively influence the validity that the sample represents the phenomenon of interest (Patel et al., 2003). Moreover, the characteristics of male gender and advanced age have been known to adversely affect response rates for research studies (Patel et al., 2003). I contend that my approach of utilizing a multi-pronged approach to recruitment was successful in attracting individuals with a diversity of experiences in relation to rural caregiving.

Sample Size

Recommendations for non-probability sample sizes in the literature are limited, with only seven identified academic sources (Bernard, 2000; Bertaux, 1981; Creswell, 2006; Guest, Bunce, & Johnson, 2006; Guest, Namey, & Mitchell, 2013; Kuzel, 1992; Morse, 1994) that provide any guidelines for adequate sample sizes in qualitative research. An empirical study conducted by Guest, Bunce, & Johnson (2006) found data saturation occurred consistently after twelve interviews. Therefore, I employed in-depth interviews as the main data collection technique, and sought 10 to 15 participants that were selected using a stratified purposeful sampling technique (Neuman, 2011). Stratified purposeful sampling requires the researcher to break the study population into strata that have theoretical importance to study objectives (Guest et al., 2013). Commonly used strata include gender, age, education, income level; and can also be more specific, such as the amount of experience using a product or degree of exposure to an intervention (Guest et al., 2013). With my research, strata of gender, age and length of time being in a caregiver role have been identified as participant selection criteria. Another reason I chose stratified purposeful sampling is because existing studies on male caregivers are limited by small sample sizes and a reliance on convenience sampling that may not adequately reflect the experience of caregivers (Houde, 2002; O'Rourke & Tuokko, 2000). The second sampling approach I employed after conducting several interviews was theoretical sampling.

Theoretical sampling. Grounded theory employs a sampling strategy termed 'theoretical sampling' (Corbin & Strauss, 2008). When applying conventional methods of sampling, such as stratified purposeful sampling, researchers are sampling people and are

not attempting to control variables (Guest et al., 2013). Theoretical sampling involves sampling concepts uncovered in the field and then purposely searching for indicators of these concepts in further interviews to uncover how concepts vary under different conditions (Corbin & Strauss, 2008). Theoretical sampling is especially important when studying new or uncharted areas, as it allows for discovery and enables researchers to take advantage of unforeseen events that occur in the field. It has a cumulative effect, as each interview builds upon previous data collection and analysis and contributes to future data collection and analysis, allowing the researcher to follow an analytic trail. Finally, theoretical sampling enables researchers to discover the concepts that are relevant to the research question(s) and population(s), which permits researchers to explore concepts in depth (Corbin & Strauss, 2008). Indeed, sampling should continue in the grounded theory until “theoretical saturation-the point at which no or little new information is being extracted from the data-is reached” (Guest et al., 2013, p. 59). I am confident that I achieved adequate theoretical sampling and data saturation (Luckerhoff & Guillemette, 2011) with a sample of 12 participants for my research study. The main reason I am confident is when I was conducting the last two interviews, the participants were reiterating and making observations that I had either directly or indirectly recorded and analyzed in previous interviews with caregivers. I had reached the point of theoretical saturation (Guest et al., 2013) in relation to my data.

Ethical Considerations

As I selected male spousal caregivers who provide care to their spouse living with dementia, I anticipated that the vast majority of participants would be aged sixty-five or older. Inclusion criteria for my research included observed cognitive impairment for the

care recipient, as many medical conditions (both chronic and temporary in nature) can mimic the signs and symptoms of dementia (Fletcher, 2012). The participant must have resided in rural southern Alberta when in the caregiving role for at least three months. Qualitative research consisting of interviews generally poses no greater risk of physical harm or discomfort than that encountered in daily life; however, special consideration must be taken with the elderly population (Szala-Meneok, 2009). There is the remote possibility that in-depth interviews with caregivers may negatively impact a caregiver's ability to cope, and may potentially cause unnecessary emotional distress (Funk & Stajduhar, 2009). However, when interviewing is performed ethically and with sensitivity, it has been found to positively influence caregivers' coping skills and have other unintended therapeutic effects (Corbin & Morse, 2003; Hutchinson, Wilson, & Skodol Wilson, 1994; Kvale, 1996; Lowes & Gill, 2006). I had a memorable incident where the son of an interview participant emailed me and thanked me for speaking to his father about his caregiving experiences. This demonstrated to me that that particular interview provided some therapeutic benefit and may have indirectly led to dialogue between the son and his father regarding his father's caregiving experiences for his mother.

Following the ethics of justice, I did not exclude elderly caregivers with pre-existing medical conditions (Szala-Meneok, 2009). However, it is crucial to consider that cognitive impairment incidence increases dramatically beyond the age of eighty (American Psychiatric Association, 1994), which could lead to the collection of data that cannot be substantiated or is unintentionally falsely recalled by the caregiver. I needed to remain aware that mental health issues that are encountered with more frequency in the

elderly include mild cognitive impairment, dementia, depression, and delirium (Szala-Meneok, 2009). Specifically, two studies have linked caregiving to higher incidences of depression, with an estimated 23% of spousal caregivers suffering from depression (Dura, Stukenberg, & Kiecolt-Glaser, 1990). The ethical consideration with depressed individuals is that some individuals experience progressively diminished or fluctuating capacity to consent to research (Szala-Meneok, 2009). I believe that my professional background in geriatric nursing enabled me to ensure that ideals such as voluntarism, justice, beneficence, and respect for participants (Szala-Meneok, 2009) would not be compromised.

There are practical considerations for the elderly participant in relation to informed consent documents. Russell-Minda, Jutai, & Strong (2006) suggest that font size should be a minimum of 16 to 18 point Times New Roman, with attention paid to contrast, font heaviness, color, line spacing, and use of non-glossy paper that contributes to the clarity of the document. The goal is to develop an informed consent document that is comprehensible, comprehensive, and concise (Szala-Meneok, 2009). The reading level of the document needs to be considered, as material written for the public is normally at a grade eight reading level (Rudd, Moeykens, & Colton, 1999). I have adopted the guidelines of human subject research for the letter of consent from the University of Lethbridge Research Services department (see Appendix C) for the purposes of my research study. I applied the suggestions made by Russell-Minda et al., (2006) for the informed consent document in order to make the document as clear as possible to the elderly participants involved in my research.

Data Collection Methods

Two further characteristics of grounded theory that make it a distinctive qualitative methodology are the systematics in the methodology applied and the constant comparative method (Corbin & Strauss, 2008; Hallberg, 2006; Hunter et al., 2011). Systematics in the methodology refers to the specific procedures for data collection and analysis that are to be followed while conducting a grounded theory study (Corbin & Strauss, 1990). Straussian grounded theory method has explicit analytic strategies in place for coding data, while data collection methods remain implicit (Charmaz & Belgrave, 2012). Researchers applying grounded theory must follow the systematics in methodology such as applying the constant comparison method, or the study is fundamentally flawed (Elliott & Lazenbatt, 2005). The constant comparison method requires that all segments of data are systemically compared to and contrasted with one another in order to make data progressively more focused and the analysis successively more theoretical (Hood, 2007; Guest et al., 2013) as data is collected from the field via theoretical sampling. It is also imperative that data collection and analysis proceed simultaneously, as each method informs and streamlines the other; they are not separate activities (Bryant & Charmaz, 2007).

Data collection in grounded theory is performed with the idea that all things are data: everything I see, hear, smell, and feel about the research participant, as well as what I already know from my studies and life experience, are data (Stern, 2007). Furthermore, grounded theorists can treat any relevant medium or combination of media as data, such as photos, videos, newspapers, social media, even statistical data (Corbin & Strauss, 2008; Pidgeon & Henwood, 2004). I requested and received ethical approval to take

photographs of the rural places where the informants reside as part of my study (see Appendix D). A difficulty encountered with photographs of a home or location in rural central and southern Alberta is the possibility to identify a particular location, which could compromise the confidentiality of the study participant. To alleviate this concern, I took photographs only after obtaining the informed consent of the participant (see Appendix D). The photographs augment my data analysis and allow me to visually capture the meaning that rural place and space had for the men who were interviewed for this research.

Interviews. The main data collection methods when attempting to create a theory about a social phenomenon are in-depth interviews and observational data collected in the field (Charmaz & Belgrave, 2012; Stern, 2007). For the purpose of my research, I relied mainly on data collected from semi-structured interviews conducted in the field (Liamputtong, 2013). I took observational, theoretical, methodological and personal notes in a field journal (Schatzman & Strauss, 1973) and dictated voice memos on my observations from the field. Prior to conducting the interview, Esterberg (2002) suggests developing a demographic fact sheet that includes data such as the age, gender, ethnicity, religion, and employment history of each participant. I utilized a demographic sheet (see Appendix E) as an introduction to the interview, which placed the interviewer and interviewee at ease with simple-to-answer, direct, closed-ended questions (Liamputtong, 2013). This also allowed time for myself as the interviewer and the interview participant to relax and engage in conversation that was noncommittal in nature.

Various forms of interview design can be used to obtain thick, rich data about a phenomenon occurring in a natural setting (Creswell, 2013; Pidgeon & Henwood, 2004).

My questions reflect a symbolic interactionist emphasis focused on the participant's subjective meanings and on the male caregiver's actions (Charmaz & Belgrave, 2012). With the use of selected probing questions, my intent was to obtain data that would otherwise be lost (Creswell, 2013). Interview questions in a grounded theory study need to be broad enough to cover a wide range of possible experiences, but with the ability to be narrowed down enough to stimulate and explore the participant's experience of male caregiving (Charmaz & Belgrave, 2012). I used an interview guide (see Appendix F) to provide structure for the interview (Marshall & Rossman, 2011, Turner, 2010). Although I digitally recorded the interviews, an observation was made by Corbin & Strauss (2008) that interview participants often offer some of the most interesting data once the tape recorder is turned off at the conclusion of the interview. Therefore, I always had a pen and note pad while conducting taped interviews with my interview participants. Some of my most profound and insightful moments came following the interviews, and I was able to either write down my observations or thoughts, or record a voice memo upon leaving the participant's home.

Previous researchers have found that male caregivers responded to open-ended questions with brief responses (Mathew, Mattocks, & Slatt, 1990), so it was important that I applied probing questions appropriately to elicit a more detailed response. Furthermore, although examples of semi-structured interview questions for male caregivers are in the literature, it was important for me to develop interview questions for this study and rural setting (Corbin & Straus, 2008). Consistent with theoretical sampling and constant comparison of data, I expected that my interview questions would change and evolve as my analysis proceeded, in order to reflect the concerns and experiences of

the participants (Charmaz & Belgrave, 2012). Indeed, demonstrating that interview questions have been revised from experiences in the field contributes to a grounded theory study's rigour (Creswell, 2013). The way my questions were asked was updated, and the ordering of the questions was adjusted as I had them memorized. I did not require the written questions to prompt me while conducting interviews during the latter half of my data collection.

The challenge was organizing and managing the data while concurrently conducting data analysis. In order to efficiently and effectively store, manage, shape, organize, and manipulate the large volumes of data (Creswell, 2013; Miles & Huberman, 1994; Smith & Hesse-Biber, 1996) that were collected, I used NVivo9 and NVivo10 qualitative analysis software.

Data Analysis

A compelling reason for choosing the grounded theory method was my need for a meticulous process of qualitative data analysis. I chose the method developed by Glaser & Strauss (1967), which enhances analytic rigour. Grounded theory method provides guidance for novice researchers who apply the principles of grounded theory throughout their study. I will describe the three levels of data analysis employed in Straussian grounded theory method: open, axial, and substantive coding (Grbich, 2007; Hunter et al., 2011). Prior to beginning the coding of data, Agar (1980) suggests reading interview transcripts and other forms of data collected in the field in their entirety several times to gain a sense of the message as a whole before breaking it down. Glaser & Strauss (1967) caution researchers against placing their focus solely on the accuracy of the collected transcribed interview data, as this can lead to a rich description of the social setting where

the interview takes place at the expense of the development of a substantive theory of the social process (Stern, 2007). The analogy that Glaser & Strauss use is that the ‘cream’ (essential information) would rise to the top during data collection and data analysis; that it would “stick in the investigator’s mind” (Stern, 2007, p. 118). This analogy in relation to data collection and analysis in grounded theory resonates for me, due to my past employment on a dairy farm where the cream in the milk is literally seen rising to the top of the tank.

Open coding. Open coding is analysis where the data is dissected meaningfully while keeping the relations between the parts intact (Miles & Huberman, 1994). More specifically, thematic analysis begins with open coding, where researchers break open the data to consider all possible meanings (Strauss & Corbin, 1998). It is done line-by-line and questions are asked of the data to gain broader dimensions throughout open coding (Strauss, 1987). The step of open coding in data analysis is time consuming and tiring (Miles & Huberman, 1994), but well worth the effort as the data is broken down and reconceptualised (Guest, Namey, & Mitchell, 2013). I estimate that open coding was the most time consuming and drawn-out process that I engaged in with this research study. Weeks went by with minimal progress in my writing, but long hours were logged when I was attempting to break down the meaning of phrases spoken by interview participants, and reading and rereading copious field notes. A grounded theorist must not only fracture the data, but must also question the process(es) that produced the data with questions like: What is happening here? What process is taking place? (Charmaz & Henwood, 2008).

Axial coding. Axial coding is where the data is put back together in new ways by making a connection between a category and its sub-categories (Strauss & Corbin, 1990; as cited in Liamputtong, 2013). Specifically, axial coding aims to provide key insights into specific coding categories that relate to other categories (Creswell, 2013; Lonkila, 1995). This is achieved by having coding sessions more intensively and concertedly around single categories (Strauss, 1987). An example from my research was a code initially labelled ‘caregiver emotions.’ I had dumped data to that code that I felt described caregiver emotions. A key point is made by Pidgeon & Henwood (2004) when they caution researchers that axial coding could lead researchers to *verification* and away from *discovery* of what lies within the data. Glaser (1992) calls this ‘forcing’ the researcher’s ideas on the data and it is more likely to happen when the researcher thinks that the data is talking, when in reality the data is talking through the ‘eyes’ of the researcher.

As I read and concentrated on the data contained within the ‘caregiver emotions’ code, I began to see a pattern of one emotion being mentioned repeatedly - that emotion being patience. I proceeded to the second step inherent in axial coding, where “the analyst hypothesizes about and increasingly can specify varieties of conditions and consequences, interactions, strategies, and consequences” (Strauss, 1987, p. 64) in the codes. I began to build up a relationship around the ‘axis’ of the category being focused upon (Strauss, 1987), which led me to the category of persevering patience which all of my interview participants described or alluded to when I had interviewed them. If I had ‘forced’ (Glaser, 1992) my original idea of caregiver emotions on the data and original code, I seriously doubt if I would have been able to capture the eventual category of persevering patience. The category of persevering patience became increasingly related

to other identified categories. The relating of “categories and sub-categories is done in terms of monitoring being a condition, strategy, interaction, and consequence” (Strauss, 1987, p. 64). Thus, the strategy of persevering patience led caregivers to seek out their voice within when interacting and deciding on a plan of care for their spouse. Strauss (1987) asserts that analysts must be able and willing to exert great discipline to stay “concertedly on target, not allowing diversionary coding temptations to interfere with this specific and highly directed coding” (p. 65). I agree fully with this statement, as I engaged in these coding sessions at the beginning of the day, when I was rested and I could place my full concentration and focus to axial coding.

Selective coding. The third step in thematic analysis is selective coding, where all of the identified categories are unified around a core category that represents the main theme of the research (Corbin & Strauss, 2008). Contributing significantly to selective coding, memo-writing is the written record of identifying indicators and categories and linking them with emerging theoretical concepts (Grbich, 2007). I used the memo-writing feature built into NVivo to capture any abstract thoughts or ideas that came to mind as I was coding interviews and field notes. When I was at home or in the field, I wrote any memos in a spiral-bound looseleaf binder. I found it interesting to note when some of my insights and thoughts related to my research came to me. An example was the use of a maple tree to symbolize my theory when I was on a walk and stopped to admire a newly planted maple tree during the summer. Memo-writing makes researchers aware of their potential effects on the data (McGhee, Marland, & Atkinson, 2007) while also providing an ‘audit’ (Cooney, 2011) trail for other researchers. Memos are the recording of ideas that come to the researchers demonstrating the researcher’s decision making as they

analyze and interact with the data throughout the study (Mauk, 2012). Selective coding can require the recategorization of codes with the emergent theoretical analysis, or a realization that initial terms and concepts used do not, in fact, fit the data in the ways originally assumed (Pidgeon & Henwood, 2004). This occurred with a number of my initial codes that did not reflect the data contained within them, generic codes such as 'rural home' changed over time and through reflections in several memos to 'rural life,' and 'where they hang their hat.' Finally, in substantive coding the researcher employs tactics to force analysis to a theoretical level, such as writing definitions for core categories identified or building conceptual models grounded in the data (Pidgeon & Henwood, 2004). My conceptual model grounded in the data is a maple tree that connects all the categories and subcategories into one coherent model of rural male caregivers.

The three levels of coding are not only used in Straussian grounded theory method, but are the tenets of thematic analysis. The fundamental difference between grounded theory and thematic analysis is that grounded theory applies theoretical sampling and saturation (Charmaz, 2011; Morse, 2007). A further difference is that constant comparison of the data in grounded theory method may prompt the researcher to return to the field to collect more data or reconnect with previous participants in order to verify emerging ideas or to extend the detail and scope of the emergent theory (Pidgeon & Henwood, 2004). To summarize, the concepts that set grounded theory apart from other qualitative methods are; theoretical sampling, constant comparison of data with the development of theoretical categories, and application of the methodology that leads to the development of a substantive theory following theoretical saturation of categories (Hood, 2007; Liamputtong, 2013). A visual representation of how data collection,

theoretical sampling, the constant comparison method, and the three stages of coding that eventually lead to selective coding and theoretical integration was created by Santos, Santos, & Goldman (2011) and is shown below.

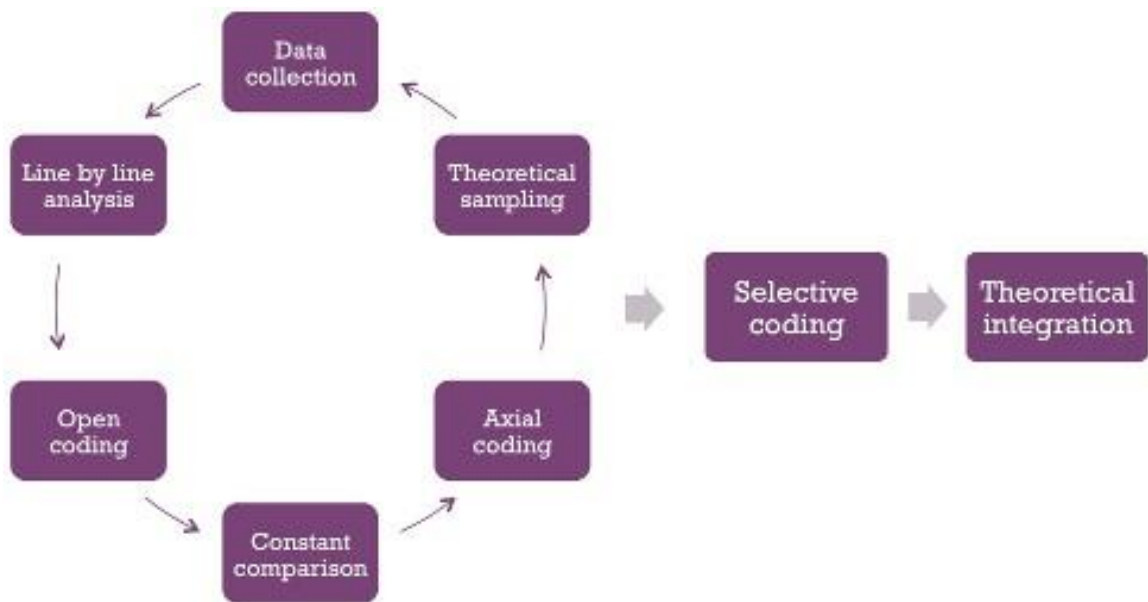


Figure 3.2. Visual Illustration of Grounded Theory Process

Qualitative Rigour

I felt I would encounter difficulty in ensuring that this research, my first attempt at undertaking a research study, might fall short of meeting the requirement for trustworthiness (Liamputtong, 2013). Trustworthiness, in relation to qualitative research, is established by demonstrating rigour (Lincoln & Guba, 1985). Cooney (2011) and Davies & Dodd (2002) argue that rigour is built into grounded theory when care is taken to apply the methodology correctly. This even applies to the incorporation of reflexivity that can substantially enhance the rigour of grounded theory studies (Hall & Callery, 2001; Morse, Barrett, Mayan, Olson, & Speirs, 2002). I have taken great care when applying Straussian grounded theory in relation to my research. The detailed description

of the steps I undertook when I applied the analytical process to data collected from the field is evidence of that. I reflected in the reflexivity section of this chapter, and I remain mindful of the partiality and limits (Davies & Dodd, 2002) of my research findings. I followed methodological rigour, which emphasizes best practices in the conduct of grounded theory research (Fossey, Harvey, & McDermott, 2002) when I was conducting this research. In relation to establishing and maintaining rigour I ensured that the principles of validity and reliability (Hunter, Murphy, Grealish, Casey, & Keady, 2011) combined with credibility, auditability, and fittingness (Beck, 1993; Lincoln & Guba, 1985) were applied throughout my research study.

Validity. A core principle of Straussian grounded theory is validity, which literally means truthfulness (Neuman, 2011). To achieve truthfulness, researchers must be willing to offer “a fair, honest, and balanced account of social life from the viewpoint of the people who live it every day” (Neuman, 2011, p. 214). This is achieved in a number of ways. The first of which is that research, to be considered valid, must be plausible (Fine, 1999). Plausible refers to data and statements about the data not being exclusive; they are not the only possible claims (Fine, 1999). However, they can be powerful, persuasive descriptions that reveal a researcher’s genuine experiences with the empirical data (Fine, 1999; Neuman, 2011). Secondly, empirical claims gain validity when supported by numerous pieces of diverse empirical data (Neuman, 2011). An example from my research was identifying that all the caregivers related that *persevering patience* is essential when caring for a spouse with dementia. This was supported not by one or a number of caregivers, but all of the caregivers I interviewed. Validity arose out of the cumulative impact when each caregiver identified *persevering patience*. The third and

final criteria for validity is when researchers search continuously among diverse data and consider the connections among them. Validity grows as the researcher recognizes a dense connectivity; it grows even further with the creation of a web of dynamic connections across diverse realms (Neuman, 2011). I achieved this third criterion for validity when I was able to form a theory that interconnected rural, men as caregivers, and the experiences of rural male caregivers.

Reliability. Reliability is necessary for validity, and it is easier to achieve than validity (Neuman, 2011). Researchers who use techniques to record observations consistently in qualitative studies are applying the principle of reliability. An example of reliability was the use of a specified digital recorder and the use of an interview guide that I used consistently when I was in the field. I found it critical to use the same device for taking photographs in the field as well, so there was consistency in the quality of photographs taken and they could all be organized on a specified digital file.

Credibility. Credibility is established when “such a vivid and faithful description that people who had that experience would immediately recognize it as their own” (Guba & Lincoln, 1998, p.245). To achieve this, Chiovitti & Piran (2003) encourage the researcher to use participants’ actual words in the theory and checking the theoretical construction generated against the participants’ meanings of the phenomenon in question. I have used the actual words of my participants in the sub-theme of *dying by inches*, and I took time during that interview to come to an understanding of what the male caregiver meant when he was referring to watching his spouse *dying by inches*. Although it has been argued by Elliot & Lazenbett (2005) that grounded theory does not require the researcher to return to the research participant to perform member checking, I did

perform four member checks. The member checking of the typed transcripts did not change any of the content; rather, the spelling of locations and individual's names were clarified and dates of events that were alluded to during the original interview were confirmed.

Auditability. In relation to grounded theory, audibility refers to the “audit” (Cooney, 2011) or “decision” (Sandelowski, 1986) trail in the form of memos. Memos are the recording of ideas that demonstrate the researcher's decision making as they analyze and interact with the data throughout the study (Mauk, 2012). Audibility is achieved when another researcher can follow the original researcher's audit trail independently and come to the same conclusions (Beck, 1993; Koch, 1994). This was achieved when I reviewed my data analysis findings with my supervisor, who followed my train of thought back to the original ideas and memos written regarding the theme that was created. An example of this was the theme of *crossing over*, originally named *life everlasting* that shifted to *new horizons* following discussion with my supervisor when I showed her the audit trail that made up the theme of *life everlasting*. I also kept a loose-leaf binder with sketches and random thoughts that came to me at various times of the day, and typed up some of these thoughts into memos that assisted me in analyzing the data and developing themes.

Fittingness. Fittingness refers to the extent that the results of a study can be generalized to other populations or groups of people (Beck, 1993). The first step toward achieve fittingness is a clear, concise description of the sample subjects that answers who, how, and why the participants were included in the study (Beck, 1993; Cooney, 2011). The inclusion and exclusion criteria in this research achieve this objective, which

was discussed earlier in this chapter. Sandelowski (1986) contends that fittingness is achieved when “findings can ‘fit’ into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experience” (p.34). It is my intention, following successfully defending my thesis, to disseminate my research findings throughout rural communities in Canada. One avenue to achieve this would be to send a summary page of my research findings to the Alzheimer’s Association chapters located in rural areas. If my findings were viewed to be meaningful and applicable, that would meet the fittingness criteria.

My concern with establishing and maintaining rigour in this research was justified. The lack of responsiveness of the researcher during all stages of the research process has been identified as one of the greatest hidden threats to validity (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Lack of responsiveness has contributed to the lack of knowledge, overly adhering to instructions rather than listening to data, the inability to abstract, synthesize data, and from previously held assumptions (Morse, et al., 2002) in regards to the researcher conducting the research. I have taken steps to become more responsive by adding to my knowledge base, being open to the data and willing to approach the data repeatedly, and documenting my previously held assumptions and beliefs and being aware of them while conducting this research.

Conclusion

Qualitative research undertaken using a grounded theory methodology describes the socially constructed nature of reality and allows for an in-depth analysis into the world of men caring for a spouse diagnosed with dementia (Denzin & Lincoln, 2013; Harris, 1995). The theoretical framework was informed by masculinity theory (Coltrane,

1994; Connell 1987, 2000, 2005; Connell & Messerschmidt, 2005), which allowed for critical analysis on how subjects' gender and displayed masculinities influenced their caregiving and how they viewed themselves as caregivers. I have explained in great detail the steps and decisions made in researching rural male caregivers and the rationale for utilizing Straussian grounded theory (Hunter, et al., 2011) to gather, analyze, code, generate themes and ultimately create a theory from the data. It was my goal to ensure this chosen study methodology provided a deep, rich description of rural male caregiving and how men come to understand their role when providing care to spouses with dementia. The presentation of the findings in the next chapter will illustrate that I achieved this goal.

CHAPTER FOUR: RESULTS

This chapter focuses on the findings that were generated from the interviews with 12 rural male caregivers. I begin by presenting a brief discussion of the demographic characteristics of the interview participants. Thereafter, I discuss the findings that were generated, beginning with the substantive theory that emerged from the data. Photographs and a visual presentation of the theory are included to enhance understanding of the findings.

Demographic Information of Male Caregivers

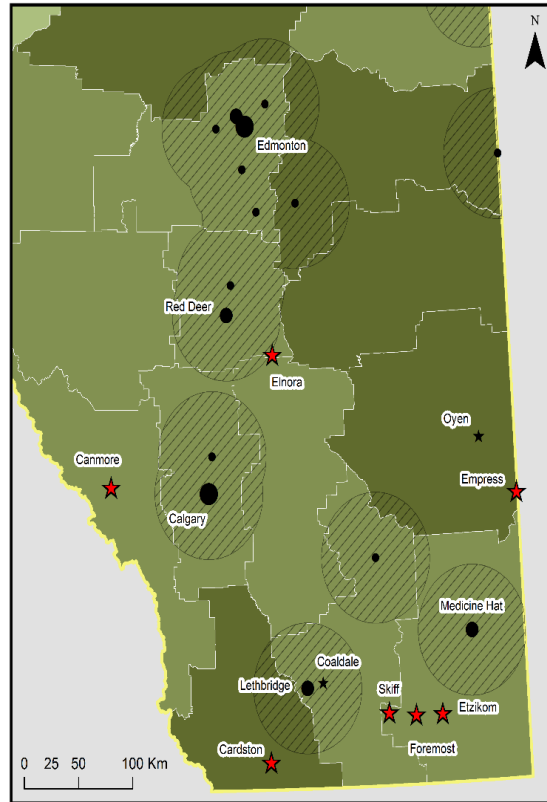
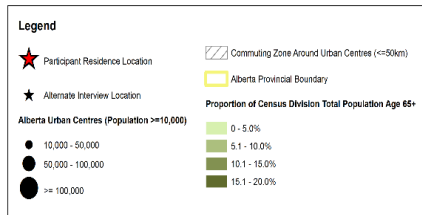
I collected demographic information on the study participants either immediately prior to or following each interview. Due to time limitations, one caregiver completed the demographic sheet and faxed the information to me at his convenience. I interviewed a total of twelve male caregivers in central and southern Alberta, as determined by the inclusion criteria in Chapter Three. In order to provide a visual representation of the geographical coverage and the time period when the interviews were conducted in the field, Figure 4.1 was created. The first interview I conducted was on December 23, 2013, and the final two interviews were completed on April 2, 2014.

The age range among the male caregivers was 66 to 90 years, with a mean of 78.4 years of age. Ten of the participants were married at the time of the interview, one was recently widowed, and one was in a common-law relationship. Caregivers' education had a broad variance, ranging from completion of middle school to a graduate degree. What can be misleading is the stated occupation of the caregivers. Four out of twelve identified themselves as farmers/ranchers. However, two of the interview participants related that they had a primary occupation and a secondary farming/ranching occupation. Taking into

account primary and secondary occupation would revise the number of farmers/ranchers to 6 out of 12 or 50%.

Interview location/date:

Interview Number:	Participant Residence:	Interview Date:
1	Foremost	23-Dec-2013
2	Skiff (Coaldale)	2-Jan-2014
3	Elzikum	3-Jan-2014
4	Elnora	23-Jan-2014
5	Cardston	31-Jan-2014
6	Cardston	5-Feb-2014
7	Cardston	7-Feb-2014
8	Elnora	11-Feb-2014
9	Empress (Oyen)	12-Feb-2014
10	Cardston	12-Mar-2014
11	Canmore	2-Apr-2014
12	Canmore	2-Apr-2014



Data Source:
 ESRI Canada Schools & Libraries CD
 Alberta 10TM Map Projection
 Created June 2014
 J. Montan, University of Lethbridge

Figure 4.1. Interview Locations with Corresponding Dates

The majority of the men were retired (83.3%), with two men still being active on their farm/ranch. The caregivers were all Caucasian. Three of the men had immigrated to Canada, two as children, one as an adult.

I experienced difficulty in capturing the length of time that each caregiver had been in a caregiving role. A number of men did not self-identify as caregivers, and 25% of the men could not pinpoint a time when they entered into their caregiving role. Half of the men (50%) had placed their spouse in a long-term care facility because their personal care needs and behaviors could no longer be managed in their home. All of these men visited their spouse daily or twice daily to assist them with activities of daily living. One participant had scheduled health care aides augmenting his care and providing periodic respite care so that he could attend church services. Table 4.1 displays the demographic information that was gathered in the field.

Table 4.1. Demographic Characteristics of Male Caregivers

Demographics	n = 12
Age	
Range	66 years to 90 years
Mean Age	78.4 years
Marital Status	
Married	9
Widowed	2
Common-law	1
Education	
Middle School	3
Part High School	2
High School	1
College/Technical	2
Partial University	1
University Degree	3
Occupation	
Farmer/Rancher	4
Teacher	1
Small Business	2
Engineer	2
Plant Supervisor	1
Minister	1
Salesman	1
Employment Status	
Working	2
Retired	10
Religion	
Catholic	1
Latter-Day Saints	4
Protestant	4
Not Specified	3
Active in Religion	9
Number of Children	
Range	0 – 6
Mean Number	3
Ethnicity	
Caucasian	12

The Experiences of Rural Male Caregivers

In this section, I discuss the experiences and perceptions of the rural male caregivers who participated in this research study. To maintain the confidentiality and privacy of the participants, unique linguistic mannerisms were edited from direct quotes used to exemplify and clarify my identified themes and sub-themes. I do not refer to the men by their actual or pseudonym names, but refer to them using the general term ‘participant.’ Rationale for using the general term ‘participant’ was employed to maintain the highest degree of confidentiality and privacy for the caregiver who was interviewed. For example, despite the large geographical area where the participants were targeted, it would be possible to isolate a male caregiver in a rural community consisting of a small number of individuals. Moreover, their identity could also be determined because they are in a unique situation of caring for their spouse with dementia. Finally, the use of photographs in the thesis also means that identities can more easily be recognized.

The following theory was developed to help illustrate the experiences and perceptions that male caregivers expressed and alluded to when they were interviewed. Every identified theme written in blue will be described through detailed discussion of the findings that were generated from the men.

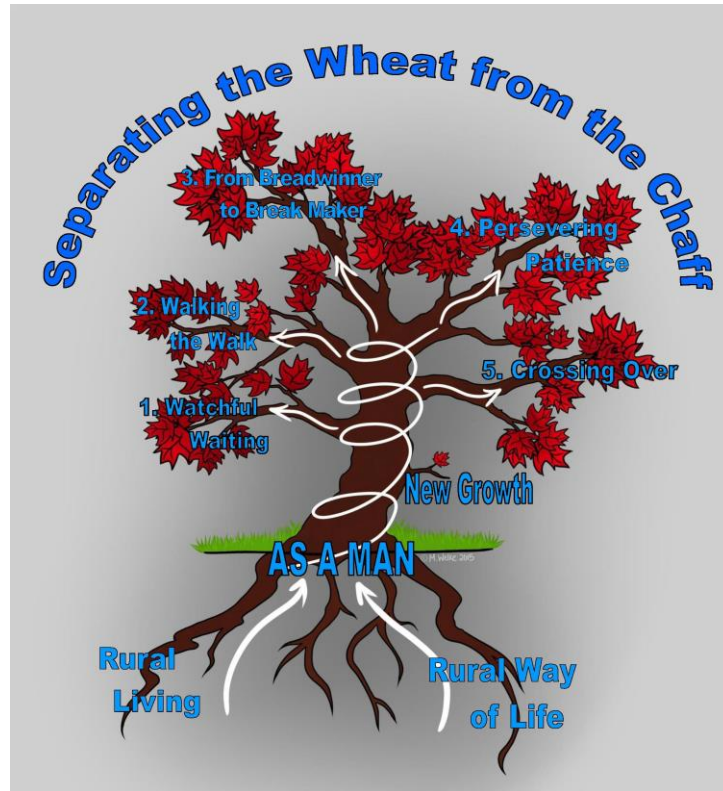


Figure 4.2. Rural Male Caregiving Theory

Separating the Wheat from the Chaff

I find it necessary to provide background on where the core category for this study originated. Upon conclusion of our formal interview, the interviewee and I had taken cups of coffee and had settled in his living room. A conversation ensued that delved into the knowledge and keen assessment skills that he had acquired when he began suspecting that his wife had dementia. The interviewee emphasized that “one must be able to separate the wheat from the chaff” about “what one believed and knew to be true in regards to certain material that was published.” As an example, the interviewee got up and shuffled through some magazines, choosing a monthly magazine that asserted on the front page in glossy print that Alzheimer’s disease could be arrested. I have included the

photo of the magazine to illustrate the bold assertion that such an outcome can be realized.



Figure 4.3. Arresting Alzheimer's: Elnora, AB, February 11, 2014

“You know how many people would believe this; they would buy this magazine thinking it had the answers and treatment for Alzheimer's?” the interview subject stated as he tapped the cover of the magazine; shaking his head back and forth in apparent frustration and disgust. This verbal exchange was captured in a field note that I recorded as I was leaving his residence.

The meaning of the proverb ‘separating the wheat from the chaff’ is “to separate what is useful or valuable from what is worthless” (Spears, 2005, p. 595). The origin of the proverb comes from the New International Version of the Bible; Matthew 3:12 “His winnowing fork is in his hand, and he will clear his threshing floor, gathering his wheat into the barn and burning up the chaff with unquenchable fire.” Interpreting these words from Scripture according to the literal sense of each word and the author's intended

meaning (Rhodes & Bodine, 1995) was enlightening. “His winnowing fork” (Barker, 1995, p.1441) is figurative for the Day of Judgment at Christ’s second coming. In this context, the meaning of the passage is that Jesus Christ will come and separate the chosen ones (the wheat) and allow them into heaven (the barn). Individuals not chosen (the chaff) will be separated and will be sent to hell to suffer for all eternity (burning up the chaff with unquenchable fire) (Barker, 1995). Moving from the religious interpretation to the farming production viewpoint, the wheat is valuable and the chaff is worthless and is separated by threshing the wheat from the husk, with the chaff being deposited into the swath, and the valuable wheat falling through the sieves and being augured into the hopper of the combine. The photograph below is a visual representation of a combine threshing a barley crop, taken in the fall outside a small village in southern Alberta.



Figure 4.4. Combining: Glenwood, AB, September 29, 2014

For the purpose of my research, I will discuss separating the wheat from the chaff from the meaning implied in the proverb - to separate what is valuable from what is worthless (Spears, 2005). The Biblical passage relating to the Day of Judgment has no direct or indirect connection (Barker, 1995) to the creation of the title for the core category.

In relation to being a male caregiver who is caring for a spouse with dementia, separating the wheat from the chaff means making the difficult choices and decisions on determining what is valuable for the caregiver and what could be set aside or not seen as a priority for the caregiver in the moment. For example, one husband disclosed what a good caregiver must be willing to do when caring for a spouse with dementia:

I guess.... keep an open mind. Don't close the door and don't put blinkers on. You got to look.... you got to look at the big picture....you've got to be inside your...person that you're looking after. You got to be *where she is*.

This husband decided that he would not go on any extended vacations or leave their rural home environment, as past excursions had been very difficult for him in the role of a caregiver. Moreover, the care recipient had experienced generalized anxiety when leaving her familiar home environment and undertaking an extensive excursion. The caregiver was attempting to see the world and the environment from the view of their spouse who was dealing with dementia. What was important to separate for this caregiver was the need to be where the care recipient is; not to force his perception of what her behaviour should be onto her. He was setting aside his perceptions and thoughts and making a sustained effort to understand the care recipients' perceptions and thoughts in the moment.

Another caregiver believed that you must be genuine when providing care, not just go through the motions. He expanded on the importance of being genuine:

...not just the case I'm there, you know? No...I'm....she knows I'm there, you know what I mean? For her, and...anything that I can do. I mean...I'm observant.

The caregiver related that he advocates for various changes to his spouse's menu items, as she was being cared for in a long-term care facility at the time of the interview. For him, what was important was being with his spouse physically, mentally, and emotionally, and to consistently advocate for her proper care and treatment in the facility. He was being holistic in his approach to her care, and being vigilant about every aspect of her care regime. Regardless of what he was doing or planning, he contended that when he spent time with his spouse, he was there for her. His activities, responsibilities, and volunteer work were moved to low priority and his spouse became his priority and the focus of his undivided attention when he was at the facility with her.

Caregivers also separated what was important in their physical environment and what could wait to be tended to when the time or season of the year permitted. As one gentleman stated bluntly "...you prioritize your fixes. And you can only fix what you can fix." In his context and role as a caregiver, this caregiver had limits due to the finite time and financial resources he could allocate to home repairs and maintenance. His primary concern was ensuring that the home was conducive to caring for his spouse, who required full assistance with her personal care. It had been necessary to renovate the home to allow a live-in caregiver to have their own living quarters separate from the main living quarters. I observed that aesthetic issues such as having the walls freshly painted or the furniture in the living room coordinated was not a concern for this caregiver. What was in need of fixing was separated out, and priority was given to projects that had beneficial outcomes for the caregiver and his spouse. The next project for the husband

was to install radiant heating in his garage so that he could continue to perform vehicle repairs and ready vehicles for resale, which contributed to income for the household.

Taking the initiative and gaining knowledge and skill in detecting signs and symptoms of dementia and recognizing these in their spouse was critical for a caregiver. One participant related that he purchased a number of texts on dementia and independently performed the cognitive tests that authors recommended to screen for dementia. When pressed, he divulged that he had “Read four or five medical books (sic; the texts were mail ordered from Reader’s Digest).....on how they diagnosis it.” He asserted that he knew his spouse had dementia before seeking out any medical opinion. When he did seek out a formal medical diagnosis, he asserted that he could predict how his spouse would perform on the Mini Mental Status Exam [MMSE] (Folstein, Folstein, & McHugh, 1975) supplemented with the clock drawing test that the physician utilized to screen for cognitive impairment. It was necessary for this participant to gain knowledge and develop insight into the disease of dementia in order for him to tailor his care and to ensure that his spouse was indirectly supervised in public settings. Ensuring her safety and limiting the excursions taken from their farm environment were priorities for this caregiver. The diagnosis of dementia did not come as a surprise; it was a confirmation and reaffirmation of what he knew to be true. What was important for him was ensuring that her quality of life on the farm was optimized and her physical environment was made as safe and stable as possible.

On the other end of the spectrum, one caregiver recalled his surprise and concern that his wife had become more and more dependent on him. He verbalized “I mean...I guess we both knew that one day one of us might become ill....but the idea of

Alzheimer's.... really....I don't think that had ever occurred to me." The caregiver emphasized that he felt it would be a physical disability that limited their mobility that would be the cause of morbidity and mortality for him and his spouse. However, once the diagnosis was made and the effects of dementia became more and more apparent, the caregiver was definitive in his stance that "...once it started, I mean...it was...there's no question in my mind that I had to look after her as long as I could, you know?" What was valuable and important to this caregiver was his ability to provide care and comfort to his spouse with dementia as long and as safely as possible in their rural home and community. *Separating the wheat from the chaff* is therefore the core category and is connected to all of the themes and sub themes which I will now turn to and discuss in detail.



Figure 4.5. Rural Male Caregiving Theory: Core Category

Rural Living

I begin the discussion of the Rural Male Caregiving theory that was generated from the data by writing about *Rural Living: Starting from Scratch* and *Rural Way of Life: Where They Hang their Hat* which are the roots of my theory.

Starting From Scratch. Building their homes or moving to homes already built was a positive memory and experience for all of the caregivers. A number of the caregivers established farms on their own, while others had land on which to build their homes passed down to them. Three of the twelve participants had farms and farm houses passed down to them from their parents; two more had instituted succession planning to

transfer their farms to their children to continue to operate their family farm(s). What struck me was that all of the participants who farmed had at least one aerial view of their farm hanging prominently in their dining room or living room. With the majority of these, there were time lapse photographs that visually represented what the farm looked like upon conception and what it had transformed into over the years. A sense of pride and accomplishment in establishing and managing their farm was evident when interviewing the men. The photo taken below was one of the participant's home quarter. In the foreground was his pasture land for cattle and irrigated land where he grew his cereal crops. This aerial photograph was framed and was displayed prominently in the participant's living room.



Figure 4.6. Home Quarter: Cardston, AB, January 31, 2014

One participant and his wife imagined together the home they had always dreamed of. Then they proceeded to have the blueprints of their home completed by an engineer. Following that, they worked on the interior and exterior design as a couple and built it right from scratch; from the foundation up. The attention to detail when they were completing the home was evident, from the selection of antique light fixtures and doorknobs to cast-iron Victorian vent gratings. They did eventually decide to sell and move out of this unique home when they retired, but had deep regrets when they eventually returned to the same rural area to live out their retirement years. The regret ran so deeply that when she was well, the wife could not even walk past their former home and, even to this day, they refrain from travelling through the neighborhood where the house is situated.

Another gentleman resided in a home that was one of the first structures to be built in 1906 in the rural hamlet where he resided. The heating system presently consists of radiators in each room, which were visible and functioning when I interviewed the participant. The original coal furnace had been upgraded to natural gas to supply the energy required to heat the boiler that circulated the warmed fluid to the radiators in each room in the home. What the home owner was impressed with was his ability to “live off the grid” and not be dependent on electricity if he so desired. In the event of experiencing a prolonged power failure, he had wired a generator that was out in his shop near the home so they could run their appliances. The heat for the home would rely upon a functioning wood-burning fire place if natural gas was not readily available. The homeowner described the original frame of the house as being hand-sawn rough fir 2x8s

that had not deteriorated for the entire life span of the home. He had added a porch entry and addition to the home when he and his first wife were raising their children. He relished his ability to have his own space and to be connected to and aware of the inner workings of this home. If he wanted to, “he could stomp around in his pajamas and kick the fridge. He was free to laugh or sing at the top of his lungs.” This was related to the large size of the lot the house was built on; his actions would not be observable by neighbors or passersby on the street. He had the freedom and ability to express himself as he wanted in his home. A photograph of this home was taken from a vantage point in a corner of the lot. The lot the house was built is spacious; the homeowner had built a shop in the back of the lot and he maintains a large greenhouse and outdoor garden.



Figure 4.7. Home: Elnora, AB, January 23, 2014

An interview participant recalled memories of his community coming together and organizing a day when they would set up the forms and pour an entire basement by

bringing together everyone's individual cement mixer and wheelbarrow. On the chosen day the laborers, consisting of the men from neighboring farms and their older children, would congregate at the site where the foundation was to be poured. The wives and significant others would provide a picnic for the men working, and the younger children played near where the work was taking place. Individually, it would have taken months for an individual to pour a foundation on their own. Paying for cement to be hauled out to rural areas in central and southern Alberta was cost prohibitive for these rural men. The solution was to bring rural community resources together and delegate the jobs and tasks that had to be completed in a timely manner to get the foundation poured properly and efficiently within a fixed time frame. The rural community was literally pouring and setting the foundation for rural families to start their lives together in a home to call their own. The photo on the next page is a barn that was constructed in 1909. The farmer noted that the foundation that this barn was built on had not shifted or settled since that time, due to the preparation and quality of the concrete underlying the structure and the levelled wood beams upon which the structure rests.



Figure 4.8. Foundations: Etzikom, AB, January 3, 2014

Rural Way of Life

Where They Hang Their Hat. The place where the caring occurs contributes to what makes a number of the men successful caregivers. When questioning if they felt the rural place where they lived was limiting them in their caregiving role, the responses were quick to come and very brief in duration. For example, when I questioned a caregiver as to whether or not he thought about moving or relocating to an urban setting when his spouse was diagnosed with dementia, the caregiver adamantly said “Nope, not

for a minute.” I waited for him to elaborate, and when he did not, I posed the question “Not even one minute?” He responded “Exactly the opposite!” He then went on to elaborate his contention that the rural place they had called their home for a large portion of their lives was paramount to his being. To bring home the point about his feelings about rural place, he recollected a conversation he had with an individual who had inquired whether he attended church. He responded to that individual, “Well, I’m in church all the time. These mountains and this valley is my church, you know, as far as I’m concerned!” He valued and felt that the rural setting he resided in was so instrumental to him that he correlated the physical setting to being his place of worship. The connection this participant had with nature, appreciating the fact that nature provided him with a river where he could fish in a tranquil setting, gave this participant a clear, pure feeling. Connell (1990) correlates this feeling to having a transcendental experience. The photo taken was a view of the Rocky Mountains along a walking trail less than a block from the caregivers’ primary residence. His hobby is fly fishing; he fishes on a regular basis in the Bow River.



Figure 4.9. Valley: Canmore, AB, April 2, 2014

Another participant, when asked if he would ever consider moving or relocating to an urban setting where more programs, resources and respite care are available for individuals with dementia and their caregivers, related that “As long as I can look after her...I’m not doing anything...anything different.” When saying this statement, he was moving his arm in an outward arc, displaying that he was not going to change anything in their environment; that he believed the rural setting was meeting their needs as a couple.

Living close to nature and in a pastoral setting was an identified benefit to living in a rural environment. One interview participant captured the significance of his rural environment:

...we’ve got openness... and we’ve got Mother Nature and, you know, we can do whatever. In the wintertime...yeah, it’s not so good. But we, we’ve still...the environment...yeah, the surroundings and stuff, yeah. It’s *better for her*.

The caregiver emphasized that the environment and familiar surroundings were beneficial for his spouse. He had even brainstormed the possible need to apply a GPS bracelet monitor on his spouse's wrist if it came to a point where she was exhibiting wandering behavior. He believed he would then be able to control and monitor her movements in their present rural setting in a safe manner. This caregiver had insight into the possible detrimental effects of uprooting and moving his wife from this familiar rural setting and was aware that moving an individual with dementia can contribute to increased confusion and disorientation when moving to an unfamiliar environment.

When I was conducting an interview with both the husband and wife with dementia at their kitchen table, she interjected and made a remark about how she valued residing in their rural setting. "Yeah, and in the summertime...when it is good...I can get up and go out whenever I want...and do whatever I want to do, you know?" The husband did communicate to me following the interview (when his wife was not in the immediate vicinity) that periodically she had unintentionally pulled or pruned 'weeds' in their garden. These 'weeds' were, in fact, the vegetables that they had planted in the spring. However, he did not correct her or reprimand her. He was happy for her to be enjoying working the soil and tending to the garden on their rural property. The husband had even built raised and narrow gardens, so they did not have to be on their hands and knees when tending to the garden. I was fortunate enough to be able to photograph his back yard, where he had constructed the raised beds.



Figure 4.10. Gardening: Cardston, AB, February 5, 2014

Another husband placed a great deal of emphasis on having the ability to have his spouse with him at all times when he worked on his farm. For example, when he was seeding or combining, his spouse rode in the farm equipment on the passenger seat beside him. When portaging farm equipment to various fields, and because of the slow speeds that farm equipment travel, his wife was able to drive their truck behind the farm equipment. An added benefit of living on their family farm was her ability to get regular physical activity by walking four miles per day with their two pet dogs. He noted that she had always loved the outdoors and loved animals and being with animals. She relished getting regular physical activity and was an “outdoorsy person.” When asked if he

worried or was concerned about his spouse with dementia walking alone, he emphasized that she had never become disoriented or lost. He also felt that the dogs would be able to lead her home if she ever got disoriented. He was adamant that in an urban setting this activity would not be considered safe, but in a rural setting with familiar landmarks that change little over the seasons, it could be undertaken. For another husband, having ready access to a park adjacent to their back yard in their rural community ensured that he and his spouse could walk safely. Furthermore, the area was protected from many of the elements due to the paths being sheltered by trees. The paths were paved and well maintained, so he did not have to be overly concerned about the risk of falls for his spouse, who had been experiencing increasing disequilibrium that was attributed to the area of the brain that was affected by her form of dementia.

Communicating his feelings towards the rural community in which he resided, a caregiver summed it up in this statement “I love it here, I love this little town....and I do not want to live anywhere else.” Rural living contributes to their way of life, and having a familiar home and physical environment provided the caregivers and their care recipients a safe environment where they could be reminded of what they had built together. *Rural living* and *rural way of life* were purposefully chosen to be the roots of my theory. This is especially relevant when considering how groves of Redwood trees thrive. A large number of trees have root systems that grow deep and long into the earth and seek out moisture to anchor the tree and feed it (Fritzemeier, 2012). However, groves of Redwoods, being considered the tallest and strongest trees known to man, have roots that intertwine and integrate with the roots of other redwoods close to the top of the earth. In this way, they learn to rely on one another to weather storms and the natural elements.

Being in a grove of redwoods provides the oldest and largest trees, situated in the center of the grove, protection from the elements of wind and erosion of the topsoil from runoff. My contention is that the rural setting and rural place give nourishment to the male caregivers and those for whom they care. The connections between the rural community members are represented by the grove of trees and their intertwined roots that give them strength to overcome adverse and unpredictable events. Without these connections to rural communities, male caregivers who are alone could suffer from the consequences of being the sole tree, open to the elements and more prone to encountering damage and possible destruction that can topple them. The impact of rural place and space has grounded these spousal caregivers and contributes directly and indirectly to their sense of well-being. *Rural Living: Starting From Scratch* combined with *Rural Way of Life: Where They Hang their Hat* constitute the roots of my theory, which is visually illustrated in the diagram below.

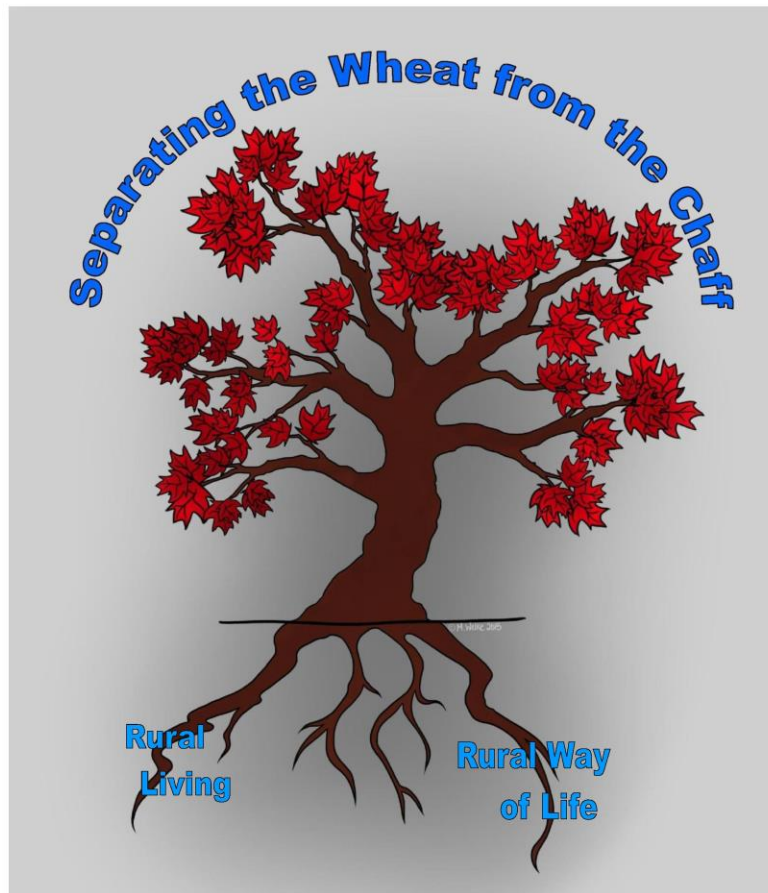


Figure 4.11. Rural Male Caregiving Theory: Rural Roots
As A Man

The theme of *As A Man* originated when I was able to recognize the overt and covert expressions of masculinity that the men were exhibiting during the course of their interviews. The subtheme of *New Growth* was identified to illustrate how one caregiver grew as a man when providing care. The theme of *As A Man* represents the trunk of my theory, and connects the rural roots to the branches of the theory. The subtheme of *New Growth* adds to the strength of the trunk and provides unanticipated growth to the tree as a whole.

Relationship Blossoming

All twelve of the men I interviewed stated that following their marriage, it was discussed and decided that their wives would leave the workforce. A number of the wives, early in their marriage, had attempted to work from home for a period of time. One wife sold her hair dressing business in the urban setting, then purchased the necessary equipment and set up a hair salon business, so she could develop a local client base from their home on the family farm. Two other women assisted with bookkeeping, one for their rural small business, the other for their growing family farm. Following courtship and marriage, the remaining women predictably moved or relocated with their husbands to the rural areas in which they choose to reside. When their spouses began showing signs and symptoms of dementia, the men were forced into taking control of all aspects of the household and the management of their wives' care. Ultimately, these women had to assume a more passive role in the marriage and be cared for. The men were placed in a position of ultimate responsibility in their caregiver role.

Power and Production Relations

There were a number of overt instances I noted through my analysis that depicted gender relations influencing how tasks were allocated. A caregiver recalled the work that his wife had done in the home for the family:

She - I don't think I ever knew anybody that worked harder than she did. She cooked and she cooked. She sewed and she made dresses and stuff for herself and the kids and - she just, she just did it all you know, anything - more than you'd ever expect anybody to do! I-I just....

His spouse had "done it all" in the domestic sphere of their home. However, one regret the caregiver had was that he did not allow her to pursue her desire to work the cattle.

She would drive the truck and follow the herd, but she had always expressed a desire to

learn how to ride a horse and direct the herd on cattle drives. The gender division of labor was obvious: she worked in the domestic sphere, while he controlled and directed the management of their cereal and hay crops and worked their herd of cattle. He was not willing to teach her how to ride, as one horse “took lots of manpower to hold him back” and another horse was a great walker, but was “kind of spooky.” He repeated on multiple occasions that he regrets having never taught and allowed his spouse to ride a horse and work the cattle on cattle drives; instead, she was relegated to following the herd in a truck.

Another caregiver acknowledged that he had the ability to cook and had assisted periodically with food preparation in the kitchen. At times, he even took the initiative to prepare and cook meals. However, in their household, prior to his spouse being affected by dementia, the unspoken rule was that she planned and cooked the vast majority of meals. He was responsible for the tasks related to the upkeep and maintenance of the exterior of the home; his spouse managed the tasks and chores for the interior of the home. This ranged from choosing new wallpaper to the coordination of holiday events hosted in their home for immediate and extended family members.

Male Desire

It was evident that the emotional relations and practices that shape and realize desire (Connell, 2000) played an integral role in the relationship between the caregivers and care receivers. For spousal relationships, that desire is often expressed by the act of sexual intercourse between two consenting adult individuals. During the course of one interview of a male caregiver, he established that I was married and had children prior to confiding in his sexual relationship with his spouse and how the disease of dementia had

ended that aspect of their marriage. It was a certain incident that the caregiver recalled that was the tipping point and demise of their sexual relationship:

We would make love in the morning. She liked it often in the morning better than in the night, because you are tired. So, I'd make love in the morning and then go to...to, away for shopping. And, in the [grocery] store suddenly... she wanted to take the shopping cart outside, and you can't take the shopping cart outside in that store, as the stairs are coming down. And she made a fuss! [I said to her] "Why do you want to go out? [She replied] "Oh, I don't know!" And finally, I got her quieted down, or so I thought. You can't take the cart out to the car because....so. But... she pulled the cart out, anyways. Boom, boom, boom down the stairs. (Laughing in apparent disbelief at his spouse's actions.) Little bit of an argument all about the carts, you know? And, that was the last time we make love. It was gone suddenly, poof, like that. (Snapping his fingers to reinforce the point.)

What I did not determine was whether this incident precipitated his spouse not wanting to engage in sexual intercourse with him any longer, or if her actions that pivotal day led him to believe that she could no longer make rational judgments or informed decisions. Perhaps he believed if she could not be reasoned with concerning her judgment in taking a full shopping cart down a set of stairs, then engaging in sexual relations could no longer be seen as an activity to which she could consent.

The same caregiver referred to the loss of their sexual relationship when discussing love and how he expressed love for his wife, when he emphasized "I still love her, but she is not my wife any longer, and I know that. Not in my wife, at least in the sense of *being a wife* (Interlocks his fingers of left and right hand and making an arch). My interpretation of the interlocking of his fingers was his representation of the physical act of lovemaking, of two individuals becoming one. He mourned the loss, but was also acutely aware that his wife had changed. He related that one moment his wife could be telling him softly how much she loved him. In the next moment, still looking

into his eyes she could yell at him in anger and scream “Shut your ugly face!” He reiterates that a form of love remains, when he stated once, then repeated the statement “...what is *left yet*, I still love of her...” The disease of dementia has changed her personality and their ability to have a mutual loving physical attachment. However, I observed this same caregiver kissing the palm of his hand and laying it on his spouses’ forehead when he was leaving her to participate in our interview. He is still able to express his physical love indirectly by a soft touch or caress that might not be acknowledged by his spouse with dementia, but it is important for him to express his love for her.

Companionship

For one caregiver, the physical presence of his spouse filled an emotional void. Their relationship had initially began as they were widowed neighbors who enjoyed spending time together. He related during the interview:

...you know, even when you’re watching television or something-- if you watch the best program in the world you’re sitting there alone. There’s no spice in it. It seems like you got to have somebody there to appreciate these things with you.

Despite the fact that she experienced cognitive impairment with a tendency for her to repeat questions and to ask for his input and confirmation of statements that she made during the interview, he was incredibly understanding and giving to her. He related that initially, he would walk over and invite her over for a meal, and they would have the meal, watch television, and then he would walk her back home and ensure that her house was safely locked up. As her cognitive impairment became more pronounced, her children were grateful and supported their decision to move in together, as he felt she needed to be with somebody on an ongoing and consistent basis. He had encouraged her

to be present for the whole interview, where she was free to interject her thoughts. I believe she captured the importance of being together when she verbalized “He was here all by himself. And I was by myself, you know? Well, what kind of a life is that, being by yourself all the time?” For this couple, it was their mutually agreed upon decision of not wanting to be alone; it was the desire to have another person with which to engage and share moments.

Symbolizing the Relationship

Specific instances of how the male caregiver believed their spouse’s gender should be symbolized was evident. Symbolizing your gender can also occur through communication when men address their wives in conversation with others. What fascinated me was the apparent need of all of the caregivers to show me, either through photographs or a vivid verbal description, what their spouses looked like either when they were courting or first married. The word most commonly used to describe their spouses was “beautiful.” Periodically, I was asked to confirm whether or not I thought their spouses were beautiful, and it was always in the affirmative; they were all beautiful women.

One caregiver struggled immensely with his wife’s disinterest and motivation to apply any make-up. He was solemn when speaking to me regarding this choice: “She doesn’t wear makeup anymore. She was a pretty looking girl. We all get old, we don’t get pretty anymore, (brief smile, deep sigh in and out) that’s not the issue.” The caregiver was expressing that we all age, it is inevitable. What he did not understand was his spouse’s refusal to apply makeup, as he felt that it might lift her spirits. She verbalized to him periodically following her diagnosis with early onset dementia that

“I’m sure I’m sad because I’m getting so old looking.” His response to her comment was brief and to the point “That’s life, that’s the way it is. You get old. Try makeup.” He contended that applying makeup would present a version of a younger self, one that he believed was a pretty looking girl. She adamantly refused and still refuses to apply any makeup. He reiterated twice during the course of the interview that it “Would not hurt her to put on makeup. Whatever. If she doesn’t want to, she doesn’t want to...” For him, the application of makeup symbolized beauty for the female gender. The photographs that he pointed to hanging on the wall of the living room were of a woman wearing gorgeous dresses; her hair was styled and she had tastefully applied makeup that highlighted her eyes and cheekbones.

A second caregiver had a spouse who worked as a hairdresser from their home on their farm and curled her hair and styled it perfectly every day prior to leaving their master bedroom after awakening. He elaborated “On the farm, when she had...she had longer hair. She curled her hair every day. You would never see that woman without curled hair!” Her symbolic presentation of her female gender was her ability to style her hair everyday. Unfortunately, the husband has had to get her hair cut shorter, so he could style her hair for her, as she is unable to safely do so on her own. However, he does attempt to curl her hair and was proud that he was able to curl her hair without unintentionally burning her. Although not done to her previous level of expertise, he is able to perform simple styles that his spouse examines with a mirror and offers suggestions to improve his technique.

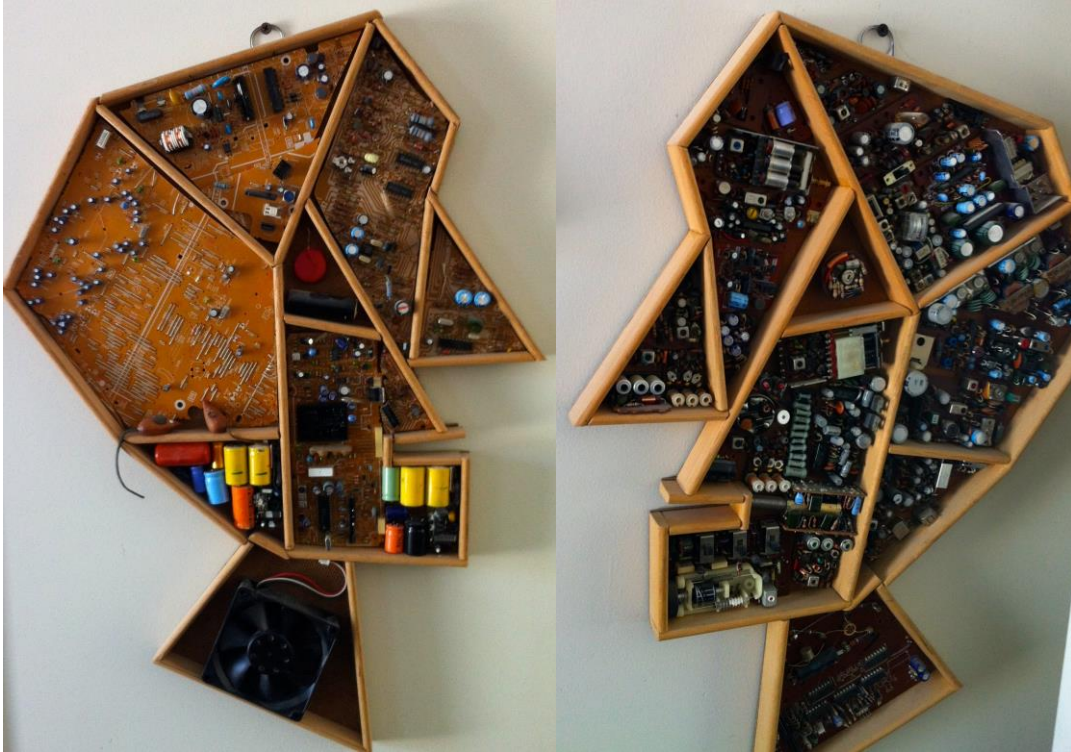


Figure 4.12. Silhouettes: Cardston, AB, February 5, 2014

A visual illustration of symbolization created by a male caregiver who hand-crafted a female and male silhouette using old computer hard drive components is included above. When comparing the female and male silhouette, the female brain has little ‘hardware’ in its lobes, and a pair of mice sit at the bottom of one lobe of her brain. The male caregiver noted that he had “...run out of pieces of hardware” when he was filling in what represented the lobes of the female brain. I contend that the female silhouette represents the male caregiver’s perception of his spouse’s mental functioning and the destruction of her mental capacity following her diagnosis of and treatment for dementia.

New Growth

The theme *New Growth* demonstrates how the past, present, and hopes for the future fundamentally changed men and forced them to grow in ways they had not anticipated. A caregiver used art, displayed in the photograph below, to visually represent the struggles he had gone through as a man that, even though painful and trying, led to new growth for him. The first photograph is a mosaic of glass shards that he had painstakingly chipped to size and glued over an extensive period of time. When I noticed the art hanging on the wall, I was drawn to it, and I believed it held special meaning for the caregiver, as it was hung prominently in his living room. The multitude of colors made it striking. When the sunlight from the window opposite the room struck the shards, they reflected and refracted the light in a beautiful array of colors.



Figure 4.13. Firs on the Mountainside: Cardston, AB, February 5, 2014

When I questioned what the piece of art represented to him, I was enthralled at the interviewer's description of what compelled him to complete this work. He began by describing the mountain: it was steady and strong, not prone to movement or upheaval. The mountain represented him as the spouse and caregiver. The three trees growing out of the mountain represent his three wives. His first wife had succumbed to cancer, his second marriage had ended in divorce, and the third wife, represented by the largest tree, had been diagnosed with dementia and required long-term care placement in a local rural facility. When discussing his interpretation of the art, the male caregiver elaborated:

....I looked at that and I thought, LOOK AT THAT, now look at that mountain, if those trees...those cedar trees can grab that and HANG onto there, well I can hang on through this divorce and death situation, you know what I mean?

The work of art had multiple symbolic meanings, from the mountain representing him as a man, to the fir trees representing his relationship(s) with his wives and the struggle the trees had to hang onto the mountain despite being connected by their roots.

The same caregiver had a second work of art that was hung on the opposite side of the living room. We walked over to the second piece of art that the caregiver had also painstakingly created over a period of time. When I first examined it, I was not clear what meaning it held for the caregiver. After a brief conversation, the caregiver elaborated on what the art symbolized:

So that is what I meant there, and this too, is the same type of thing. You got a pine tree, and you can see the leaves and cones at the bottom there are getting dark, like they are dying, you see? [Yup.] Then suddenly at the top...NEW GROWTH! [New growth!] And that is like me, too, you know what I mean? I saw the...you know, well maybe somebody else wouldn't see that. But for me-- I turned it and I thought, hey, with that in mind-- that's *given me new life*....

The art depicted below is a view of a pine tree from the vantage point of looking from below up into the tree branches. The death of the leaves and cones below can represent two things: one would be the death of his first wife and the divorce from his second wife; that part of himself had died with them, as well. It could also represent his inner emotional state of being, that he was experiencing depression and a sense of worthlessness, until he met and courted his third wife.

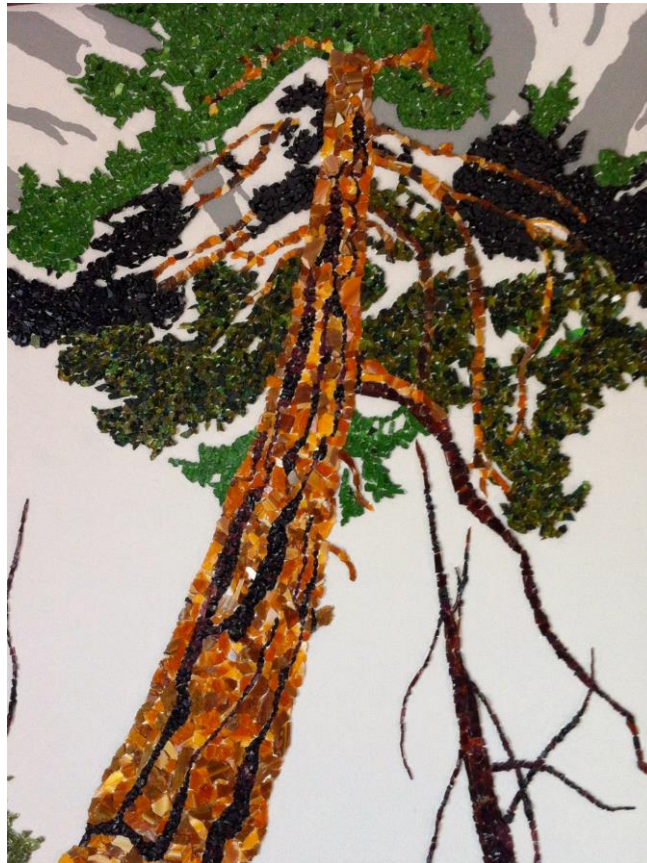


Figure 4.14. New Growth: Cardston, AB, February 5, 2014

Despite the struggles they faced together following her diagnosis of dementia and eventual need for placement in a long-term care facility, it allowed the caregiver to experience new growth as a man. For this caregiver, being in his third marriage and in

the role of a caregiver has given him new life; a new purpose that was lacking prior to the experience of becoming a caregiver.

The trunk of the theory is how the participant's express their gender and masculinities described in the theory (Figure 4.6) through the phrase *As A Man*. The trunk is representative of the male gender, solid and strong at the core and not easily changed or moved from its path of slow circular growth. The connection to the central category is an individual's gender; it is the core of who they are. It directly and indirectly contributes to their actions and behavior in society and cannot be easily undermined or pushed of its path of growth and development. The offshoot near the top of the trunk refers to the *New Growth* as a man. *New Growth* contributes to the strength of the trunk, making men stronger and more resilient. The growth of a small leaf on the single branch demonstrates that the growth experienced by male caregivers can indirectly contribute to their experiences of being a caregiver in their rural setting, and was totally unanticipated and unexpected when entering into the caregiver role.



Figure 4.15. Rural Male Caregiving Theory: The Trunk

Branches of Experience and Perception

Thus far, I have discussed and described the overarching theme of *Separating the Wheat From the Chaff*, and how the caregivers had developed the ability to focus on what was critical or in need during times of providing care and making caregiving decisions. The roots of the theory *Rural Living: Starting From Scratch* and *Rural Way of Life: Where They Hang Their Hat* describe how rural place and space held meaning and contributed to their ability to provide care and to have the connection with nature and outdoor spaces that invigorated both the men and their wives in a variety of rural settings across southern and central Alberta. The trunk of the tree represents *As A Man* and discusses the role of male gender and how the male gender influenced men when providing care to their wives in their home. *New Growth* symbolizes how one caregiver grew and added to the strength of his trunk by developing the strength to move on

despite repeated adversity experienced in his past and present marriages during his life course.

The following themes of *Watchful Waiting*, *Walking the Walk*, *From Breadwinner to Bread Maker*, *Persevering Patience*, and *Crossing Over* incorporate and integrate findings from all of the caregivers and expands on their perceptions of their caregiving experiences. Although at first glance they appear to be separate branches on the tree, in reality they are all interconnected through the trunk and are developed through the caregiver's experiences. The process of entering into the caregiver role when they observe signs and symptoms of dementia in their spouse is explored under the theme of *Watchful Waiting*. The process continues as the men develop into the role of a caregiver and experience being a caregiver, captured in the themes of *Walking the Walk*, *From Breadwinner to Bread Maker*, and *Persevering Patience*. Finally, the final theme of *Crossing Over* discusses and describes the caregivers' thoughts and beliefs of the afterlife and how their religious beliefs and faith contribute to them being a caregiver. Each theme is aligned and displays the growth of men as caregivers and is numbered in sequence from 1: *Watchful Waiting* to 5: *Crossing Over*. The caregiving theme branches are the nourishment and concurrently provide nutrients to the tree through the uptake of sunlight and carbon dioxide; the branches have the ability to weather each season and to grow against all odds. I begin my discussion with the theme *Watchful Waiting*

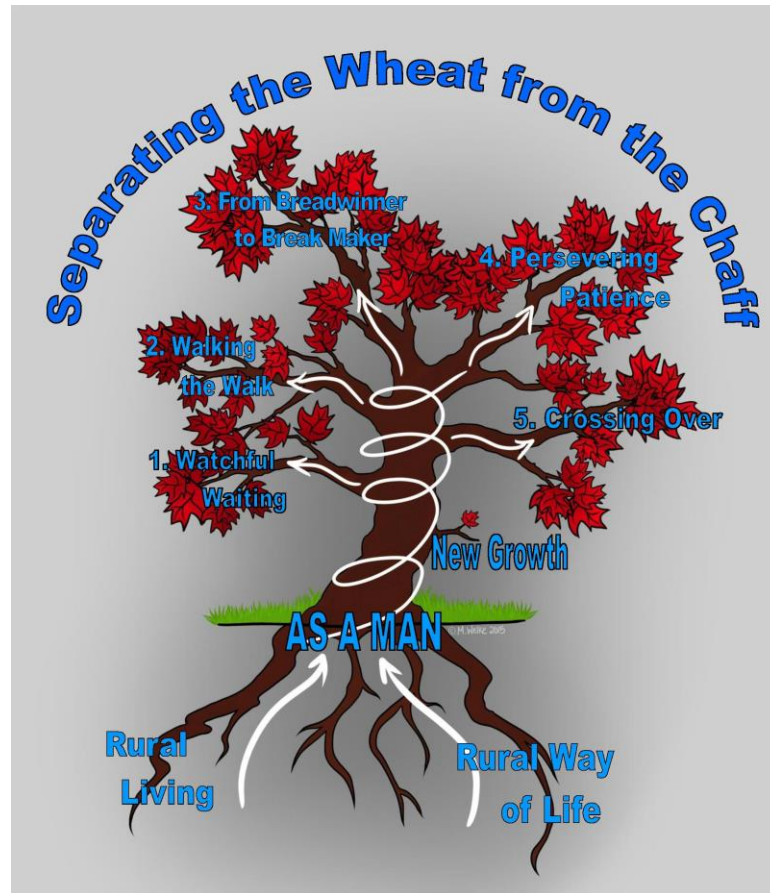


Figure 4.16. Rural Male Caregiving Theory: With Branched Experiences

Watchful Waiting

Watchful waiting is a theme with two underlying subthemes: *Change in the Air* and *Dying by Inches*. *Watchful Waiting* represents the realization that the men witnessed their spouse changing, and they began to exhibit more overt signs and symptoms of dementia. A husband discussed with me how he ensured his wife was safe when shopping in an urban mall:

Like, even before that... when we were in the stores...I'd let her go about her business; but I was always on the outskirts watching her.
 Question: And what were you watching? Just making sure....?
 I was just.....just making sure she didn't get lost.

This watchful waiting meant observing and being aware of where their spouse was at

all times, not to impose control or restrict their spouse, but to ensure their safety.

Change in the Air

It is common for ranchers and farmers alike to mention that “There is a change in the air.” This is a figure of speech used when describing weather conditions and a change of seasons. Lyrics from a song titled “A Change in the Air,” (Black & Hayden, 2007, track 5) captures what I believe is experienced by male caregivers when their spouses begin exhibiting signs and symptoms of dementia:

It takes me back to all the times
I've been here before
But crossroads, old familiar signs
Tell me, there's something more...
And tonight, I feel a change in the air

The feeling that the spouse they have known is changing, that the disease of dementia was causing their spouse to experience cognitive decline, changes in personality, and restricting their ability to function independently in the home was a period of time all of the caregivers reflected upon as a time of considerable stress and anxiety.

One of the caregivers I spoke with first recognized changes in his spouse when she became frightened of large groups of people and would only want to see or associate with people she knew intimately. These individuals were her spouse, her daughter and two of her closest friends. He then observed her memory failing, which concerned and troubled him as she was the one that he had primarily relied upon for remembering events and occasions.

A second caregiver knew something was amiss when he engaged in a new diet regime but his spouse refused to prepare him meals. She insisted on cooking pot pies in the oven, meals that required minimal preparation and instruction. Despite this, she

would overlook putting the timer on and inadvertently burn the pies. His wife also began withdrawing cash from the local bank and paying cash for everyday items, which was unusual for her. He also observed that when she paid for items, she did not request or wait for change from the teller. In hindsight, the husband recognized that she could not manage the multiple prompts and steps needed to complete an electronic transaction with a credit or debit card. Paying for items with cash meant placing the majority of control of the transaction with the teller.

Changes were sometimes attributed to old age, as a third caregiver felt that his spouse was having age-related changes that could be contributing to her memory loss. Initially, it was not a concern for him, until she began to get lost when going for a walk on her own. When a concerned passerby, neighbour, or business owner recognized her and her inability to recall where she lived, they indicated to the spouse that further investigation into her declining cognition should take place. This was initiated by her son, who also resided in the community. She was eventually assessed and placed in a locked long-term care facility. He related to me "...you are getting old, it is expected you will lose a little bit of memory. But it turned out that she got something more serious." This caregiver suffered a severe gastric bleed that culminated in him collapsing at the front door of their home, where he was discovered by a neighbour coming home for lunch. He contends that the development of the gastric bleed was related to his subconsciously worrying about his spouse. Despite him asking if he could accompany her, she refused to allow him to walk with her or follow her on her excursions.

Even when overt signs and symptoms of cognitive decline were apparent, it was difficult for some of the husbands to accept. One husband recounts his thoughts at the time:

That is when I started to....this would have been about eight years ago...I started to know things were not kosher. They were....she was not understanding....what I...I KNEW in my mind that things were not right, but I did not want to admit to myself what was the matter.

Despite observing his spouse exhibiting signs and symptoms of dementia, this husband was in denial that his wife could have dementia. Once a medical diagnosis of dementia was given by their family physician, the husband began to see the dementia progressing at a more rapid pace, as he recounts:

...it was getting worse and worse....seems like by the week. Now it is getting to the point where it is day by day. Literally day by day. (Interviewee whispers last sentence under his breath and is looking down at his clasped hands on the tabletop.)

It is evident that in her specific trajectory of dementia, the beginning signs and symptoms of dementia were obscured, or hidden from others. When the disease progressed, the signs and symptoms became more evident and the individual's ability to conceal or disguise her cognitive decline could not be maintained.

At the opposite end of the spectrum, a caregiver recounted that he knew his spouse had a form of dementia. He independently completed his own 'research' and read numerous books related to cognitive impairment and the various forms of dementia. What frustrated this caregiver immensely was the hesitation of local rural family physician(s) to attempt novel and experimental treatments, such as collecting stem cells from his pregnant daughter-in-law. Following delivery of the baby, the stem cells from her umbilical cord could have been collected and cryogenically frozen. The caregiver had

hoped if the stem cells were a match for his spouse, specially trained health care professionals could transfuse these cells in an attempt to enhance her cognition and delay the cognitive decline associated with dementia. He was informed by the physician that he was on the right track, but his thinking was twenty years ahead of his time. He pressed and pleaded, saying that he would sign a waiver absolving the physician of any responsibility for this unique treatment, as he felt the physician was concerned about a lawsuit if the treatment caused harm to his wife. The physician adamantly refused, and the caregiver contended that physicians are not willing to push their comfort zone in treating dementia with unproven therapies.

The same caregiver passionately advocated for his spouse to be placed on oral medication that has been shown to slow down the progression of dementia. However, prior to being able to be prescribed the medication, a formal medical diagnosis of dementia had to be given. He came up against resistance with rural physicians who declined to diagnose his spouse with dementia, or pursue any treatment options, stating her cognitive decline was due to her age. He was insistent and pleaded with them to write him a referral to see a specialist in geriatric care. He reflects on that time:

They said, "There is nothing to worry about." And I said, "LOOK! Look it, she is changing. There is something happening! She used to be as sharp as a tack." They kept putting me off and putting me off...

Two years after he had noted the cognitive changes that his spouse was exhibiting, a referral for a geriatrician was given. Following their initial meeting with the geriatrician, the diagnosis of dementia was given and the medication was prescribed. However, the geriatrician indicated that starting the medication earlier in the progression of the disease could have benefited his spouse. The caregiver contends that

the rural physicians caused a delay in the diagnosis and treatment of her dementia, that the process of her dementia could have been slowed down and her quality of life at home with him could have been extended.

Dying by Inches

For all of the caregivers, it was agonizing and draining to see their spouses deteriorate in front of their eyes. When asked what the most troubling aspect of having a spouse with dementia was, a caregiver became emotional when he related:

Well...it is the fact that you can see them slipping away and there's nothing that you can do! It is HARD...was HARD to think that somebody with that brilliant mind could go down like that...

The most graphic illustration used to describe the deterioration related to dementia was a term that one caregiver specified as 'dying by inches.' When questioned as to the origin of this saying, he related that his parents had used this figure of speech to describe someone being sick for a long period of time in their community. It is a moving description when he applied it to his wife with dementia, as he related that a middle aged man who just up and has a heart attack - and just drops dead - that is fine. But, with the disease of dementia, "you lose a little bit of your independence and what it means to be your own person EVERY DAY. A little bit every day." The worst part for this male caregiver was that he could not reverse the changes associated with dementia, he only had the ability to acknowledge that it was the disease that was changing his spouse and she had no control over the disease and the disease process.

Having to bear witness to their loved ones' deterioration over time makes dementia a daunting disease. Occasionally, their spouses had changed into someone who no longer resembled the person that they had married and with whom they had raised a

family. The deterioration of his wife and shock felt by one spouse who was attempting to come to terms with his wife's decline was captured throughout his interview. The drastic change in personality, from having a spouse who was very outgoing - to an individual who sits for hours on end in a nearly catatonic state - distressed the caregiver. She is often ignored at public outings, which makes her spouse so distraught that he avoids public venues and dreads family gatherings. He described his spouse as being a shell, not an *actual* shell, but a completely different person. He elaborated that:

All of the things she used to do, she doesn't do anymore. She...*it* is fading her. She just doesn't really care anymore.

The description of his spouse fading, and the reference to "it" as the disease of dementia that is responsible for her fading represents the profound and drastic changes that can occur in individuals with dementia. The use of the word "fading" also depicts the husband's gradual loss of his wife and that although she is still there, he cannot reach her in a comprehensive way as he had in the past.

Walking the Walk

The second theme is *Walking the Walk*, with the subtheme of: *In the Bedroom*.

In the Bedroom

Caregivers identified different barriers and obstacles they encountered: some anticipated, and others that blindsided caregivers. One caregiver articulated his difficulties with clothing his spouse and the effort required to plan what clothes his spouse would wear:

the cooking I can handle - but like I said...it's the bedroom that...that just keeps me...to get her clothed, to get her dressed, and choosing the clothes...I just don't...don't - (shaking his head slowly back and forth)...it's hard to get my head around that and I probably never will....

This caregiver recognized that he could not overcome his difficulty choosing outfits and having an eye for what blouse matched with what pants. He had a female friend who would come to their farm and organize her clothes, going to the extent of lining them up in the closet and matching and marking the tags. This was done so he would recognize what clothes matched following washing and ironing her outfits. At the change of season, she would return to their home, store the out of season clothing, and bring out the appropriate clothes for the upcoming season.

The caregiver recounted to me that prior to his spouse exhibiting signs and symptoms of dementia, she would pick out suits for him to wear to Alberta Wheat Pool board meetings. On one occasion, he made an independent decision on what tie matched a certain dress shirt. When communicating with his wife via telephone that evening, he discovered that his choice had been made in bad taste, the two were not meant to be worn together. He was acutely aware that their roles have reversed; he was now the one that had to dress his spouse, despite his ignorance in knowing what was appropriate or fashionable.

Walking the Walk for one husband required him to monitor his spouse's ability to shower herself appropriately, as he was noticing his spouse developing a persistent body odor that she did not have in the past. Eventually, he had to stand outside of the shower door and talk with her. He spoke softly when he told his wife that they "have to change the showering methods." Following that conversation, she had burst into uncontrollable tears and cried like a baby. From that day forward, he was required to be in the bathroom to assist and cue her with bathing and ensuring proper hygiene was

being performed consistently. He was visibly distraught when he elaborated on what was required of him on a continual basis:

When you have to stand there and tell your wife how to wash her face...how to brush her teeth...how to... dress her and undress her. When you get up in the morning you start that and when you go to bed the last thing you do is you put your wife in bed. And they-- the average person doesn't realize that that's what it's come to-- you know!?

The amount of and constant cueing for his spouse's activities of daily living were not acknowledged by family and friends. The care that this husband gave, he felt, was largely invisible to individuals, as it was provided in isolation and behind the four walls of their home.

Breadwinner to Bread Maker

The theme *From Breadwinner to Bread Maker* demonstrates how the roles at home had changed for the caregivers. With this generation of men, there can be a deeply ingrained breadwinner mentality, of being the primary wage earner and financially supporting the household. Even if it meant working all the time and having to hold down two or three jobs in the first few years of married life, the expectation was to make the sacrifice for the family to maintain a set standard of living. As one caregiver recounted, his career had eventually culminated into having a full time supervisory position where he managed a crew of men at a nuclear power plant. Nearing retirement, he had earned a full pension, plus he was given a severance package based on his accepting early retirement from the workforce. The caregiver related to me that the length of his retirement would soon surpass that of his working career.

Despite having the ability to move to a rural area closer to his children and grandchildren, it was necessary for him to create a new role for himself, one that I have

termed being a *bread maker*. This caregiver was compelled to take on the role of cooking and preparing and planning meals for the household. In particular, he related to me that “He could barbeque, but that was about all the culinary skills that he had.” In the beginning stages of his spouse’s dementia, he observed that she was purchasing and preparing freezer dinners that he did not find appetizing or healthy. In hindsight, this was the beginning of his role of becoming a *bread maker*, as he began taking on purchasing fresh produce and meats and preparing meals. His evolving *bread maker* role led to him being the sole preparer of foods, as his spouse was no longer able to operate their stove in a safe and reliable manner. At the time of the interview, his spouse was being cared for at a local long-term care facility. With only himself to cook for, the male caregiver had decided that it made more economical and practical sense to prepare one to two large dishes per week at his home, then divide and freeze meals that could be warmed up when he returned home in the evening.

A humorous recollection was made by the wife of a caregiver about her observations when she was coming out of her family physician’s office following a check-up he had taken her to:

Wife: Now- this is funny. I was [coming out of] the doctor’s office and I caught him cutting outta - a recipe out of a magazine!

Interviewer: Really? (Raises eyebrows at caregiver.)

Wife: Yeah, because he never cooked for a long time. I don’t think he even knew where the kitchen was!

Husband: Yeah...well.... (Shrugs shoulders.)

Wife: Now he does, in spades. He makes cookies.

Interviewer: Ok. So you bake, too?

Husband: Yeah, every now and again. (Soft chuckle under breath.) I can follow a recipe - but if it gets a little difficult - I...I tend to avoid it.

The husband caregiver had grown in his role as a *bread maker*, to the point of clipping out recipes in magazines that he finds of interest. This was a humorous account, but also showed how the husband was attempting to become a better cook with more skills. The couple relied heavily on takeout from a rural restaurant that had a limited menu and was much more expensive than being able to prepare meals at their home on a consistent basis.

One caregiver had a great deal of pride in his spouse's ability to cook. He fondly recounted:

She was an excellent cook, an excellent cook and... a baker.... and stuff like that, and she baked for the neighbors and she'd bake buns. Her thing was butter horns; she'd make butter horns and I'd deliver butter horns.

Sadly, she could no longer cook or prepare recipes that she had previously completed "off the top of her head." This point, when his spouse could no longer be relied upon to make the meals for the household, was a low point in the progression of her dementia, as she was an avid cook. A struggle this caregiver had was the need to plan for and prepare meals - for example, the need to thaw out meat or make certain preparations for meals that could be produced at a specified meal time. This had to be done despite busy times of the year on their farm, such as seeding and harvest when he was working the fields from sunrise to sunset. It was his responsibility to be thinking and planning meals both he and his spouse would find appetizing and nutritious. The caregiver has embraced the role of being the baker, having freshly made doughnuts prepared for our scheduled interview. The doughnuts were a family recipe that the male caregiver had observed his mother preparing when he was a child.

The role changes experienced by male caregivers went beyond domestic household tasks. One caregiver recounted that his spouse was the bookkeeper for a small vehicle repair business. Following their marriage and relocation to his farm, his spouse took on and maintained the role of bookkeeper, which he heavily relied upon. His spouse had been thrust into the role of breadwinner for her family when she was just an adolescent due to the untimely death of her father. This past experience made her vigilant and careful with the management of their finances. Whenever the farm made a profit, his spouse had invested the money or set aside money for upcoming purchases required for the farm. She also enjoyed doing the books, as it gave her a change of pace from completing common domestic tasks and chores for the household. An hour of books was a positive change and she looked forward to working through the books. Having his spouse complete the bookwork and balance the bank accounts allowed the farmer to pursue other side businesses that contributed to the financial success and prosperity of their farm. The bookkeeping took her minimal time, from fifteen to twenty minutes a week, to complete. When his spouse began to labor at the bookkeeping, it was the first indication of her cognitive impairment. She was distraught and saddened when she could no longer consistently balance their bookkeeping. The male caregiver was compelled to take on the bookkeeping duties. He confessed to hating bookkeeping and that his bookkeeping pales in comparison to his spouse's. What he remains tremendously proud of, and grateful for, was his spouse's prudent investment in term deposits that are coming due at specific times. This ensures a continuous supply of the income that is required to run two households, as he resides

alone at home and she requires full-time care in a care facility. Without this prudent investment in the past, the caregiver related that they would be in dire financial peril.

Persevering Patience

A consistent finding spontaneously verbalized by all of the men was the need for patience when in a caregiving role for a spouse diagnosed with dementia. Patience was needed in varying degrees and at unpredictable times when caregiving. One participant emphasized that patience is the toughest part of caregiving and “most men don’t have patience, I’ve learned a lot about being patient.” Two participants relayed how they had been impatient in the past with their spouses, but following the diagnosis of dementia, the men noted that their tempers ‘mellowed.’ This allowed them to have patience and tolerance when providing care and interacting with their spouse. Another participant discussed patience in relation to the time it took him to plan and complete caregiving tasks that might have to be placed aside if more pressing demands are made by the care recipient. The increased patience has allowed him to handle the multiple and unpredictable demands that are made by the home environment, family members, and his spouse.

Caregivers’ patience was discussed in relation to the personality changes some of the individuals with dementia underwent over the course of the disease. One caregiver had a care recipient with violent and unpredictable behaviours that led to her requiring placement in a facility for his personal safety. His advice for other caregivers entering the role was to be:

Patient...I guess, is to be patient, and...it takes a...a lot of forgiving, I guess you’d call it, ‘cause it’s definitely not the same as it...they used to be like, so. And, you just got to put up with a lot and you’re not gonna modify it...it’s just not going to change. Just go with what you got and do the best you can.

This caregiver is discussing his ability to acquire patience relating to how he reacted to his spouse's violent and unpredictable outbursts when he was attempting to care for her at home. It is being patient with the person you are caring for. It is the patience developed internally when reflecting on past events and how the disease of dementia cannot be modified; you cannot make it fit with your perception and model of care. Accepting yourself and being patient with the signs and symptoms being displayed by the care recipient were key for this caregiver and his understanding of what it meant to be patient.

Another caregiver, when asked by the interviewer to describe the most important lesson he had learnt about being a caregiver, emphatically replied patience, repeating the word four times to bring the point home that patience was vital. One male caregiver identified himself as being a patient man in the past, but being in a caregiver role has increased his ability to be even *more* patient. Specifically, the caregiver contends that his development of patience has made him handle his spouse in the beginning stages of dementia more effectively when he performs certain tasks or completes certain jobs and chores around the house. An example of his patience was demonstrated during the interview, as his spouse had repeated requests for refreshments, leg rubs, and the need to be readjusted in bed.

When asked what he felt characteristics of a good caregiver are, a participant became animated in his response, stressing that:

A good caregiver has to HAVE LOTS OF PATIENCE. Have to continually remind yourself that, sure she is doing this, but you - no use giving her hell - because it is not her fault. She don't realize she is doing it. That's the *big thing*...

The caregiver is relating that attempting to control a person with dementia can result in profound frustration for the caregiver. Exercising self-control and reminding yourself that

the person with dementia has minimal to no insight into their behavior and how their behavior is affecting the caregiver. The big thing for this caregiver was not placing fault on his spouse for her behaviors, as she has impaired insight into her actions and behaviors that can be distressing for the male caregiver.

Patience was needed overall but was also required for brief periods, as one spouse related that he knew in most cases his spouse's behavior would change:

....most of the time I...I....I [knew how to] keep her cool. I know what it is and she can't help it, it will, it will change again after a couple of minutes. She can be angry, she is....it is also of course, a question "Is she not able to express herself anymore?" I don't know what still goes on there and there is *no way* to express it when it frustrates her. Now, she gets angry with me. In a couple of minutes, it will hopefully change again...

This caregiver was describing the rapid fluctuations related to his spouse's presentation of dementia. She was prone to varied and sudden mood swings, going from a state of anger and physical confrontation to hugging him and telling him over and over that she will always love him. The dramatic mood swings required patience and the knowledge that they will be brief in duration. I was deeply moved that the caregiver questioned that the displays of anger and violence could be related to his spouse not being able to express her emotions appropriately. There no longer seemed to be the internal ability for her to have restraint or insight into her emotional state and reactions to stimuli in her environment.

Crossing Over

The twelve interview participants had a diverse range of philosophies relating to their religion and religious beliefs and how it affected them as caregivers and as men. Four of the twelve participants were Latter-Day Saints, and their faith and belief in the afterlife were evident throughout the course of my interviews with them. One interview

participant who had worked and taught in the seminary and continues to volunteer for his local LDS stake in his rural community shared a passage taken from the Book of Mormon. “For the Lord looketh not on the outward appearance of a man but God looketh on the heart.” He had placed this specific passage on a plaque and presented it to all of his seminary students upon completion of their studies. One of his reasons for choosing this certain scripture passage was to remind them that it is not the signs and symptoms and the process of disease that you should focus on, you have to attempt to focus on what is inside the person. The passage was written above the outline of a human face and upper chest region, with a heart carved into the wood and painted to symbolize what all individuals in the seminary should be focused on, the inner being of the individual.

Here and Now

All interview participants of the LDS faith identified that you must not focus on the here and now, of being a caregiver for their spouse with dementia. They had a steadfast belief that they will be together following death as a family unit following death. Latter-Day Saints believe in pre-mortality, mortality, and post mortality (Rhodes & Bodine, 1995). In post mortality, you will see a sign that ‘families are forever.’ The belief is that when you die, you are resurrected and experience no illness or infirmity and you are together as a family unit. However, Latter-Day Saints teach that membership in the church is required for salvation through resurrection and being together as a family unit in post mortality (Rhodes & Bodine, 1995). This belief is integral to the male caregivers for them to persevere and to carry on in their caregiver role. When you look at things in the eternal perspective instead of just the here and now, it makes a difference to these caregivers. The Christian belief and wedding vows that you are together until death do

you part have no bearing on the Latter Day Saints faith. Death does not part people of the LDS faith. One participant graphically describes his thoughts and actions that he might have resorted to if he did not have his Latter-Day Saints faith:

I mean...I would be pulling out a gun, shooting the kids... and shooting the wife and shooting myself and saying "If there is nothing after this...let's get out of this!"

For this caregiver, the only rational escape from his arduous caregiving role would be to take the lives of his family members and then himself. This dramatic and violent act would end his own and his spouse's suffering in the present life. However, he also stated that he would never act on this impulsive thought, as his faith and religious beliefs do not allow the taking of life.

The topic of assisted suicide was indirectly broached and discussed by one of the interview participants. The subject was not raised by the interviewer, but was spontaneously spoken about by the interviewee towards the conclusion of the interview. The conversation immediately prior to this focused on the type of behavior that necessitated the need for the male caregiver to seek out and have his wife placed in a local long-term care facility. The interview participant stated:

...but, in the meantime...I mean...we certainly don't believe in helping them along here...but. (Deep sigh followed by a short, sad laugh.) Like, some of these places, well - you know, I give them a little medicine that will fix her right up - yeah....you know, then she would be gone...you know. But, no, I would never be involved in anything...even to think about....you know...anything of that description....no, nope.

It was verbalized by the male caregiver that to even think about the subject of assisted suicide was considered taboo. When he refers to "we," I believe that he was using the plural term to describe his faith and other members of his faith. He also specifically refers

to the place “here,” denoting the local rural long-term care facility that was partially funded by the LDS.

The subject of suicide from someone diagnosed with, and experiencing, the beginning stages of dementia was recounted by another LDS male caregiver. The wife of this husband approached him privately and spoke with him. He shared with me that she held his hands and looked into his eyes and beseeched him “Why can’t we just both die and go together...just get out of here?” Visibly distraught when recounting her request, he stated that “You see.... she KNEW something was going wrong. She couldn’t explain it....you know...and I couldn’t. So, we just...kept working with it.” Despite the faith and belief that they would be together in the afterlife as a family, the daunting prospect of living with a diagnosis of dementia - which would ultimately contribute to her death - was a very difficult prospect for both the caregiver and his spouse. The photograph of the abandoned church below represents the history and prominence of religious rural faith communities and a recognition that they are becoming a less common feature in current rural communities.



Figure 4.17. Rural Abandoned Church: Etzikom, AB, January 3, 2014

Caring in Theory

Five out of eight of the remaining male caregivers were of Christian faith. One of the caregivers was a retired minister from a rural community. He had witnessed and provided guidance for members of his congregation who had suffered from various ailments, including dementia. He had visited the local rural hospital as a minister, and was now at the same hospital in the role of a husband and caregiver, as his wife was a resident in the long-term care facility attached to the hospital. He related that it was tough to see people of his congregation being affected by dementia, either having the illness themselves or praying for a family member who was diagnosed with dementia. The following dialogue is an excerpt taken from the interview:

Participant: And also yeah...I seen; of course.... with hospital visitation. I've seen a lot of people with dementia and....

Interviewer: Yeah, it's tough to see that as a minister....?

Participant: Yeah.

Interviewer: So you were...helping people through that, and their families and now you're... (Motioning to the walls of the room.)

Response And now...I have to admit that I knew it all in *theory*, but the *practice is different*.

The caregiver is acknowledging the difference from being an observer in his profession of a minister to his experience being in the role of a caregiver. All of the theory and observation could not have prepared him for the emotional turmoil and hardship that led to his wife requiring long-term care following a fall in their home that resulted in a hip fracture. This caregiver visited his wife at the long-term care facility every day, which required a 45 minute commute from their primary residence.

Putting Them Out to Pasture

The caregiver was shocked and saddened by the fact that other residents at the long term care facility received minimal visitors. The term he used for this decreased visitation was “putting the people out to pasture.” When he was a minister at his church, he implored people in the congregation not to pay your last respects at a person’s funeral, but rather to visit them while they were still alive, whether they were living at home or being cared for in a hospital. *Putting people out to pasture* was equated with the act of placing people in a facility or hospital, then not making the effort or telling yourself that you are too busy to visit them on a regular basis. He correlated this behavior to a veterinarian telling a dog owner that “the dog is getting old. The beast is old and peeing all over the carpet. Take it to the dump and do the fair thing. Get it done with, you know?” By placing elderly individuals with dementia and other ailments in a facility and not visiting them, you are putting them out of sight, out of mind. He was amazed at how some individuals could be so rough with their spouse, but did state that he did not know their history and what may have contributed to them behaving in this manner.

What troubled this caregiver immensely was that their own children had also stopped coming to visit him and his spouse following her placement in the long-term care facility. One of his sons declined to ever visit his mother following her diagnosis with dementia. Only after a visit from a grandchild, who recognized the rapidly declining health of his grandmother and his grandfather appearing exhausted, did his other children visit and offer some short term respite for him. The caregiver recognizes that there will be no “happy outcome” as his spouse becomes increasingly weaker and more reliant upon nursing home staff and himself to provide the necessary care that she requires. When questioned if his faith in God had ever wavered following his wife’s diagnosis of dementia and resulting decline in her health, he noted that “he never promised us.....that we would have a life free from war, worry, and illness.” ‘He’ is referring to God, and the caregiver was very calm and serene when he made this statement. What was critical for this caregiver was:

His presence is important. I know that His presence with me and that His presence with Susie, and that is our faith. Uh, but I’m not angry with God, no. No, no. I just wish it were different.

Knowing that God was present in his daily struggles and having the faith that it was a part of his plan gave this caregiver the reassurance that his spouse will eventually succumb to the effects of dementia, but that they would both have the presence of God no matter what the future brought. A photo taken of a billboard in a church parking lot that I have included here brought what this caregiver told me into perspective, It stated:

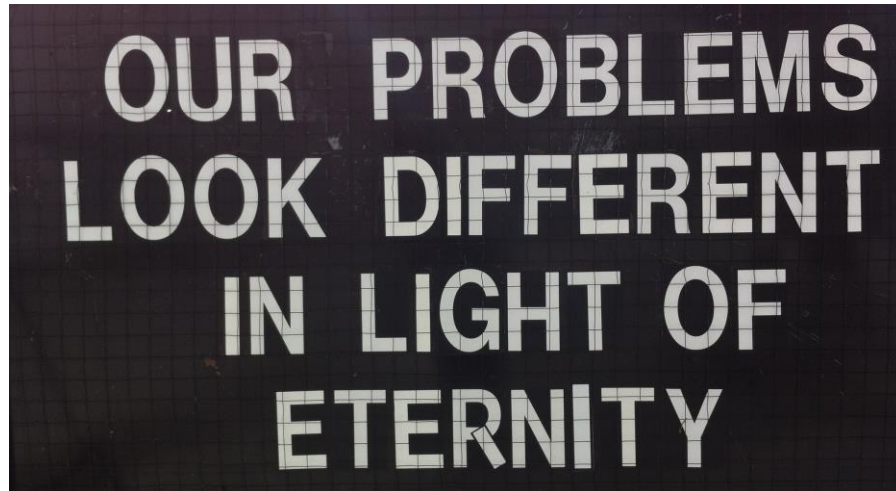


Figure 4.18. Church Billboard: Oyen, AB, February 12, 2014

Summary of Main Findings

The geographical region for the participants encompassed various rural locations across central and southern Alberta; and their unique descriptions of what it means to be a male caregiver have been captured in Rural Male Caregiving Theory, which includes the themes (*Rural Living; Rural Way of Life; As A Man; New Growth; Separating the Wheat from the Chaff; Watchful Waiting; Walking the Walk; From Breadwinner to Bread Maker; Persevering Patience; Crossing Over*) and the sub themes (*Starting from Scratch; Where They Hang Their Hat; Relationship Blossoming; Production Relations; Male Desire; Companionship; Symbolizing the Relationship; Change in the Air; Dying by Inches; In the Bedroom; Here and Now; Caring in Theory; Putting Them Out to Pasture*) arising from their own words (Figure 4.7). These findings are all supported by and intertwined with the overarching theme of what makes male caregivers unique: their ability to *separate the wheat from the chaff* and to persevere in a role that challenged them all in various ways. Having the experience of being a caregiver is one chapter in these men's lives, and the culmination of these experiences

will contribute to what it means to be a rural man who stepped up and embraced the role of being a caregiver. Although these men were older, the mean age being 78.4 years, they were able to forge ahead against difficult and trying circumstances and became more complete men when in the role of a caregiver. Living and growing old together in a rural setting and in their rural home was vital and contributed to the caregivers' and care recipients' sense of well-being and their connectedness to nature. Being a male caregiver reinforced some aspects of what it meant to be a man and allowed some men to experience new growth as a man.



Figure 4.19. Rural Male Caregiving Theory: Experiences Nourishing the Tree

CHAPTER FIVE: DISCUSSION, RECOMMENDATIONS, AND CONCLUSION

In this chapter, I will place my research findings within relevant current literature and how they relate and add to certain aspects of the Rural Healthy Aging Assessment Framework (Jeffery et al., 2013), Connell's (2005) Model of Gender Relations, and O' Lynn's (2010) Gender-Cultural Model of Caregiving: Rural Male Caregivers. Specifically, my research question was: How do male caregivers of spouses with dementia in rural southern and central Alberta come to understand their role as a caregiver? This question was explored through a grounded theory study that consisted of 12 interviews with male caregivers who lived in rural settings in southern and central Alberta. The findings led to a substantive Rural Male Caregiver Theory that identifies and describes rural as a place for providing care. The core category was *separating the wheat from the chaff*. The themes of *watchful waiting*, *walking the walk*, *from breadwinner to bread maker*, *persevering patience*, and *crossing over* describe the experiences of the male caregivers. The trunk of the theory, *as a man*, uncovers how caregiving is approached by the male gender. The roots of the theory are the themes of *rural living* and *rural way of life* that expand upon how rural place and space influence the men who are caring for their wives with dementia in rural settings in southern and central Alberta. A visual representation (Figure 5.1) of the theory was created that demonstrates the connections between rural, being a male caregiver, and the experiences of male caregivers.

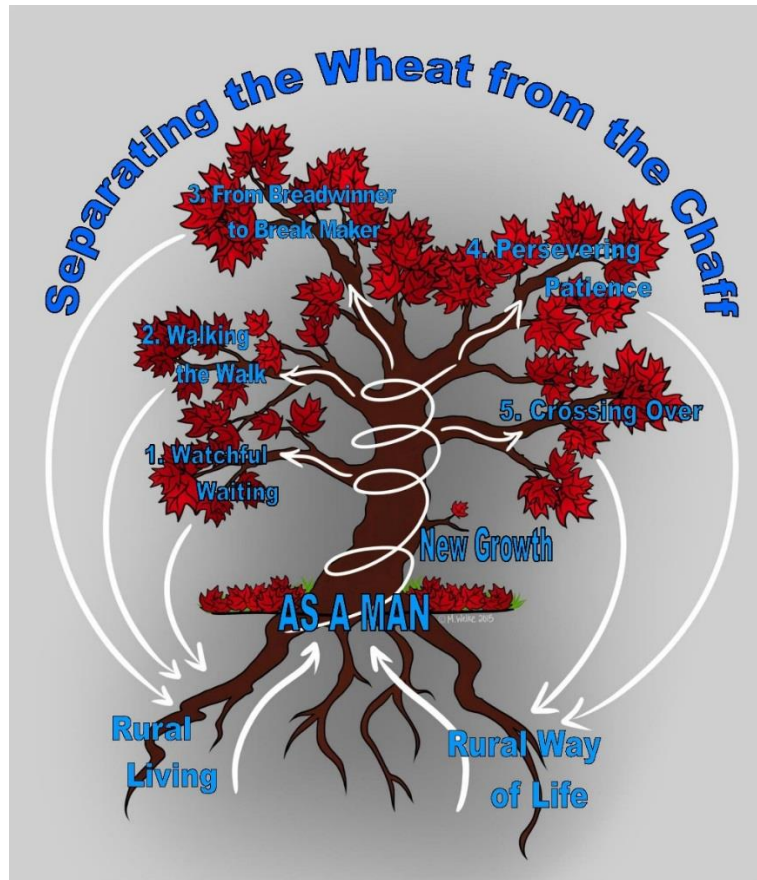


Figure 5.1. Rural Male Caregiving Theory

Discussion

From my rural farming background, I like to draw the analogy that dementia is like the erosion of fields during a rapid spring thaw. When a fast snow melt occurs in the spring, the resulting runoff can overrun the ditches and waterways that normally divert the flow of water. The flow of water cannot be contained, and the runoff spreads into the fields and cuts into the productive farm land. The runoff can be so intense and sustained that it makes decisive and deep cuts in the field. Topsoil and vegetation are swept away leaving bare clay earth with few to no nutrients for future plant growth to occur. The landscape is forever changed. Much like the disease of dementia, individuals diagnosed

with the disease are changed; part of themselves and who they were can be lost. Fortunately, I found that the caregivers I interviewed worked hard to ensure that the former selves of their spouses who were living with dementia were not forgotten or set aside. However, it was extremely difficult for one caregiver to reconcile that his spouse, who was previously outgoing and personable, had become an individual who refrained from making eye contact and now stands behind his shoulder when they are in public. He, and the other caregivers I interviewed, worked diligently at remembering and honouring the person that their spouses were and are now. They viewed them as one and the same; the symptoms of dementia that they exhibited were just that--symptoms that did not represent the person that they knew. This action of holding onto who their spouse was has been discussed in reference to the quality of their relationship prior to receiving the diagnosis of dementia (Siriopoulos, Brown, & Wright, 1999). Siriopoulos et al., (1999) sample of eight husbands spoke about how they missed the things that they used to do with their wives. However, I could not locate any discussion in the caregiving literature regarding the purposeful action of holding onto who their spouse was before exhibiting signs and symptoms of dementia.

Rural Aging in Place

Older rural adults prefer to stay and be cared for in their own homes (Bacsu et al., 2012). When compared to younger adults, a lower proportion of older adults move to new locations (Serow, 1987). Those who do choose to move are less likely to be living with a spouse (Biggar, 1980; Colsher & Wallace, 1990; Litwak & Longino, 1987). However, when older adults do move, the common reasons are to seek out better health services and resources, a better climate, additional amenities such as recreational opportunities, and to

be in closer proximity to family (Colsher & Wallace, 1990). Due to these reasons older adults, once settled into a community, have high residential stability and become attached to their homes and neighborhoods (Rowles, Oswald, & Hunter, 2004; Scharf, Phillipson, & Smith, 2005). All but one of the men I interviewed implied that they were determined to continue residing in their rural homes and communities, despite caring for a spouse with dementia. Indeed, the number of individuals diagnosed with dementia is rising dramatically in rural areas (Johnson, 1996), but spousal caregivers have expressed the desire “to go on as before and not to let the problems take over their lives” (Fänge, Oswald, Clemson, 2012, p.2). These spousal caregivers contend that aging in place is “about being able to continue living in one’s own home or neighborhood and to adapt to changing needs and conditions” (Fänge et al., 2012, p. 1). A more comprehensive approach to aging-in-place seeks to identify the long-term care needs of older adults and provide them with opportunities to remain meaningfully engaged in community life as they age (McDonough & Davitt, 2011).

Eleven out of the twelve men interviewed expressed a desire to age in place; the twelfth caregiver had relocated in order to be near the facility that his wife was placed in so he could visit her on a daily basis. Four of the caregivers recognized that the movement of their spouse from familiar surroundings could impact their health and quality of life, coupled with the financial burden that may include the need for two separate residences if their spouse required facility care. These observations were consistent with the literature that found moving individuals with dementia from familiar surroundings can have deleterious effects on their health, economic factors, and quality of life (Brown et al., 2002; Colsher & Wallace, 1990; Lutgendorf et al., 1994). The ability

for individuals to age in place has become a focal concept of policy makers and researchers to support communities that facilitate the recognized preference of older adults to remain in their homes and communities for as long as possible (Vasunilashorn, Steinman, Liebig, & Pynoos, 2011).

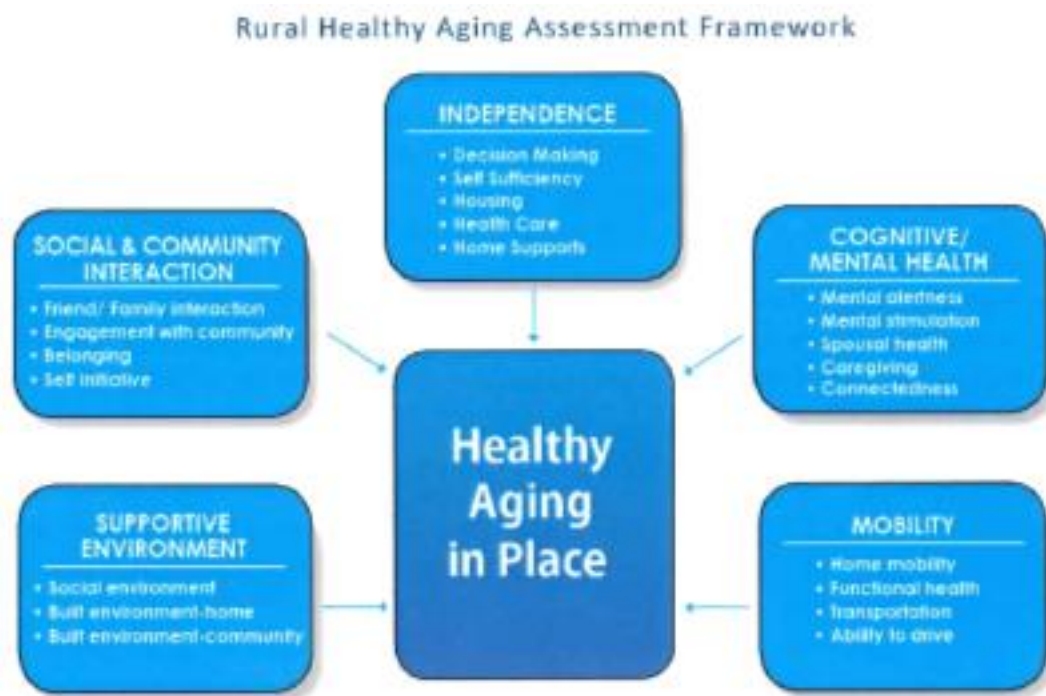


Figure 5.2. Rural Healthy Aging Assessment Framework

Rural healthy aging in place. In reference to rural communities, one available framework facilitates understanding of the elements that must be considered to ‘age in place’ (Jeffery, et al., 2013). My research findings support elements of this framework as it identifies spousal health and caregiving under the theme of cognitive/mental health. It also coincides with the supportive environment(s) of social and built environment(s) of home and community being integral to aging in place. Finally, this framework mirrors my own research as it identifies the need for healthy aging in place for rural individuals (Jeffery et al., 2013). It reinforces and supports the themes that comprise the roots of my theory, which arose from my research findings: *rural living: starting from scratch*, and

rural way of life: where they hang their hat, where I identified that the place where the caring occurs contributes to what makes men successful caregivers. My research adds to the framework by describing how the built environments of home and community contribute to the experiences of male caregivers.

Rural Therapeutic Places

A critical matter identified by one participant, and echoed in varying degrees by other participants, was their intent to provide care and comfort to their spouse with dementia for as long as possible in their rural home and community. Home for these caregivers goes beyond the recognition of their home as merely a dwelling. I contend that the concept of therapeutic landscapes of care (Milligan & Wiles, 2010) can be applied, as it explores “the physical, individual, social and cultural factors that come together in the healing process in broadly defined traditional (and non-traditional) landscapes” (Gesler, 1992, p. 736). As dementia has no cure and remains a fatal disease, the concept of therapeutic landscapes can be applied to the maintenance and gradual deterioration of the care recipients’ health and well-being (Williams, 1999) in the comfort of their own home. In regards to spousal caregivers and their home environments, “if a healthy, definitive place identity fit exists, the home is deemed therapeutic as it contributes to well-being” (Williams, 2002, p. 142). What is significant about this statement is that the rural homes and communities in which the men reside can contribute to their well-being as caregivers. Forcing these men to move to an urban environment where there are more readily available resources and facility care for their spouse with dementia is not the solution. As a society, we have to be willing and able to support these male caregivers in the rural areas that they have chosen to call their home. Williams (2002) does acknowledge that

the home as a therapeutic landscape for the care recipient has been well documented; less is known about whether and *how* the home operates as a therapeutic landscape for family caregivers. The men I interviewed took great pride in their homes and what needed to be changed or modified in their homes in order for them to provide care to a spouse with varying degrees of immobility. Wile's (2003a; 2003b) examined the experience of caring at home and found that the home as a context for care both shaped the care itself and had a huge impact on how individuals perceive and experience their homes. The men I interviewed were not ashamed or disappointed when they had to modify or adjust the layout of their home to provide care; they were able to adapt to the changing care needs of their spouse and perceived their homes as a safe place to provide care.

Rural Faith

The men spoke to the connectedness to rural place and rural environment, with one caregiver relating that the rural place and environment that he lived in was his church; he correlated the physical setting of being a place of worship. Four other men alluded to the rural place where they chose to reside, work, raise their families, and retire had added positively to their social identity and standing in the community. They lived in a rural community in southern Alberta that was dominated by their religious affiliation. In this context, rural place involved emotional ties and a sense of shared interest and values (Williams, 2002) with others in their community. Their rural place was:

... imbued with personal, social, and cultural meanings, provides a significant framework in which identity is constructed, maintained, and transformed. Like people, things, and activities, places are an integral part of the social world of everyday life; as such, they become important mechanisms through which identity is defined and situated (Cuba & Hummon, 1993, p.112).

Indeed, the place of worship for this community was prominent and centrally located in the community. This rural place was a magnet for individuals wanting to convert to or practice this religion in a community that mirrored their principles and way of living. All of the caregivers interviewed in this community were actively involved in their religion and volunteered their time to the church in varying degrees. The rural place and their homes situated in the community near to their place of worship, contributed to their sense of self and standing in their community.

Rural Men Being Bread Makers

I was invited into and listened to descriptions of how care was provided in numerous rural homes. The men I interacted with were able to cope with spouses who required varying degrees and amounts of care. What was intriguing was the influence of how the home functioned prior to the men becoming the primary caregivers and being responsible for all household tasks. For example, one caregiver had removed all of the houseplants from their home when he was moving into the role of caregiver as he found it difficult to maintain all of the plants to the extent that his spouse had prior to her illness. Another gentleman had accepted the hiring of a housekeeper, as his daughter had visited him over the holidays and was distraught at the amount of dust accumulation in the home. For this gentleman it was not necessary for the home to be dusted, what mattered to him was for the home to be “dry and warm and free of infestations.” Williams (2002) contends that the home is often constructed as a feminine space, with women continuing to be viewed as the ‘natural’ providers of care. What I observed were homes that may be devoid of houseplants and had accumulations of dust, but they were a space where care was provided compassionately by all of the men.

Being a Male Caregiver

I had a strong desire to explore and come to an understanding of what it meant to male caregivers to be a man while engaged in a caregiving role. Indeed, Russell (2001) stresses that research on elderly men should focus on the experiences of men *as men*, as gendered beings. Harris & Bichler (1997) uncovered that men employ a masculine mystique, where the expression of feelings and emotions are avoided, seeking help and support is a sign of weakness, and avoiding displays of vulnerability and intimacy with other men is imperative. However, as men age, they demonstrate more relaxed gender roles and become more nurturing and caring (Harris & Bichler, 1997). I was not optimistic when I began my interviews that I would be able to uncover how men felt about being a man in a caregiver role. I perceived that, for some rural men, being a 'real man' might not be thinking or talking about being a man. Specifically, I wondered if they might need to maintain the perception that they are completely at ease with their masculinity and are focused solely on getting on with the job of dealing with practical matters (McLean, 1996). Roberts (1992) makes the observation that men are largely unconscious "not only of their own motivations and the roots of their prejudices, but also of the range and variety of attitudes within their own sex" (p.116). This internal blindness can result in men remaining "oblivious of the force of their united pressure on women" (McLean, 1996, p.13). In contrast to these traditional views of masculinity, I found a number of the elderly rural men had stopped trying to be the man that our western society wants them to be (Hicks, 1993). The participants were forthcoming with their emotions, willing to cry; they were willing to examine and share both negative and positive aspects of how they had performed as husbands, fathers, and caregivers. These men recognized

that they had to seek out support and ask for help in their roles as caregivers, although one caregiver stated that the toughest part of being a caregiver was to develop the ability to ask for help. Knutsen (2009) contends that some men can have feelings of guilt associated with asking for help. I believe this guilt stems from the belief that it is viewed as a weakness for men to seek out or ask for help or support when in a caregiving role. In order to come to an in-depth understanding of these men, I found it valuable to apply a theoretical model of hegemonic masculinity (Connell, 2005) when examining the data I had collected in the field.

Hegemonic Masculinity

The theoretical model that informs this study is hegemonic masculinity theory (Connell, 2005). When initially analyzing the data, I had grouped all data related to gender and masculinity together. Masculinity theory guided me to approach how rural men demonstrate their masculinity along with their gender. In some direct or indirect way, all of the men interviewed exhibited from one to all four of the pillars of hegemonic masculinity (Connell, 2005) when they were interviewed. The following chart illustrates the connections between Connell’s Model of Gender Relations (2005) and the theme of *As A Man* that symbolizes the trunk of my theory.

Table 5.1. Comparing and Contrasting Model of Gender Relations and *As A Man*

Connell (2005) Model of Gender Relations *As A Man*

- | | |
|---|---|
| <ol style="list-style-type: none"> 1. Power relations: The main axis of power in contemporary gender order is the overall subordination of women and dominance of men. | <ol style="list-style-type: none"> 1. As their spouse became more dependent on them for activities of daily living, it became necessary for men to take over all tasks and decisions relating to the functioning of the household. |
|---|---|

2. Production relations: Gender divisions of labor are familiar in the form of task allocations, sometimes reaching fine detail
2. Men allocated tasks, such as working the cattle, outside the sphere of their wives. Men drove the family vehicle. Men participated minimally in cooking or baking for the household prior to their spouse being diagnosed with dementia.
3. Cathexis: Desire being the emotional energy attached to an object. The practices that shape and realize desire are thus an aspect of the gender order.
3. Sexual intercourse no longer occurs for majority of the men. Rely upon physical touch to convey their love for their spouse (i.e. stroking of hair).
4. Symbolism: Gender subordination may be reproduced through linguistic practices. The symbolic presentation of gender through dress, makeup, body culture, gesture, tone of voice, etc. (pp.72-76)
4. When referring to their wives, some men refer to them by their given name, others by nicknames or terms of endearment. One particular spouse refuses to apply make-up or to dress up for special events or holidays.

The ability to examine men in relation to how they perform their gender by relating it to the four pillars inherent in hegemonic masculinity allowed me to see patterns and similarities in their behavior. I appreciated having the ability to analyze the data in relation to their male gender and also to explore how the men I interviewed chose to display and speak about their masculinity.

Male Caring

Consistent with what I had expected to find, all participants associated the caregiving role with the female gender. This occurred despite some allegations of questionable care given by female workers in facilities where their wife was placed, or when a number of the men had been in caregiving roles prior to their spouses being

affected by dementia. When pressed as to why they selected the female gender, one caregiver elaborated:

... but traditionally...with giving birth to children and raising children, the female is the caregiver in a traditional sense. Of course the world changes...you go through a learning curve. (Indicates curve with his hand.)

Perhaps as a society we are not willing to accept and acknowledge men as competent and capable caregivers (Pretorius et al., 2009). I concur with Kirsi et al., (2000), who found that men experience a tension between being a caregiver and being a man and that this tension should be acknowledged by healthcare professionals. Men have to be reassured that they are competent and capable as male caregivers.

One particular caregiver was adamant when he informed me that “men are just not--nurturing in nature. *By nature.*” Researchers Kaye & Applegate (1990) noted that male participants in their research expressed that women are more sensitive and men are more efficient and less tender when providing care. A study by Russell (2007) found that men perform care in a joint managerial and nurturing style. Can this managerial role that men embrace when providing care be a carryover from men being in positions of power in the work force? I believe they carry over their power relations, which--in its most basic meaning--means the overall subordination of women and dominance of men (Connell, 2005) while in their role as a caregiver. This can be inappropriately viewed by individuals observing them as being less nurturing in providing care. What must be acknowledged is that men who provide this type of care in a home environment are able to adapt to the changing needs of the care recipient in an efficient manner (Kramer, 2000). I contend that these men have the best interests of the care recipient in mind, they

may *display* their care in a different manner, but the *intent* of the care provided meets the needs of the care recipient.

Caregiver Fulfillment

Participants in my study found the caregiving role gave meaning to their life. One caregiver had sunk into a deep depression following his retirement from the workforce, where he had spent his career creating and managing a successful and prosperous company. Indeed, it has been observed that entering into retirement can entail men losing vision for their lives, where life is reduced to mere functioning and maintenance (Hicks, 1993). For this participant, the requirement for him to enter into a caregiving role gave him renewed sense and purpose. Despite his spouse being placed in a facility, he continues to be actively involved, initiating a fund raiser to have wi-fi integrated in the facility so patients and their family members can communicate via tablets from the privacy of their rooms. Perhaps this is one of the reasons that male caregivers have been found to identify more positive aspects of their caregiving role than females (Martin, 2000). It gives them back a role that they have relinquished when leaving the work force that challenged them on a daily basis.

Gender-Cultural Model of Caregiving

A train of thought that was persistent when I was conducting interviews in the field and gathering and analyzing the data was: What if this had already been done? Was there existing theory in relation to rural male caregivers? When reviewing the literature, a chapter in a book written by Chad O'Lynn (2010) discussed and described how rural male caregivers negotiate their construction of gender when entering into a caregiving

role. What resulted was a gender-cultural model of caregiving: rural male caregivers (O’Lynn, 2010), visually displayed below.

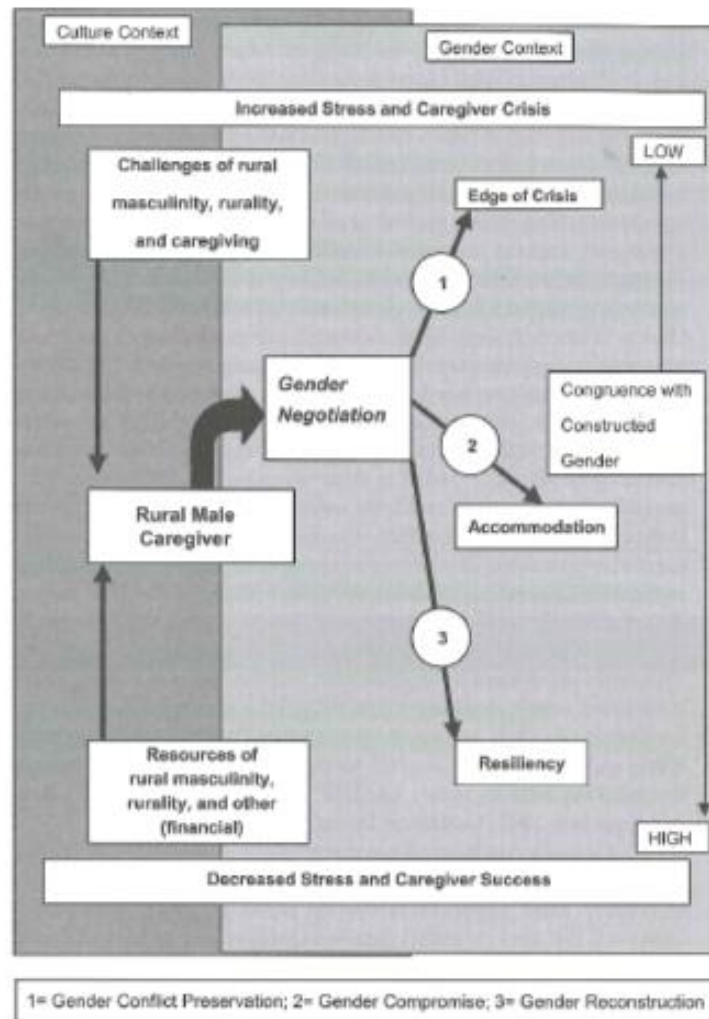


Figure 12.1. Gender-cultural model of caregiving: Rural male caregivers.

Figure 5.3. Gender-Cultural Model of Caregiving: Rural Male Caregivers

From *Rural Nursing Concepts, Theory, and Practice: 4th Edition* (p. 189), by C. O’Lynn, 2013, New York, NY: Springer Publishing Company. Copyright [2015] by Copyright Clearance Center. Reprinted with permission.

It is necessary to expand upon what O’Lynn (2010) refers to when he writes about rural culture. Rural culture, according to O’Lynn, is characterized by relatively close and long-term relationships with family and neighbors that result in a lack of anonymity and a

blurring of social roles. O'Lynn further observed that rural people value individualism, hard work, independence and self-sufficiency. I added stoicism to these values; this encapsulates what Campbell, Bell, & Finney (2006) referred to as the 'hypermasculine swagger of rural masculinity' that men can display.

Geographical isolation substantially shapes rural culture (Bigbee, 1991; Wagenfeld, 2003) and driving long distances placed great financial and time burden on all rural caregivers (O'Lynn, 2010). The Gender-Cultural Model of Caregiving demonstrates overlap of the gender and rural culture contexts that contribute to the rural male caregivers' negotiation of their gender, or a redefining of one's gender role. The following chart compares and contrasts O'Lynn's (2010) Gender-Cultural Model of Caregiving: Rural Male Caregivers with the themes and findings from my research on rural male caregivers.

Table 5.2. Comparing and Contrasting Gender-Cultural Model of Caregiving: Rural Male Caregivers and Rural Male Caregiving Theory

O'Lynn (2010) Gender-Cultural Model of Caregiving: Rural Male Caregivers	Rural Male Caregiving Theory
Challenges of Rural:	<i>Rural Living: Starting From Scratch</i>
- participants described geographic isolation consistent with rural areas	- positive memories and experiences of building their homes, farms, and ranches
Resources Required for Rural:	<i>Rural Way of Life: Where They Hang Their Hat</i>
- travel to services placed great emotional, financial, and physical stress on both caregivers and care recipients, a hardship common among rural dwellers	- rural place contributed to making men successful caregivers

Gender Negotiation:

1. Gender Conflict Preservation: Edge of Crisis

- group of men stubbornly clung to attributes of rural masculinity, excessive self-reliance, a need for total control of the caregiver context

2. Gender Compromise: Accommodation

- some men implemented a compromise between necessary caregiving work and one or more attributes of their rural masculinity

-allowed for completion of caregiver tasks

3. Gender Reconstruction: Resiliency

- men in this group had experienced intense caregiver challenges that had eventually overwhelmed them, overloading any gender compromise

- sent out frequent, less task specific calls for help

As A Man:

1. Power Relations meant male caregivers taking primary caregiving and manager of household duties and tasks related to spouses diagnosis and cognitive deterioration related to dementia

2. Production Relations referred to the gender divisions of labor are familiar in the form of task allocation

- example of past request for wife to work cattle with husband was denied, as he was concerned about her managing the horse during cattle drive

3. Cathexis refers to the desire being the emotional energy attached to an object.

- sexual intercourse no longer occurrence for majority of the men

- rely upon physical touch to convey their love for their spouse (i.e. stroking of hair).

This model was constructed to illustrate the process of gender negotiation for all rural male caregivers.

- rural male caregiver embedded in overlapping cultural and gender contexts.
- attributes serve as challenges and resources for caregivers.

- interplay between challenges and resources move caregiver on a continuum between episodes of high stress and caregiver crisis and episodes of low stress and caregiver success

- at individualized points on caregiver's trajectory, a stress point is reached at which he must respond to non-congruence between constructed gender and caregiver work (p.210)

4. Symbolisation is the symbolic presentation of gender through dress, makeup, body culture, gesture, tone of voice, etc.

- when referring to their wives, some men refer to them by their given name, others by nicknames or terms of endearment.

- spouse refuses to apply make-up or to dress up for special events or holidays

New Growth

- demonstrates how the past, present, and hopes for the future fundamentally changed men and forced them to grow in ways they had not anticipated. The experiences of the process of caregiving, as described by the caregivers themselves are captured under the themes of:

Watchful Waiting: Dying By Inches

Walking the Walk: In The Bedroom

From Breadwinner to Bread Maker

Persevering Patience

Crossing Over

In my research, I did not place male caregivers on a continuum, nor did I consider how men negotiated or reconstructed their gender roles when becoming caregivers (O'Lynn, 2010). Rather, the perspective I took was to take the combined effect of rural place and space and incorporate the four pillars of hegemonic masculinity (Connell, 2005) to identify how men exhibit their masculinity while in their role as a caregiver. From this, the themes of what men experienced as rural caregivers are presented and discussed. I appreciate O'Lynn's (2010) ability to place rural male caregivers on a continuum and being able to uncover what attributes can lead men to experience crisis or resiliency when they are in a caregiving role. However, the ability to elucidate the three levels of gender negotiation is difficult to decipher from the visual graphic provided by

O'Lynn (2010). It is necessary for the reader to read the entire chapter to uncover the category of gender negotiation and the types of experience that the men encounter at each level. Another troubling aspect of the theory was men had to fit into one of three categories, there was no parameters or discussion involving men who may not fit neatly into a category (O'Lynn, 2010). The men I interviewed approached the rural setting and rural place as positive aspects that contributed to their caregiving experiences. O'Lynn's (2010) work focus is related to the challenges of living in the rural setting and the challenges of role and work adaptation that conveyed negativity and struggle with the new role of being a caregiver. My research uncovered the experiences that rural men move through when entering into a caregiving role in a rural setting. My research adds to O'Lynn's (2010) work, as it describes what the men experience as *men* when in their role as a caregiver. Caregivers that I interviewed showed me that caregiving did not have to be negotiated with their masculinity, it was a positive contribution to their masculinity. I will explore this positive contribution further by expanding upon the sub-theme of *New Growth* attached to the trunk of my Rural Male Caregiving Theory. In the next section I will discuss the sub-theme of *New Growth* and the five branched themes that describe and discuss the experiences of rural male caregivers.

New Growth

The theme *New Growth* captures how an individual caregiver experienced his caregiver role, what it meant for him, and the influence it had on him as a man. The works of art that one of the caregivers created (see pages 140 – 142) provided me, as the interviewer, a glimpse of how he attempted to symbolize his previous relationships and how the third marriage to a spouse who was eventually diagnosed with dementia

contributed to his overall growth as a man. The growth that this caregiver experienced was totally unanticipated and unexpected when he entered into the caregiver role, but it was a positive growth that gave him internal strength and fortitude to move on despite the struggles and obstacles that presented themselves. While *New Growth* was based entirely upon one unique caregiver experience that I uncovered, the meaning and symbolism of *New Growth* can directly and indirectly relate to all of the caregivers who I interviewed.

New Growth also depicts a positive experience, whereas O'Lynn (2010) theory focuses on the struggles and challenges that men face when in a caregiver role. Success for the caregivers that O'Lynn (2010) was the ability to accommodate their rural masculinity with their caregiver role and be willing and able to ask for help from others. Success for the caregiver experiencing *New Growth* was to acknowledge his growth and abilities as a man, a positive asset, while in a caregiver role. He did not have the need to negotiate his caregiver role with his masculinity. Providing care as a man, gave him new life. He was able to respond to the evolving conditions encountered in his environment, the most vital one having a spouse with a diagnosis of dementia who had a tendency to wander from the safety of her home environment. This caregiver responded to the wandering behavior by beginning the process of placing his spouse in a locked long term care facility in their rural community and by immediately informing neighbors and local business owners of her tendency to wander from the safety of their home. I contend that all the participants in my study experienced a degree of *New Growth* as a man without having the overt identification of it displayed with pictures of art hanging in their living room that symbolized the growth.

Watchful Waiting

Timely diagnosis. A concern identified by a number of men interviewed was the delay they had in receiving a timely diagnosis and resulting treatment for their spouse. It was an agonizing experience for these men to watch someone they love deteriorate; to literally be dying by inches, despite the amount of care and support they provided. The men were bearing witness to the gradual progression of a disease with no known cure, a disease that slowly breaks individuals down. Research has confirmed a delay of more than two years can occur before a medical diagnosis is made for someone suffering from dementia (Cahill, 2000; Speechly, Bridges-Webb, & Passmore, 2008; Sternberg, Wolfson, & Baumgarten, 2000). To overcome this recognized gap, the Rural and Remote Memory Clinic [RRMC] was formed at the University of Saskatchewan. The goal of the clinic is “to develop and evaluate a streamlined integrated clinic for patients from rural and remote Saskatchewan for diagnosis and management of dementia and to evaluate telehealth as a means of delivering follow-up care” (Holfeld et al., 2014). The clinic was formed in recognition and appreciation of the fact that rural and northern Saskatchewan have low population density, resulting in a large travel burden for multiple medical visits to occur. The combined travel burden and need for multiple visits and long wait times to see specialists who diagnose dementia were identified as significant barriers to care. From its inception to the present day, the RRMC has clinically diagnosed 411 individuals suffering some form of cognitive impairment (Holfeld et al., 2014). The RRMC is unique to Saskatchewan and has not been replicated or duplicated elsewhere in Canada.

For many of the men interviewed for my research, they and their spouses would have benefited immensely from a clinic such as the RRMC. A number of the men implied

that health care professionals in rural areas were unwilling to assess or to refer their spouses to specialists for further assessment; they had attributed their spouses' cognitive decline to their advanced age. One caregiver went to the extreme to wait until the regular clinic staff were on vacation, then brought his wife to their local rural clinic for assessment and to begin the process of obtaining a referral to a specialist in an urban centre. The benefits of early recognition, diagnosis and treatment for dementia are numerous (Alzheimer Society of Canada, 2010). A class of medication, known as acetylcholinesterase inhibitors, can make the onset and severity of symptoms of dementia more gradual. This can contribute to delays in placement of individuals into long term care facilities, with the added benefit of having older individuals with dementia being able to stay in their rural communities and home residence with their caregiver(s) for longer periods.

Becoming a Bread Maker

The tasks and work involved in caregiving and the role changes experienced by male caregivers were described by the themes of *walking the walk* and *from breadwinner to bread maker*. My findings echoed other researchers, whose themes revealed that caregivers in general feel “forgotten: abandoned to care alone” (Lily, Robinson, Holtzman, & Bottorff, 2012). Russell (2007) recognized that care work seldom elicits formal recognition; the work caregivers perform is unappreciated and largely invisible. This was confirmed and discussed in detail under my identified theme of *walking the walk* with the subtheme of *in the bedroom*. Many of the men noted that their spouse was able to engage in conversation and be presentable for short periods of time in public settings or when family and friends came to visit. They could not appreciate what

occurred on a daily basis in the home, or the degree of impairment that necessitated them completing all activities of daily living for their spouse.

Persevering Patience

The emotions expressed by the participants during the interviews were varied. I was anticipating that caregivers would refer to having hope, not necessarily hoping for a cure for dementia, but hope that their spouses would maintain the optimum quality of life while progressing through dementia. Harris & Bichler (1997) identified eleven themes when they were interviewing husbands and sons, with one theme titled “a sense of hope” (p.20). A sense of hope referred to not giving up hope, hope for a better life, and just for hope in general (Harris & Bichler, 1997). I found no evidence of hope being discussed or alluded to in my interviews, one participant indicated that “I knew...I have seen it before in others... it was going to get a whole lot worse, that it would never get better...” for his wife following her diagnosis of dementia. The theme that did arise from my data in relation to a common emotional state men experienced by all of the men to some degree was that of *persevering patience*. Upon identifying this theme, I had several questions in relation to patience and caregiving. Initially, is the ability to obtain a high degree of patience correlated to lower caregiver stress and burnout? Secondly, is patience required only when caring for individuals diagnosed with dementia, or is it universal amongst all caregivers? Thirdly, was patience something that came with growing older? Do older male caregivers possess more patience than younger adult men?

As I had not objectively measured patience and the degrees of caregiver stress and burnout that the men were experiencing, I could not answer the first question. It is beyond the scope of this research study. The second question would require a much

larger and more diverse sample size that compares and contrasts caregivers of patients with dementia to other caregivers. I contend that the course of dementia and the resulting signs and symptoms displayed by the person with dementia places patience above all other attributes of an effective caregiver. For the caregivers I interviewed, the third question was answered by the caregivers' responses and their ability to reflect upon the levels of patience that they had exhibited from the past to their present state.

Overwhelmingly, the caregivers affirmed that they had developed a higher degree of patience as they aged, and not just in relation to providing care to their spouse with dementia. A number of the men expressed that they were more patient with their grandchildren than they had been with their own children. Some caregivers noted they were more patient when dealing with members of the public, including being patient and remaining calm while waiting in line at the cash register during the holiday season. Patience permeated many aspects of their lives, but the act of caring for a spouse with dementia forced these men to achieve a higher degree of patience that they had not experienced in the past. *Persevering patience* is a finding unique to my research that has not been identified by previous research on male caregivers.

Crossing Over

I did not anticipate the fifth and final theme of *crossing over* when entering the field. I did not expect caregivers to divulge how their religion and religious beliefs and practices impacted them when caregiving. An intriguing finding from a psychiatrist at Duke University uncovered that religious elderly patients cost the health care system less money than those who were less observant of religious practices (Tapp-McDougall, 2004). Religious patients reported spending 6 days in the hospital, compared to 12 days

among less religious and non-practicing individuals (Tap-McDougall, 2004). Does practicing and being active in your religious faith have benefits for caregivers? That has not been investigated to my knowledge, but it is apparent that religious individuals experience less time in the hospital. Three of the participants believed that listening to their intuition, or inner voice, in times of crisis or turmoil had contributed to them experiencing positive outcomes. At times, this intuition or inner voice had led to men assisting themselves or someone else in physical danger. For one caregiver, this inner voice led to him choose a career path in the ministry. The same inner voice let him know that his spouse would never return home again following a fall that required him to telephone the ambulance to transport her to the hospital. *Crossing over* went beyond what male caregivers were experiencing in this life; they shared with me their perceptions of what they believed would occur in their afterlife. When the difficult subjects of assisted suicide or a suicide pact were discussed, the resolve and strength of their faith gave these men the ability to forge ahead against all odds. The men discussed that they did not succumb to the temptations of taking their own life or the life of their spouse due to the strength and influence of their personal faith and religious practices in which they engaged.

Separating the Wheat from the Chaff

The central category of *separating the wheat from the chaff* has several meanings, but for the purpose of this research, the proverbial meaning has been integrated into the discussion. In reference to male rural caregivers, *separating the wheat from the chaff* means that these men must be able to separate what is valuable to them as a caregiver, and what could be set aside or seen as low priority. For a number of men, ensuring that

their spouse with dementia was cared for in a rural setting surrounded by Mother Nature was valuable to them as a caregiver and contributed to the care recipients quality of life and interaction with nature on a daily basis. Some men desired a timely diagnosis in order to explore all available treatments to optimize their spouse's independence and sustain their quality of life for as long as possible. For others, their priority was to ensure that their spouse was well nourished and all of her activities of daily living were attended to; for these men, housework and maintenance to the home was given low priority.

A majority of caregivers relied upon their faith and religious beliefs to provide them with guidance on the appropriate actions and responsibilities that were required of them in this present life. All of the caregivers recognized the need for patience to be a calm and consistent caregiver for a spouse with dementia. Having the ability to separate their priorities ensured that the care recipients' needs are being met and accommodated for, and all of the male caregivers had made a number of difficult decisions to meet the various needs of their care recipients. What was less clear was if male caregivers were able to objectively and consistently identify what priorities were important to separate for their ability to continue functioning as an effective caregiver.

Practice Implications

Rural male caregivers have needs in relation to learning about being a caregiver and providing the required care for their spouses. When I was driving through rural areas conducting interviews, I noted the lack of regular meeting places for farmers and ranchers throughout southern and central Alberta. This loss, of the community grain elevator(s) was also identified by some of the participants I interviewed. They related that the elevator was a place where farmers and ranchers, the majority of them men, would meet

informally to discuss their crops and cattle and current events. What could occur at these gatherings was informal 'horse trading,' where men could partake in trading goods and services to ensure the efficient and seamless management of their farms and ranches. This bargaining with formal and informal suppliers and buyers and engaging in the financial calculations of long-term investments and annual profits has been identified as a commonality among all North American farmers (Barlett, 2006).

Another key aspect of these informal meetings was the chance for local rural community members to catch up and reminisce about their families and general health. Periodically, invitations to a local community event took place, or spontaneous invitations to come over for a meal. A number of the participants interviewed expressed that they missed this aspect of informally connecting with others. Rural community grain elevators are a thing of the past in many rural communities, to the point that murals on the walls of rural businesses have paintings or drawings of grain elevators indicating their historic significance to their rural economies. This is captured in the photo taken below in a rural village, where grain elevators have been destroyed, replaced by large grain terminals in distant locales.



Figure 5.4. Mural: Trochu, AB, February 11, 2013

An environment and setting that encouraged these informal gatherings of men to maintain social connectedness to their community was the creation and establishment of “community men’s sheds” in Australia (Misan & Sergeant, 2009). Men’s sheds have been defined as “...typically located in a shed or workshop-type space in a community setting and [that has] become a focus for regular and systematic, hands-on activity by groups deliberately and mainly comprising men” (Golding, Brown, Foley, Harvey, & Gleeson, 2007, p.12). The sheds have been recognized as an innovative community grass-roots approach to promoting the mental health and well-being of men (Morgan, Hayes, Williamson, & Ford, 2007). I attended a two-day caregiving conference this past April (2014) in Edmonton, Alberta. One of the primary objectives of the conference was to

analyze the strengths, gaps and barriers to the provision of caregiver supports, including resource utilization and costs (Parmar, 2014). The results of a focus group of caregivers was intriguing, as they wanted “upfront, straight forward, practical information with reasonable access” (Mann & Huhn, 2014). The participants in my study also stated a wish to “have another man to speak to who is experiencing what I am.” Periodically, this led to them being referred to a local or urban caregiver support group. The referral to caregiver support groups was beneficial for one of the participants in my study, with the other participants stating that they did not attend further caregiver support groups due to either the need for them to divulge their caregiving experiences or the support group times not being conducive to their caregiving schedule. Finally, there was the added requirement to find someone to care for their spouse while they attended the support group.

What I envision is a rural Canadian version of Men’s Sheds (Golding et al., 2007) that incorporates and integrates with other programs and resources already developed in rural communities. What I propose is the establishment of Rural Caregiver Cooperatives [RCC]. RCCs would be non-profit, grass-roots community initiatives throughout the province of Alberta. RCCs would create physical spaces and an environment for the dissemination of health information, education, and socialisation for male caregivers and for men in general (Morgan, et al., 2007). Organizations such as the Alzheimer’s Society, the Alberta Caregivers Association, and Building Healthy Lifestyles Programs could be affiliated with the RCCs in various communities. The spaces dedicated to RCCs would attempt to utilize spaces and facilities already established in rural communities. For example, at least 64 Royal Canadian Legions around Alberta have closed their doors, declared bankruptcy, or have been forced to sell or lease portions of their buildings

(McDermott, 2013). These spaces, many of which are located in rural communities around Alberta, could possibly be refurbished spaces for Rural Caregiver Cooperatives. This is just one suggested recommendation based on my small qualitative study; further research must be undertaken to verify or discover other options for rural communities both provincially and nationally.

What must be taken into account is that rural communities are diverse, dynamic, and matter to health (Kulig & Williams, 2012). It would be imperative for caregivers and members of the community to assess their own needs and what they want their local community to achieve (McDonough & Davitt, 2011). One community may want to fund-raise for the establishment and maintenance of paved walkways, while another would have members create and maintain a community garden. One innovative project underway in Dorset, a county in southwest England, are Care Farms (Innes, 2014), where individuals affected by dementia and their caregivers are transported to area farms where they can participate in daily and seasonal chores while interacting with nature. Two things have been demonstrated to slow the progression of dementia: exercise and social contact (Chalmers, 2015). If communities can be made accessible, individuals with dementia and their caregivers can be outside exercising when the weather is mild; in the winter a community sports centre can be utilized, as long as there are places where they feel safe, comfortable and welcome (Chalmers, 2015). Projects such as these would be limited only by the community engagement and support of the local rural municipality. What would be critical is that these settings would be bringing male caregivers together. Indeed, Neri et al., (2012) imply that performing and becoming engaged in social activities and roles outside the home are more important to the general well-being of men

when compared to their female counterparts. It has been found that 59% of those living with dementia and their caregivers report feeling lonely and isolated in their own community (Alzheimer Society, 2010). The male caregivers I interacted with described a “pulling away” of family, friends, and neighbors following their spouses’ diagnosis of dementia. One caregiver jokingly suggested that he was tempted to post a sign in his front yard stating that “dementia is not contagious, please come and visit us.” Dementia is a feared disease, possibly because it has no known cure, or due to some individuals exhibiting drastic personality changes. What we must be willing to do is combat the stigma associated with the disease of dementia and be willing to develop dementia-friendly communities and services for caregivers.

Education Implications

This research study reinforced the positive aspects of aging in place that can benefit caregivers and those requiring care. From a nursing education program perspective, I believe it would assist nursing students who are in their community and community mental health rotation(s) to engage and to interact with caregivers in our local rural communities. As Innes, Morgan, & Kostineuk (2011) have noted, there has been limited work done to examine the experiences of rural caregivers and their education and support needs. These practice settings would allow students to appreciate the geographic diversity of rural communities and the influence that rural has on the types of services that are available (Kulig, MacLeod, Stewart, & Pitblado, 2008). Furthermore, abstract concepts taught in the classroom such as community assessment (Yiu, 2008) can be applied in these settings, with resulting recommendations for program development being made to communities that benefit not just the caregivers, but all members of the

community. The ability to implement community programs could enhance and reinforce the capabilities of the local caregiver population. Nursing students would be able to apply and gain knowledge to benefit their student nursing practice, while the caregivers with whom they interact will benefit from the programs tailored to their caregiver role.

Having students engage with caregivers in rural communities would create opportunities for students to appreciate the complexities and struggles caregivers face on a daily basis. It could also demonstrate to students that rural places are diverse, dynamic, and matter to health (Kulig & Williams, 2012). Indeed, I have taken the initiative to create an augmented experience for nursing students rotating through their rural acute clinical placements to be assigned with a Community Care nurse for a period of one to two clinical days. Incorporating a community - based rural experience to complement their acute care experience provides opportunities for students to observe some of the realities of rural life and rural caregiving.

Recommendations for Research

This qualitative study will be a stepping stone or guide for other researchers who are interested in the experiences of men as caregivers. I made the choice to focus on a specific type of rural male caregiver, those who care for a spouse affected by dementia. It is my wish to continue researching male caregivers, as I contend that the number of male caregivers will continue to grow and not enough is known about their experiences, the challenges they face, and the supports required for them to thrive in their rural communities.

Further qualitative and quantitative research that encompasses a broader geographical area such as the entire province of Alberta, or comparing the caregiving

experience between different kinds of rural communities (i.e. natural resource communities such as logging and mining) or between provinces and territories in Canada would allow study participants from a variety of cultural, ethnic, and religious backgrounds to be heard. Having the ability to compare and contrast findings between rural and urban caregivers would be beneficial when developing policy and allocating resources to better support the caregiving experience. To influence and inform policy at provincial and federal levels of government, it is advantageous to have a representative sample of the population that can be generalized to larger populations utilizing quantitative methods of research. At this time, I am not aware of any large-scale studies being conducted on male caregivers at a provincial or national level.

I commend efforts taken at the federal and provincial levels to support caregivers. However, programs created by grass-roots movements in rural communities must be embraced and encouraged, as there is not a one-size-fits-all model of support for caregivers. It would be inspirational and challenging to be part of a pilot project aimed at meeting the needs of rural male caregivers. Research that is carefully documented while ensuring that the outcome(s) are measured and evaluated needs to be undertaken in rural communities to demonstrate benefit and to increase the likelihood of attracting future funding for those caregivers.

Limitations of the Research Study

By applying the method of grounded theory and ensuring that I attended to the tenets of rigour in qualitative research, I contend that my research findings are sound and credible. However, there are a number of identified limitations in my research study. The first limitation is the set geographical area that incorporated central and southern Alberta,

where I concentrated my recruitment efforts. This was due to the finite financial resources I had at my disposal to pay for newspaper and other advertising to target male caregivers in the rural communities, coupled with the required costs related to driving to rural areas to interview male caregivers. A second limitation was that my study was cross-sectional in nature, as my timeline for recruitment was limited - from the beginning of December 2013 to the beginning of April 2014. A study that is longitudinal and follows a number of caregivers over an extended period of time could show how they develop into the role of a caregiver and how the experiences of caregiving affect them as men over an extended period of time. Indeed, Padgett (1998) firmly recommends prolonged engagement in qualitative studies, with suggestions made for nothing less than a four-month period of engagement with male caregivers to enhance the rigor of the research. A third limitation was the lack of diversity in this purposive sample: all who came forward to be interviewed were Caucasian and heterosexual. Therefore, my findings are not transferable to the experiences of caregiving in minority or same-sex couples.

I made several unsuccessful attempts to recruit male caregivers from a variety of cultural and religious backgrounds. For example, I attempted to recruit men who resided on federal First Nations reserves. The fifth limitation was my inability to approach health care professionals employed by Alberta Health Services in order to enhance recruitment efforts, as ethical approval was not obtained from Alberta Health Services for this research study. I am aware that professionals in specialized areas of practice, such as geriatricians and psychogeriatric nurse consultants, would have access to individuals suffering from dementia and those people who care for them. Despite these limitations, I

was able to generate a theory from the data collected and I have been diligent in ensuring that every participant is represented in this research. The rich data that I was able to collect has contributed directly and indirectly to the results and discussion chapter.

Research Dissemination

I was encouraged and supported by my supervisor, Dr. Judith Kulig, to attend and present my current findings and their significance at the 7th International Symposium on Safety & Health in Agricultural & Rural Perspectives, which took place in Saskatoon, Saskatchewan from October 19-22, 2014. My preliminary research findings and themes were presented to a diverse multi-disciplinary audience of professionals. The presentation was brief, consisting of a fifteen-minute presentation with a five-minute discussion period following the presentation. Following the presentation, I was able to obtain feedback on the presentation from the audience and my supervisor and determine whether any themes or information presented required clarification. I incorporated that feedback to further refine my themes and to expand on terms or concepts presented.

When I was actively engaged in the recruitment of participants for my study, I was given the opportunity to be interviewed by a reporter from *The Western Producer* in order to present my research to a broad rural demographic. The article was read by a staff member of the Seniors Policy Division - Employment and Social Development Canada [ESDC]. This led to the senior policy analyst in the ESDC (who reports to the Minister of State (Seniors)) contacting me via email and telephone. Following the successful defense of my thesis, my intention is to have an informal conference call with this senior policy

analyst to present my findings from my research and to make recommendations that may be of benefit for rural male caregivers.

I have also accepted an invitation to speak at the Alberta Association of Gerontology [AAG] Calgary chapter in June, 2015. I was honoured to have been chosen for a scholarship from the AAG when I was completing my graduate studies. When I drove to Calgary to accept the scholarship, I was approached and asked if I could present at the annual AAG Calgary chapter meeting. This will provide another venue to disseminate my research findings. I will also approach and confirm dates to present at the local Alzheimer's Society chapter, as the director contacted me and requested that I present my findings to her staff. Furthermore, a local advocate and champion for rural caregivers was instrumental and encouraged me throughout my research project. I will contact her and request if I could present to rural caregivers at a meeting that she leads in her rural community. In these ways, my initial wave of dissemination will be at the local, provincial, and national levels and will give back to those individuals who supported and encouraged me when I was conducting my research.

Conclusion

Canada's public health care system is under increasing pressure to contain escalating health care costs, and evidence suggests that our aging population prefers to be cared for at home (Schroeder, MacDonald, & Shamian, 2012). These combined factors are shifting the responsibility to provide increasing care in the home to family members with chronic health conditions and disabilities onto informal family caregivers (Schroeder, et al., 2011). The elderly population, when individuals are entering the age of having a greater risk of being afflicted with many chronic conditions, including dementia

is projected to grow by 40% from 2011 to 2021 (Forbes & Hawranik, 2012; Hodge, 2008). Canada's population, as a whole, is one of the oldest in the world, with trends indicating that Canadian society will age even more in the next fifty years (Bibby, 2006). An ominous statistic is that an individual turns sixty-five years old every nineteen minutes in the province of Alberta (Hopper & Cleary, 2011). Research demonstrates that Canadian women between 50 and 64 years of age living with dementia are more likely than those without dementia to be residing in rural areas (Morgan, 2014). These women will eventually require full-time care from their spouses.

I have found, both in my nursing practice and when conducting this research, that there is no typical case of dementia. The trajectories vary greatly and proceed at individual rates, despite attempted interventions and treatments; the course of brain degeneration is as personal as an autobiography (Kleinman, 2007). Dementia not only affects the individual diagnosed with dementia, there is commonly a second individual that must be recognized and supported--the caregiver (O'Brien, Ames, & Burns, 2000). It is only recently that people with dementia, and the people who care for them, have voiced objections to being silenced and treated as if they were invisible (Alterra, 2007). To illustrate this, a recent newspaper article referred to a poem written by a female diagnosed with early onset dementia, titled: From a Spouse to a Caregiver. She writes about their marriage vows and then asks the spouse in the poem if he would have taken them again if he knew he would be caring for her to the extent that the disease will require. The answer in the poem was, simply, "The caregiver loves me more than the spouse" (McEachern, 2015). The fact of the matter is that very few individuals have been trained to be caregivers. However, there is no absolute right or wrong way of providing

care, or of *being a caregiver* (Callone, Vasiloff, Kudlacek, Manternach, & Brumback, 2006). My examination of the role that gender has in caregiving, and how men come to understand their roles as caregivers has neglected one insurmountable fact; caregiving is at the core of what it means to be human. Caregiving is what we are here for; we are all caregivers (Press, 2013). We have to be willing to support one another in our caregiving roles and recognize that it should not be done in isolation from others. It should be embraced and supported and given with great love.

The process of engaging in a research study is time-consuming and exhausting. However, I am vividly aware that the effort expended in completing this research can never compare to the daily struggles and care that men provide in rural communities throughout the province. The caregivers who I interacted with during the course of this research have undertaken an arduous journey. When faced with a spouse who had dementia, these caregivers did not appear to falter. The poignant passage below captures a moment in time for a husband caregiver who was also a writer, and was attempting to relate what it meant for him to be the primary caregiver to his wife who was diagnosed with dementia (Alterra, 2007). For me, it captures the essence of what it means to be a husband caring for a wife with a diagnosis of dementia.

That is what love is for him.

It was not a duty but a grace to be a presence to her as she was to him;
to be all the memory she had;
to have a hand to offer that might not be as skilled as the nurse's but one she trusted,
as hers was the one he knew in every freckle, vein, and sinew
and liked to have rest in his
(Alterra, 2007, p. 167)

REFERENCES

- Åberg, A.C., Sidenvall, B., Hepworth, M., O'Reilly, K., & Lithell, H. (2004). Continuity of the self in later life: Perceptions of informal caregivers. *Qualitative Health Research, 14*(6), 792-815.
- Agar, M. H. (1980). *The professional stranger: An informal introduction to ethnography*. San Diego, CA: Academic Press.
- Akpinar, B., Kucukguclu, O., & Yener, G. (2011). Effects of gender on burden among caregivers of Alzheimer's patients. *Journal of Nursing Scholarship, 43*(3), 248-254.
- Alcoff, L., & Potter, E. (Eds.), *Feminist epistemologies* (pp. 265-294). New York: Routledge.
- Aldiabat, K.M., & LeNavenec, C. (2011). Philosophical roots of classical grounded theory: Its foundations in symbolic interactionism. *The Qualitative Report, 16*(4), 1063-1080.
- Alfonso, T., Krishnamoorthy, E.S., & Gomez, K. (2010). Caregiving for dementia: Global perspectives and transcultural issues. In E.S. Krishnamoorthy, M.J. Prince, & J.L. Cummings, (Eds.), *Dementia: A global approach* (pp. 99-106). New York, NY: Cambridge University Press.
- Allen, S. (1994). Gender differences in spousal caregiving and unmet need for care. *Journal of Gerontology, 49*(4), S187-S195.
- Almberg, B., Jansson, W., Grafstrom, M., & Winblad, B. (1998). Differences between and within genders in caregiving strain: A comparison between caregivers of demented and non-caregivers of non-demented elderly people. *Journal of Advanced Nursing, 28*(4), 849-858.
- Alston, M., & Kent, J. (2008). The big dry: The link between rural masculinities and poor health outcomes for farming men. *Journal of Sociology, 44*(2), 133-147.
- Alterra, Aaron. (2007). *The caregiver: A life with Alzheimer's*. Ithaca, NY: ILR Press.
- Alzheimer Disease International. (2009). *World Alzheimer report*. Retrieved from: <http://www.alz.co.uk/research/files/WorldAlzheimerReprt.pdf>

- Alzheimer Society of Canada. (2010). *Key facts about Alzheimer's disease and related dementia*. Retrieved from <http://www.alzheimer.ca/english/disease/stats-intro.htm>
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: American Psychiatric Association.
- Archbold, P.G., & Stewart, B.J. (1996). The nature of the family caregiving role and nursing interventions for caregiving families. In E.A. Swanson, & T. Tripp-Reimer, (Eds.), *Advances in gerontological nursing: issues for the 21st century* (pp. 133-156). New York, NY: Springer.
- Armstrong, M. (2001). The pressures felt by informal carers of people with dementia. *Nursing Standard*, 15(17), 47-53.
- Aronson, J. (1992). Women's sense of responsibility for the care of old people: 'But who else is going to do it?' *Gender & Society*, 6(1), 8-29.
- Austin, C.D. (1996). Aging and long-term care. In C.D. Austin, & R.W. McClelland (Eds.), *Perspectives on case management practice* (pp. 73-98). Milwaukee, WI: Families Int.
- Baker, K.L., Robertson, N., & Connelly, D. (2010). Men caring for wives or partners with dementia: Masculinity, strain and gain. *Aging & Mental Health*, 14, 319-327.
- Baker, K.L., & Robertson, N. (2008). Coping with caring for someone with dementia: Reviewing the literature about men. *Aging & Mental Health*, 12(4), 413-422.
- Bacsu, J.R., Jeffery, B., Johnson, S., Martz, D., Novik, N., & Abonyi, S. (2012). Healthy aging in place: Supporting rural seniors' health needs. *Online Journal of Rural Nursing and Health Care*, 12(2), 77-87.
- Barbalet, J.M. (1998). *Emotion, social theory and social structure: A macro sociological approach*. Cambridge: Cambridge University Press.
- Barker, K. (General Editor) (1995). *The NIV Study Bible*. Zondervan Publishing House. Grand Rapids, MI.
- Barlett, P.F. (2006). Three visions of masculine success on American farms. In H. Campbell, M.M. Bell, & M. Finney, (Eds.), *Country boys: Masculinity and rural life* (pp. 47-65). University Park, PA: The Pennsylvania State University Press.

- Barush, A., & Spaid, W. (1989). Gender differences in caregiving: Why do wives report greater burden? *The Gerontologist*, 29, 667-676.
- Beard, R.L., Sakhtah, S., Imse, V., & Galvin, J.E. (2012). Negotiating the joint career: couples adapting to Alzheimer's and aging in place. *Journal of Aging Research*, 1-12.
- Beck, C.T. (1993). Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research*, 15(2), 263-266.
- Belenky, M.F., Clinchy, B.M., Goldberger, N.R., & Tarule, J.M. (1986). *Woman's ways of knowing*. New York, NY: Basic Books.
- Bem, S.L. (1974). The measurement of psychological androgyny. *Journal of Consulting and Clinical Psychology*, 42, 155-162.
- Berger, P., & Luckmann, T. (1967). *The social construction of reality-treatise in the sociology of knowledge*. Harmondsworth: Penguin Books.
- Bernard, H. (2000). *Social research methods: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.
- Bertaux, D. (1981). From the life-history approach to the transformation of sociological practice. In D. Bertaux (Ed.), *Biography and society: The life history approach in the social sciences* (pp. 29-45). London, UK: Sage.
- Bibby, R.W. (2006). *The boomer factor: What Canada's most famous generation is leaving behind*. Toronto, ON: Bastian Books
- Biegel, D.E., Sales, E., & Schulz, R. (1991). *Family caregiving in chronic illness*. Newbury Park CA: Sage Publications.
- Bigbee, J.L. (1991). The concept of hardiness as applied to rural nursing. In A. Bushy (Ed.), *Rural nursing* (Vol. 1, pp. 39-58). Thousand Oaks, CA: Sage.
- Biggar, J.C. (1980). Who moved among the elderly, 1965-1970: A comparison of older types of movers. *Research on Aging*, 2, 73-91.
- Black, C., & Hayden, N. (2007). A change in the air. On *Collector's Edition* [CD]. Warner/Chappell Music.
- Black, H.K., Schwartz, A.J., Caruso, C.J., & Hannum, S.M. (2008). How personal control mediates suffering: Elderly husbands' narratives of caregiving. *Journal*

of Men's Studies, 16, 177-192.

- Blackstock, K.L., Innes, A., Cox, S., Smith, A., & Mason, A. (2006). Living with dementia in rural and remote Scotland: diverse experiences of people with dementia and their carers. *Journal of Rural Studies*, 22, 161-176.
- Blumer, H. (1969). *Symbolic interactionism*. Englewood Cliffs, NJ: Prentice-Hall.
- Bollman, R.D., & Clemenson, H.A. (2008). Structure and change in Canada's rural demography: An update to 2006 (Catalogue No. 21-006-X). *Rural and Small Town Canada Analysis Bulletin*, 7(7), 1024. Ottawa, ON: Statistics Canada.
- Bradley, H. (2007). *Gender*. Malden, MA: Polity Press.
- Brannon, R., & David, D. (1976). The male sex role: Our culture's blueprint of manhood, and what it's done for us lately. In R. Brannon, & D. David (Eds.), *The forty-nine percent majority: The male sex role*. Boston, MA: Addison-Wesley.
- Brizendine, L. (2010). *The male brain*. New York, NY: Broadway Books.
- Brody, E. (1990). *Women in the middle: Their parent care years*. New York, NY: Springer.
- Brown, J., & Alligood, M. (2004). Realizing wrongness: Stories of older wife caregivers. *Journal of Applied Gerontology*, 23, 104-119.
- Brown, J.W., Chen, S.L., Mitchell, C., & Province, A. (2007). Help-seeking husbands caring for wives with dementia. *Journal of Advanced Nursing*, 59, 352-360.
- Brown, J.W., Liang, J., Krause, N., Akiyama, H., Sugisawa, H., & Fukaya, T. (2002). Transitions in living arrangements among elders in Japan: Does health make a difference? *The Journals of Gerontology Series B*, 57(4), S209-S220.
- Bryant, A., & Charmaz, K. (2007). Introduction grounded theory research: Methods and practices. In A. Bryant, & K. Charmaz, (Eds.), *The SAGE handbook of grounded theory* (pp. 1-28). Thousand Oaks, CA: Sage.
- Bryant, C., & Joseph, A.E. (2001). Canada's rural population: Trends in space and

- implications in place. *Canadian Geographer*, 45(1), 132-137.
- Buch, B. (2006). *Salutogenesis & shamanism* (Master's thesis). Retrieved from <http://www.salutogenesis-shamanism.com/2.php>
- Buckwalter, H.K., & Davis, L.L. (2011). Elder caregiving in rural communities. In R.C. Talley, K. Chwalisz, & K.C. Buckwalter, (Eds.), *Rural caregiving in the United States: Research, practice, policy* (pp. 33-46). New York, NY: Springer.
- Burden, J., & Roodt, G. (2007). Grounded theory and its application in a recent study on organisational redesign: Some reflections and guidelines. *South African Journal of Human Resource Management*, 5(3), 11-18.
- Burrell, G., & Morgan, G. (1979). *Sociological paradigms and organisational analysis: Elements of the sociology of corporate life*. Bedford Square, London: Heinemann Educational Books Ltd.
- Butcher, H.K., Holkup, P.A., & Buckwalter, K.C. (2001). The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research*, 23(1), 33-55.
- Bytheway, W. (1987). *Informal care systems: An exploratory study within the families of older steel workers in South Wales*. Report to Joseph Rowntree Memorial Trust, York.
- Cahill, S. (1999). Caring in families: what motivates wives, daughters and daughter-in-laws to provide dementia care? *Journal of Family Studies*, 5(2), 235-247.
- Cahill, S. (2000). Elderly husbands caring at home for wives diagnosed with Alzheimer's disease: Are male caregivers really different? *Australian Journal of Social Issues*, 35(1), 53-72.
- Calasanti, T., & Bowen, M.E. (2006). Spousal caregiving and crossing gendered boundaries: Maintaining gendered identities. *Journal of Aging Studies*, 20, 253-263.
- Calasanti, T., & King, N. (2007). Taking "women's work" "like a man": Husbands' experiences of care work. *The Gerontologist*, 47, 516-527.
- Callone, P.R., Vasiloff, B.C., Kudlacek, C., Manternach, J., & Brmback, R.A. (2006). *Alzheimer's disease: The dignity within*. New York, NY: Demos Medical

Publishing.

- Campbell, L.D., & Carroll, M.P. (2007). The incomplete revolution: Theorizing gender when studying men who provide care to aging parents. *Men and Masculinities*, 9, 491-508.
- Campbell, H., Bell, M.M., & Finney, M. (2006). Masculinity and rural life: An introduction. In H. Campbell, M.M. Bell, & M. Finney, (Eds.), *Country boys: Masculinity and rural life* (pp. 1-22). Pennsylvania: The Pennsylvania State University Press.
- Canadian Caregiver Coalition. (2010). *Facts on family caregivers*. Retrieved from <http://www.ccc-ccan.ca/content.php?doc=43>
- Canadian Study of Health and Aging. (1994a). Canadian study of health and aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150(6), 899-913.
- Canadian Study of Health and Aging. (1994b). Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, 13(4), 470-487.
- Canadian Study of Health and Aging. (2000). The incidence of dementia in Canada. *Neurology*, 55, 66-73.
- Carpenter, E.H., & Miller, B.H. (2002). Psychosocial challenges and rewards experienced by caregiving men: A review of the literature and an empirical case example. In B.J. Kramer, & E.H. Thompson (Eds.), *Men as caregivers: Theory, research, and Service implications* (pp. 99-126). New York, NY: Springer Publication.
- Carrière, Y., Keefe, J., Légaré, J., Lin, X., & Rowe, G. (2007). Population aging and immediate family composition: Implications for future home care services. *Genus*, 63(1/2), 11-31.
- Chafetz, J.S. (1990). *Gender equity: An integrated theory of stability and change*. Newbury Park, CA: Sage Publications.
- Chalmers, J. (2015, January). Keeping people with dementia in mind. *Canadian Nurse*, 111(1), 24.
- Chang, C.F., & White-Means, S.I. (1991). The men who care: An analysis of male

- primary caregivers who care for the frail elderly at home. *Journal of Applied Gerontology*, 10, 343-358.
- Chappell, N.L., & Penning, M.J. (1996). Behavioural problems and distress among caregivers of people with dementia. *Ageing & Society*, 16, 57-73.
- Charmaz, K. (2011). Grounded theory methods in social justice research. In N.K. Denzin, & Y.S. Lincoln (Eds.), *The Sage handbook of qualitative research (4th ed.)*, (pp. 359-380). Thousand Oaks, CA: Sage.
- Charmaz, K., & Belgrave, L.L. (2012). Qualitative interviewing and grounded theory analysis. In J.F. Gubrium, J.A. Holstein, A.B. Marvasti, & K.D. McKinney (Eds.) *The Sage handbook of interview research: The complexity of the craft* (pp. 347-365). Thousand Oaks, CA: Sage
- Charmaz, K., & Henwood, K. (2008). Grounded Theory. In C. Willig, & W. Stainton-Rogers, (Eds.), *The Sage handbook of qualitative research in psychology*. Los Angeles, CA: Sage
- Chiovitti, R.F., & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing*, 44(4), 427-435.
- Chiverton, P., & Caine, E.D. (1989). Education to assist spouses in coping with Alzheimer's disease. A controlled trial. *Journal of the American Geriatrics Society*, 37(7), 593-598.
- Cialdini, R.B., & Trost, M.R. (1999). Social influence: Social norms, conformity, and compliance. In D. Gilbert, S. Fiske, & G. Lindzey, (Eds.), *The handbook of social psychology* (Vol. 2, pp. 151-192). Boston, MA: McGraw-Hill, Inc.
- Cloke, P., Milbourne, P., & Thomas, C. (1997). Living lives in different ways? Deprivation, marginalization and changing lifestyles in rural England. *Transactions of the Institute of British geographers*, 22(2), 210-230.
- Cohen, C., Pringle, D., & LeDuc, L. (2001). Dementia caregiving: The role of the primary care physician. *Canadian Journal of Neurological Science*, 28, S72-S76.
- Collins, C., Liken, M., King, S., & Kokinakakis, C. (1993). Loss and grief among family caregivers of relatives with dementia. *Qualitative Health Research*, 3, 236-253.
- Colsher, P.L. & Wallace, R.B. (1990). Health and social antecedents of relocation in rural

- elderly persons. *Journals of Gerontology*, 45(1), S32-S38.
- Coltrane (1994). Theorizing masculinities in contemporary social science. In H. Brod, & M. Kaufman, (Eds.), *Theorizing masculinities* (pp.39-60). Thousand Oaks, CA: Sage Publications.
- Connell, R.W. (1983). 'Men's bodies.' *Which way is up?* Allen & Unwin, Sydney; AU.
- Connell, R.W. (1987). *Gender and power: Society, the person and sexual politics*. Standford, CA: Stanford University Press.
- Connell, R.W. (1990). A whole new world: Remaking masculinity in the context of the environmental movement. *Gender & Society*, 4(4), 452-478
- Connell, R.W. (1995). *Masculinities*. Allen & Unwin. St. Leonards.
- Connell, R.W. (2000). *The men and the boys*. Los Angeles, CA: University of California Press.
- Connell, R.W. (2005). *Masculinities (2nd ed.)*. Los Angeles, CA: University of California Press.
- Connell, R.W., & Messerschmidt, J.W. (2005). Hegemonic masculinity: Rethinking the concept. *Gender & Society*, 19, 6, 829-859.
- Cook, J.R., & Tyler, J.D. (1989). Help-seeking attitudes of North Dakota farm couples. *Journal of Rural Community Psychology*, 10, 17-28.
- Cooney, A. (2011). Rigour and grounded theory. *Nurse Researcher*, 18(4), 17-22.
- Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, 13(1), 3-21.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and Procedures for developing Grounded Theory (3rd ed.)*. Thousand Oaks, CA: Sage.
- Corbin, J., & Morse, J. (2003). The unstructured interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry*, 9(3), 335-354.
- Coston, B., & Kimmel, M. (2013). Aging men, masculinity and Alzheimer's: Caretaking and caregiving in the new millennium. In A. Kampf, B.L. Marshall, & A. Peterson (Eds.) *Aging men, masculinities and modern medicine* (pp. 191-200). New York, NY: Routledge.
- Courtney, W.H. (2006). Rural men's health: Situating risk in the negotiation of

- masculinity. In H. Campbell, M.M. Bell, & M. Finney, (Eds.). *Country boys: Masculinity and rural life* (pp. 139-158). Pennsylvania: The Pennsylvania State University Press.
- Courtney, W. (2011). *Dying to be men: Psychosocial, environmental, and behavioral directions in promoting the health of men and boys*. New York, NY: Taylor & Francis Group.
- Cranswick, K., & Dosman, D. (2008). *Eldercare: What we know today*. Canadian Social Trends 86. Ottawa, ON: Statistics Canada.
- Creswell, J. (2006). *Qualitative inquiry & research design: Choosing among five approaches (2nd ed.)*. Thousand Oaks, CA: Sage.
- Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches (3rd ed.)*. Thousand Oaks, CA: Sage.
- Cuba, L. & Hummon, D. (1993). A place to call home: Identification with dwelling, community and region. *The Sociological Quarterly*, 34, 25-41.
- Dandy, K., & Bollman, R. (2008). Seniors in rural Canada. *Rural and Small Town Canada Analysis Bulletin*, 7(8), 1-56. Ottawa, ON: Statistics Canada. Catalogue no. 21-006-X
- Dansky, K.H., Brannon, D., Shea, D.G., Vasey, J., & Dirani, R. (1998). Profiles of hospital, physician, and home health service used by older persons in rural areas. *Gerontologist*, 38(3), 320-330.
- Davidson, K., Arber, S., & Ginn, J. (2000). Gender meanings of care work within late life marital relationships. *Canadian Journal on aging*, 29, 536-553.
- Davies, D., & Dodd, J. (2002). Qualitative research and the question of rigor. *Qualitative Health Research*, 12(2), 279-289.
- Davies, H., Priddy, J.M., & Tinklenberg, J.R. (1986). Support groups for male caregivers of Alzheimer's patients. *Clinical Gerontologist*, 16, 385-395.
- de la Cuesta, C. (2005). The craft of care: Family care of relatives with advanced dementia. *Qualitative Health Research*, 15(7), 881-896.
- Denzin, N.K., & Lincoln, Y.S. (2013). Introduction: The discipline and practice of qualitative research. In N.K. Denzin, & Y.S. Lincoln, (Eds.), *The landscape of*

- qualitative research* (pp. 1-42). Thousand Oaks, CA: Sage.
- Donaldson, M. (1993). What is hegemonic masculinity? *Theory and Society*, 22, 643-657.
- Doty, P. (1986). Family care of the elderly: The role of public policy. *Milbank Memorial Fund Quarterly*, 64, 34-75.
- Ducharme, F., Levesque, L., Lachance, L., Zarit, S., Vezina, J., Gangbe, M., & Caron, C. (2006). Older husbands as caregivers of their wives: a descriptive study of the context and relational aspects of care. *International Journal of Nursing Studies*, 43, 567-569.
- Du Gas, B.W., Esson, L., & Ronaldson, S.E. (1999). *Nursing foundations: A Canadian perspective 2nd ed.* Scarborough, ON: Prentice Hall Canada Inc.
- du Plessis, V., Beshiri, R., Bollman, R.D., & Clemenson, H. (2001). Definitions of rural (Catalogue No. 21-006-XIE). In *Rural and Small Town Analysis Bulletin*, 3(3), 1-12. Ottawa, ON: Statistics Canada.
- Dura, J., Stukenberg, K., & Kiecolt-Glaser, J. (1990). Chronic stress and depressive disorders in older adults. *Journal of Abnormal Psychology*, 99, 284-290.
- Elliot, N., & Lazenbatt, A. (2005). How to recognise a 'quality' grounded theory research study. *Australian Journal of Advanced Nursing*, 22(3), 48-52.
- Esterberg, K.G. (2002). *Qualitative methods in social research*. McGraw Hill, Boston, MA.
- Etters, L., & Harrison, B.E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20, 423-428.
- Fänge, A.M., Oswald, F., & Clemson, L. (2012). Aging in place in late life: Theory, methodology, and intervention. *Journal of Aging Research*, Editorial, 1-2.
- Fengler, A.P., & Goodrich, N. (1979). Wives of elderly disabled men: The hidden patients. *The Gerontologist*, 19, 175-183.
- Fine, G.A. (1999). Field labor and ethnographic reality. *Journal of Contemporary Ethnography*, 28, 532-540.
- Fisher, M. (1994). Man-made care: Community care and older male carers. *British*

- Journal of Social Work*, 24(6), 659-680.
- Fitting, M., Rabins, P., Lucas, M.J., & Eastham, J. (1986). Caregivers for dementia patients: A comparison of husbands and wives. *The Gerontologist*, 26(3), 248-252.
- Fletcher, K. (2012). Dementia. In M. Boltz, E. Capezuti, T. Fulmer, D. Zwicker, & A. O'Meara, (Eds.), *Evidence-based geriatric nursing protocols for best practice (4th ed.)* (pp. 163-185). New York, NY: Springer.
- Flynn, P.A.R. (1980). *Holistic health*. Bowie, MD: Robert J. Brady.
- Folstein, M.L., Folstein, S.E., & McHugh, P.R. (1975). Mini-mental state: A practical method for grading the cognitive status of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.
- Forbes, D., Jansen, S.L., Markle-Reid, M., Hawranik, P., Morgan, D., Henderson, S., Leipert, B., Peacock, S., & Kingston, D. (2008). Persons with dementia: Gender differences in use and satisfaction with health care services. *Canadian Journal of Nursing Research*, 40(1), 38-59.
- Forbes, D.A., & Hawranik, P. (2012). Looming dementia care crisis: Are Canadians in rural and remote settings ready? In J.C. Kulig, & A.M. Williams, (Eds.), *Health in rural Canada* (pp. 447-461). Vancouver, BC: UBC Press.
- Forbes, D.A., Markle-Reid, M., Hawranik, P., Peacock, S., Kingston, D., Morgan, D....Jansen, S. (2008). Availability and acceptability of Canadian home and community-based services: Perspectives of family caregivers of persons with dementia. *Home Health Care Services Quarterly*, 27(2), 75-99.
- Forbes, D.A., & Neufeld, A. (2008). Looming dementia care crisis: Canada needs an Integrated model of continuing care now! *Canadian Journal of Nursing Research*, 40(1), 9-16.
- Fredrick, J.A., & Fast, J.E. (1999). Eldercare in Canada: Who does how much? *Canadian Social Trends*, 54 (Catalogue no. 11-008). Ottawa, ON: Statistics Canada.
- Fritzemeier, K. (2012, July 31). Food for thought. [Web log post]. Retrieved from: <http://lbrfoodforthought.blogspot.ca/2012/07/like-redwoods.html>
- Fromme, E.K., Drach, L.L., Tolle, S.W., Ebert, P., Miller, P., Perrin, N., & Tilden, V.P.

- (2005). Men as caregivers at the end of life. *Journal of Palliative Medicine*, 8(6), 1167-1175.
- Fossey, E., Harvey, C., & McDermott, F. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry*, 36(6) 717-732.
- Funk, L.M., & Stajduhar, K.I. (2009). Interviewing family caregivers: Implications of the caregiving context for the research interview. *Qualitative Health Research*, 19(6), 859-867.
- Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Cambridge, MA: Harvard University Press.
- Gesler, W.M. (1992). Therapeutic landscapes: Medical issues in light of the new cultural geography. *Social Science & Medicine*, 34(7), 735-746.
- Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B. (1992). *Emergence vs. forcing: Basics of grounded theory analysis*. Mill Valley, CA: Sociological Press.
- Glaser, B., & Strauss, A. (1967). *The discovery of Grounded Theory: Strategies for Qualitative research*. Chicago, IL: Aldine.
- Golding, B., Brown, M., Foley, A., Harvey, J., & Gleeson, L. (2007, May 23). *Men's sheds in Australia: Learning through community contexts*. University of Balart.
- Goulding, C. (2002). *Grounded theory: A practical guide for management, business and market researchers*. London: Sage.
- Government of Alberta. (2012). *2012 Municipal affairs population list* (ISBN 978-1-4601-0645-7). Municipal Affairs, Municipal Services Branch. Edmonton, AB.
- Grbich, C. (2007). *Qualitative data analysis: An introduction*. Thousand Oaks, CA: Sage.
- Guba, E.G., & Lincoln, Y.S. (1998). Competing paradigms in qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.
- Guba, E.G., & Lincoln, Y.S. (1981). *Effective evaluation: Improving the usefulness of Evaluation results through responsive and naturalistic approaches*. San

Francisco: Jossey-Bass.

- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*, 59-82.
- Guest, G., Namey, E.E., & Mitchell, M.L. (2013). *Collecting qualitative data: A field manual for applied research*. Thousand Oaks, CA: Sage.
- Gwyther, L.P. (1998). Social issues of the Alzheimer's patient and family. *The American Journal of Medicine, 104*(4A), 17S-21S.
- Hall, W.A., & Callery, P. (2001). Enhancing the rigor of grounded theory: Incorporating reflexivity and relationality. *Qualitative Health Research, 11*(2), 257-272.
- Hallberg, L.R.-M. (2006). The "core category" of grounded theory: Making constant comparisons. *International Journal of Qualitative Studies on Health and Well-Being, 1*, 141-148.
- Hamel, L.C. (2001). Caring in families. In J.C. Ross-Kerr, & M.J. Wood (Eds.), *Canadian fundamentals of nursing, 2nd edition* (pp. 138-153). Toronto, ON: Harcourt Canada Ltd.
- Hansen, E., Robinson, A., Mudge, P., & Crack, G. (2005). Barriers to the provision of care for people with dementia and their carers in a rural community. *Australian Journal of Primary Health, 11*(1), 72-79.
- Harding, S. (1986). *The science question in feminism*. Ithaca, NY: Cornell University Press.
- Hart, G.L., Larson, E.H., & Lishner, D.M. (2005). Rural definitions for health policy and research. *American Journal of Public Health, 95*(7), 1149-1155.
- Harris, P.B. (1993). The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer's disease victims. *The Gerontologist, 33*(4), 551-556.
- Harris, P.B. (1995). Differences among husbands caring for their wives with Alzheimer's disease: Qualitative findings and counseling implications. *Journal of Clinical Geropsychology, 1*(2), 97-106.
- Harris, P.B. (1998). Listening to caregiving sons: Misunderstood realities. *The Gerontologist, 38*(3), 342-352.

- Harris, P.B. (2002). The voices of husbands and sons caring for a family member with dementia. In B.J. Kramer, & E.H. Thompson, Jr., (Eds.), *Men as caregivers: Theory, research and service implications* (pp. 213-233). New York, NY: Springer.
- Harris, P.B., & Bichler, J. (1997). *Men giving care: Reflections of husbands and sons*. New York, NY: Garland Publishing, Inc.
- Hawranik, P.G., & Strain, L.A. (2007). Giving voice to informal caregivers of older adults. *Canadian Journal of Nursing Research*, 39(1), 156-172.
- Hendry, K.C., & Douglas, D.H. (2003). Promoting quality of life for clients diagnosed with dementia. *Journal of the American Psychiatric Nurses Association*, 9(3), 96-102.
- Herrmann, N., Gauthier, S., & Lysy, P.G. (2007). Clinical practice guidelines for severe Alzheimer's disease. *Alzheimer's and Dementia*, 3, 385-397.
- Hicks, R. (1993). *The masculine journey: Understanding the six stages of manhood*. Colorado Springs, CO: NavPress Publishing Group.
- Hirst, M. (2001). Trends in informal care in Great Britain during the 1990s. *Health and Social Care in the Community*, 9(6), 348-357.
- Hodge, G. (2008). *The geography of aging: Preparing communities for the surge in seniors*. Montreal, MB: McGill-Queen's University Press.
- Hodge, G., McKay, L., & Beeckmans, P. (1993). *Canada's aging rural population: The role and response of local government* (ISBN: 1-895469-27-9). Toronto, ON: Intergovernmental Committee on Urban and Regional Research Press.
- Holfeld, L., Morgan, D., O'Connell, M., Crossley, M., Kirk, N., Stewart, N., Dal Bello-Hass, V., McBain, L., Cammer, A., Minish, D., Beever, R., & Kosteniuk, J. (2014, October). *Rural and remote memory clinic – update (March 2004 – June 2014)*. Poster presented at the knowledge network in rural and remote dementia care: Healthcare delivery across the continuum for rural and remote seniors with dementia 7th annual summit, Saskatoon, Saskatchewan.
- Hollander, M.J., Liu, G., & Chappell, N. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system: New findings and the

- case for integrated care for seniors. *Healthcare Quarterly*, 12(1), 38-47.
- Hood, J.C. (2007). Orthodoxy vs. power: The defining traits of grounded theory. In A. Bryant, & K. Charmaz, (Eds.), *The SAGE handbook of grounded theory* (pp. 151-164). Thousand Oaks, CA: Sage.
- Hooyma, N.R., & Gonyea, J. (1995). *Feminist perspectives on family care*. Thousand Oaks, CA: Sage.
- Hopper, T., & Cleary, S. (2011). Preparing for the rising tide of dementia: Charting a course for older Albertans. *Rehab Dialogue*, 1, 1-8.
- Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. *The Gerontologist*, 25, 612-617.
- Houde, S. (2002). Methodological issues in male caregiver research: An integrative review of the literature. *Journal of Advanced Nursing*, 40, 626-640.
- Howcraft, D. (2004). Alzheimer's disease: Caring for the carers. *Mental Health Practice*, 7(8), 31-37.
- Howson, R. (2006). *Challenging hegemonic masculinity*. New York, NY: Routledge.
- Hoyt, D.R., Conger, R.D., Valde, J.G., & Weihs, K. (1997). Psychological distress and help seeking in rural America. *American Journal of Community Psychology*, 25(4), 449-470.
- Hunter, A., Murphy, K., Grealish, A., Casey, D., Keady, J. (2011). Navigating the grounded theory terrain. Part 1. *Nurse Researcher*, 18(4), 6-10.
- Hutchinson, S.A., Wilson, M.E., & Skodol Wilson, H. (1994). Benefits of participating in research interviews. *IMAGE: Journal of Nursing Scholarship*, 26, 161-164.
- Innes, A. (2014, October 21). Rural dementia care: Challenges, opportunities and personal reflections. In N. Koehncke (Chair), *7th International symposium: "Safety and health and agricultural and rural populations: Global perspectives*. Symposium conducted at the meeting of SHARP 2014, Saskatoon, SK.
- Innes, A., Morgan, D., & Kostineuk, J. (2011). Dementia care in rural and remote settings: A systematic review of informal/family caregiving. *Maturitas*, 68, 34-46.
- Jansson, W., Norberg, G., & Grafstrom, M. (2001). Patterns of elderly spousal caregiving in dementia care: an observational study. *Journal of Advanced Nursing*, 34(6),

804-812.

- Jauhiainen, J. (2009). Will the retiring baby boomers return to rural periphery? *Journal of Rural Studies*, 25(1), 25-34.
- Jeffery, B., Bacsu, J., Abonyi, S., Novik, N., Johnson, S., Martz, D., & Oosman, S. (2013). *Developing a framework to support rural healthy aging*. Canadian Rural Health Research Society: 12th Annual Conference, Prince George, BC, November 13-15, 2013.
- Johansson, T., & Klinth, R. (2008). Caring fathers. The ideology of gender equality and masculine positions. *Men and Masculinities*, 11, 42-62.
- Johnson, C. (1979, November). *Impediments to family supports to dependent elderly: An analysis of primary caregivers*. Paper presented at the annual meeting of the Gerontological Society, Washington, DC.
- Johnson, C.L. (1983). Dyadic family relations and social support. *The Gerontologist*, 23, 377-383.
- Johnson, J. (1996). Social support and physical health in the rural elderly. *Applied Nursing Research*, 9, 61-66.
- Johnson, J.M., & Rowlands, T. (2012). The interpersonal dynamics of in-depth interviewing. In J.F. Gubrium, J.A. Holstein, A.B. Marvasti, & K.D. McKinney (Eds.) *The Sage handbook of interview research: The complexity of the craft* (pp. 99-113). Thousand Oaks, CA: Sage.
- Jupp, V. (Ed.). (2006). *The SAGE dictionary of social research methods*. Thousand Oaks, CA: Sage.
- Kasuya, R.T., Polgar-Bailey, P., & Takeuchi, R. (2000). Caregiver burden and burnout: A guide for primary care physicians. *Postgraduate Medicine*, 108(7), 119-123.
- Kaye, L.W., & Applegate, J.S. (1990). *Men as caregivers to the elderly: Understanding and aiding unrecognized family support*. Toronto, ON: Lexington Books
- Kaye, L.W., & Applegate, J.S. (1990b). Men as elder caregivers: building a research agenda for the 1990s. *Journal of Aging Studies*, 4(3), 289-298.
- Kaye, L.W., & Applegate, J.S. (1994). Family support groups for male caregivers: Benefits or participation. *Journal of Gerontological Social Work*, 20, 3-4, 167-

185.

- Kearns, R.A. (1993). Place and health: towards a reformed medical geography. *The Professional Geographer*, 45(2), 67-72.
- Kearns, R.A. (1995). Medical geography: Making space for difference. *Progress in Human Geography*, 19(2), 251-259.
- Kearns, R.A., & Moon, G. (2002). From medical to health geography: Novelty, place, and theory after a decade of change. *Progress in Human Geography*, 26(5), 605-625.
- Keating, N., Eales, J., & Phillips, J.E. (2013). Age-friendly rural communities: Conceptualizing 'best-fit.' *Canadian Journal on Aging*, 32, 319-332.
- Keating, N., Fast, J., Fredrick, J., Cranswick, K., & Perrier, C. (1999). *Eldercare in Canada: Context, content, and consequences* (Catalogue No. 89-570-XPE). Ottawa, ON: Statistics Canada.
- Keefe, J. (2011). *IRPP study: Supporting caregivers and caregiving in Canada*. (IRPP Study No.23). Retrieved http://www.irpp.org/pubs/irppstudy/irpp_study_no23.pdf
- Kellett, P. (2010). *The contextual performance of masculinity and caring by men nurses: An exploration of men's caring within a profession numerically dominated by women* (Master's thesis). Memorial University of Newfoundland, St. John's, NL.
- Kilmartin, C. (2000). *The Masculine Self*. New York, NY: McGraw-Hill Humanities/Social Sciences/Languages.
- Kim, H., Chang, M., Rose, K., & Kim, S. (2011). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68(4), 846-855.
- Kimmel, M.S. (1987). Rethinking masculinity: New directions in research. *Changing men: New directions in research on men and masculinity*. In M.S. Kimmel, (Ed.), Sage: Newbury Park.
- Kimmel, M.S. (1996). *Manhood in America*. New York, NY: Free Press.
- King, N., & Horrocks, C. (2010). Philosophical assumptions. *Interviews in qualitative research* (pp. 6-23). Thousand Oaks, CA: Sage.
- Kirsi, T., Hervonen, A., & Jylha, M. (2000). A man's gotta do what a man's gotta do:

- Husbands as caregivers to their demented wives: A discourse analytic approach. *Journal of Aging Studies*, 14(2), 153-169.
- Kirsi, T., Hervonen, A., & Jylha, M. (2004). Always one step behind: Husbands' narratives about taking care of their demented wives. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8(2), 159-181.
- Kitwood, T. (1999). *Dementia reconsidered: The person comes first*. Open University Press: McGraw Hill.
- Kleinman, A. (2007). Foreword. In A. Alterra, *The caregiver: A life with Alzheimer's*. Ithaca, NY: ILR Press
- Knutsen, H., & Råholm, M. (2009). The dialectic movement between suffering and reconciliation: Male caregivers' experience of caring for their wives suffering from dementia. *International Journal for Human Caring*, 13(4), 50-56.
- Koch, T. (1994). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 19, 976-986.
- Kramer, B.J. (1997a). Differential predictors of strain and gain among husbands caring for wives with dementia. *The Gerontologist*, 3(2), 239-249.
- Kramer, B.J. (1997b). Gain in the caregiving experience: Where are we? What next? *The Gerontologist*, 32, 218-232.
- Kramer, B.J. (2000). Husbands caring for wives with dementia: A longitudinal study of continuity and change. *Health and Social Work*, 25, 97-108
- Kramer, B.J. (2002). Men caregivers: an overview. In B.J. Kramer, & E.H. Thompson, Jr., (Eds.), *Men as caregivers: Theory, research, and service implications*, (pp. 3-19). New York, NY: Springer.
- Kulig, J., MacLeod, M., Stewart, N, & Pitblado, R. (2008). Clients in rural areas. In L.L. Stamler & L. Yiu, (Eds.) *Community health nursing: A Canadian prespective* (pp. 301-310). Toronto, ON: Pearson Prentice Hall
- Kulig, J.C., & Williams, A.M. (2012). The future of rural health research: Concluding thoughts. In J.C. Kulig, & A.M. Williams, (Eds.), *Health in rural Canada* (pp. 503-511). Vancouver, BC: UBC Press.

- Kuzel, A. (1992). Sampling in qualitative inquiry. In B. Crabtree & W. Miller (Eds.), *Doing qualitative research* (pp. 31-44). Newbury Park, CA: Sage.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Kvale, S. (2007). *Doing interviews*. Thousand Oaks, CA: Sage.
- Louderback, P. (2000). Elder care: a positive approach to caregiving. *Journal of the American Academy of Nurse Practitioners*, 12, 97-99.
- Lauderdale, S.A., D'Andrea, J.A., & Coon, D.W. (2003). Male caregivers: Challenges and opportunities. In D.W. Coon, D. Gallagher-Thompson, & L.W. Thompson (Eds.), *Innovative interventions to reduce dementia caregivers distress* (pp. 243-266). New York, NY: Springer.
- Leira, A. (1994). Concepts of caring: Loving thinking and doing. *Social Sciences Review*, 185-201.
- Levant, R.F., & Habben, C. (2003). The new psychology of men: Application to rural men. In B. Stamm, (Ed.), *Rural behavioral health care: An interdisciplinary guide* (pp. 171-180). Washington, DC: American Psychological Association.
- Lewis, J., & Meredith, B. (1988). *Daughters who care: Daughters caring for mothers at home*. London, England: Routledge & Kegan Paul.
- Liamputtong, P. (2013). *Qualitative research methods (4th ed.)*. Victoria, Australia: Oxford University Press.
- Li, H., Edwards, D., & Morrow-Howell, N. (2004). Informal caregiving networks and use of formal services by inner-city African American elderly with dementia. *Families in Society*, 85, 55-62.
- Light, E., Niederehe, G., & Lebowitz, B.D. (1994). *Stress effects on family caregivers of Alzheimer's patients: research and interventions*. New York, NY: Springer.
- Lily, M.B., Robinson, C.A., Holtzman, S., & Bottorff, J.L. (2012). Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. *Health and Social Care in the Community*, 20(1), 103-112.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

- Litwak, E., & Longino, C.F. (1987). Migration patterns among the elderly: A developmental perspective. *The Gerontologist*, 27, 266-274.
- Lonkila, M. (1995). Grounded theory as an emerging paradigm for computer-assisted qualitative data analysis. In U. Kelle (Ed.), *Computer-aided qualitative data analysis: Theory, methods and practice* (pp. 41-51). Thousand Oaks, CA: Sage.
- Lorber, J. (1994). *Paradoxes of gender*. New Haven, CT: Yale University Press.
- Lowes, L., & Gill, P. (2006). Participants' experiences of being interviewed about an emotive topic. *Journal of Advanced Nursing*, 55, 587-595.
- Luckerhoff, J., & Guillemette, F. (2011). The conflicts between grounded theory requirements and institutional requirements for scientific research. *The Qualitative Report*, 16(2), 396-414.
- Lutgendorf, S.K., Reimer, T.T., Harvey, J.H., Marks, G., Hong, S., & Hillis, S.L. (1994). Effects of housing relocation on immune-competence and psychological functioning in the elderly. *Journal of Gerontological Nursing*, 20, 5-10.
- Lutzky, S.M., & Knight, B.G. (1994). Explaining gender differences in caregiver distress: The roles of emotional attentiveness and coping styles. *Psychology and Aging*, 9(4), 513-519.
- Mace, N., & Rabins, P. (2006). *The 36-hour day 4th ed.* Baltimore, MD: John Hopkins University Press.
- Mahalik, J.R., Locke, B.D., Ludlow, L.H., Diemer, M.A., Gottfried, M., Scott, R.P.J., & Freitas, G. (2003). Development of the conformity to masculine norms inventory. *Psychology of Men & Masculinity*, 4(1), 3-25.
- Malonebeach, E.E., & Zarit, S.H. (1991). Current research issues in caregiving to the elderly. *International Journal of Aging and Human Development*, 32, 103-114.
- Mann, A., & Huhn, A. (2014, April). *What do caregivers have to say?* Paper presented at Supporting family caregivers of seniors: Improving care and caregiver outcomes. Canadian Institute for Health Research. Lister Conference Centre, Edmonton.
- Markle-Reid, M., & Browne, G. (2001). Explaining the use and non-use of community-based long-term care services by caregivers of persons with dementia. *Journal of Evaluation in Clinical Practice*, 7(3), 271-287.

- Marshall, C., & Rossman, G.B. (2011). Primary data collection methods. *Designing qualitative research (5th ed.)* (pp. 137-177). Thousand Oaks, CA: Sage.
- Martin, C.D. (2000). More than the work: Race and gender differences in caregiving burden. *Journal of Family Issues, 21*, 986-1005.
- Mathew, L., Mattocks, K., & Slatt, L. (1990). Exploring the roles of men caring for demented relatives. *Journal of Gerontological Nursing, 16*(10), 20-25.
- Mauk, K.L. (2012). What do the qualitative data mean? In N.A. Schmidt, & J.M. Brown, (Eds.), *Evidence-based practice for nurses: Appraisal and application of research* (pp. 340-363). Sudbury, MA: Jones & Bartlett Learning.
- McConaghy, R., & Caltabiano, M.L. (2005). Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping, and well-being. *Nursing Health Sciences, 7*(2), 81-91.
- McDermott, V. (2013, December). Future of the legion hall in jeopardy. Fortmcmurraytodaycom Retrieved from: <http://www.fortmcmurraytoday.com/2013/12/12/future-of-the-legion-hall-in-jeopardy>
- McDonnell, E., & Ryan, A. (2013). Male caregiving in dementia: A review and commentary. *Dementia, 0*(0), 1-13.
- McDonough, K.E., & Davitt, J.K. (2011). It takes a village: Community practice, social work, and aging-in-place. *Journal of Gerontological Social Work, 54*, 528-541.
- McDowell, I., Hill, G., & Lindsay, J. (2001). An overview of the Canadian study of health and aging. *International Psychogeriatrics, 13*(1), 7-18.
- McEachern, T. (2015, January 19). Living with Alzheimer's changes everything. *Calgary Herald* pp. A10.
- McFarland, P.L., & Sanders, S. (1999). Male caregivers: Preparing men for nurturing roles. *American Journal of Alzheimer's Disease, 14*(5), 278-282.
- McGhee, G., Marland, G.R., & Atkinson, J. (2007). Grounded theory research: Literature reviewing and reflexivity. *Journal of Advanced Nursing, 60*(3), 334-342.
- McLean, C. (1996). The politics of men's pain. In C. McLean, M. Carey, & C. White, (Eds.) *Men's way's of being: New directions in theory and psychology* (pp. 10-

- 28). Boulder, CO: Westview Press, Inc.
- McMurphy, S., Szebeheley, M., Eliasson, R., & Olsson, H. (1993). *Caring for the elderly in Sweden: Shifting responsibilities in the welfare state* (Report No. 8). Stockholm Gerontology Research Center, Stockholm.
- Messecar, D.C. (2012). Family caregiving. In M. Boltz, E. Capezuti, T. Fulmer, & D. Zwicker (Eds.), *Evidence-based geriatric nursing protocols for best practice* (4th ed.) (pp. 469-499). New York, NY: Springer Publishing Company.
- Miles, M.B., & Huberman, A.M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.
- Miller, E.G. (2004). Frontier masculinity in the oil industry: The experience of women engineers. *Gender, Work and Organization*, 11(1), 47-73.
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist*, 32, 498-507.
- Miller, B., & Montgomery, A. (1990). Family caregivers and limitations in social activities. *Research on Aging*, 12, 72-93.
- Milligan, C., & Wiles, J. (2010). Landscapes of care. *Progress in Human Geography*, 34(6), 736-754.
- Ministerial Advisory Council on Rural Health. (2002). *Rural health in rural hands: Strategic directions for rural, remote, northern and Aboriginal communities*. Ottawa, ON: Ministerial Advisory Council on Rural Health.
- Misan, G., & Sergeant, P. (2009). *Men's sheds-a strategy to improve men's health*. Paper Presented at the 10th National Rural Health Conference, Cairns, Australia.
- Moen, P., Robinson, J., & Fields, V. (1994). Women's work and caregiving roles: A life course approach. *Journal of Gerontology*, 49(4), S176-S186.
- Morgan, D. (1981). Men, masculinity and the process of sociological enquiry. In H. Roberts, (Ed.), *Doing feminist research* (pp. 83 – 113). London: Routledge & Kegan Paul.
- Morgan, M., Hayes, R., Williamson, M., & Ford, C. (2007). Men's Sheds: A community approach to promoting mental health and well-being. *International Journal of Mental Health Promotion*, 9(3), 48-52.

- Morgan, D., Semchuk, K., Stewart, N., & D'Arcy, C. (2002). Rural families caring for a relative with dementia: Barriers to use of formal services. *Social Science and Medicine*, 55(7), 51-64.
- Morgan, D. (2014, September 05). Debra Morgan Rural and Remote Dementia Care. Retrieved from <http://www.cchsa-ccssma.usask.ca/ruraldementia/care/affiliated.html>
- Morse, J.M., Barrett, M., Mayan, M., Olson, K., & Speirs, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 1-21.
- Morse, J. (1994). Designing funded qualitative research. In N. Denzin & Y. Lincoln, (Eds.), *Handbook for qualitative research* (pp. 220-235). Thousand Oaks, CA: Sage.
- Morse, J.M. (2007). Sampling in grounded theory. . In A. Bryant, & K. Charmaz, (Eds.), *The SAGE handbook of grounded theory* (pp. 229-244). Thousand Oaks, CA: Sage.
- Morse, J.M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13-22.
- Motenko, A.K. (1988). Respite care and pride in caregiving: The experience of six older men caring for their disabled wives. In S. Reinhartz & G. Rowles (Eds.), *Qualitative Gerontology* (pp. 104-126). New York, NY: Springer.
- Nadler, J. (2014). *Valour Road*. Toronto, ONT: Penguin Canada Books Inc.
- Nagatomo, I., Akasaki, Y., Uchida, M., Tominaga, M., Hashiguchi, W., & Takigawa, M. (1999). Gender of demented patients and specific family relationship of caregiver to patients influence mental fatigue and burdens on relatives as caregivers. *International Journal of Geriatric Psychiatry*, 14, 618-625.
- National Alliance for Caregiving. (2009). *Caregiving in the U.S. 2009*. The National Alliance for Caregiving/ AARP. Retrieved from: http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf

- National Institute for Health and Clinical Excellence. (2006). *Dementia: Supporting people with dementia and their carers in health and social care. NICE Clinical Guideline 42*. London, EN: National Institute for Health and Clinical Excellence.
- Neri, A.L., Yassuda, M.S., Garofe Fortes-Burgos, A.C., Mantovani, E.P., Arbex, F.S., de Souza Torres, S.V...et al. (2012). Relationships between gender, age, family conditions, physical and mental health, and social isolation of elderly caregivers. *International Psychogeriatrics*, 24(3), 472-483.
- Neufeld, A., Kushner, K.E., & Rempel, G. (2007, November 1-3). *Men negotiating the maze of care for a relative with dementia*. Paper presented at Chinook Winds: Shaping the Landscapes of Aging, 36th Annual Scientific and Educational Conference of the Canadian Association on Gerontology, Calgary.
- Neuman, W.L. (2011). *Social research methods: Qualitative and quantitative approaches (7th ed.)*. Boston, MA: Allyn & Bacon.
- O'Brien, J., Ames, D., & Burns, A. (2000). *Dementia*. London, England.
- O'Lynn, C. (2010). Negotiation of constructed gender among rural male caregivers. In C.A. Winters, & H.J. Lee, (Eds.), *Rural nursing concepts, theory, and practice (3rd ed., pp. 193-224.)* New York, NY: Springer Publishing Company.
- O'Neil, J.M. (1981). Male sex role conflicts, sexism, and masculinity: Psychological implications for men, women, and the counseling psychologist. *The Counseling Psychologist*, 9, 61-80.
- O'Neil, J.M. (1982). Gender role conflict and strain in men's lives. In K. Solomon & N.B. Levy (Eds.), *Men in transition* (pp. 5-44). New York, NY: Plenum Press.
- O'Rourke, N., & Tuokko, H. (2000). The psychological and physical costs of caregiving: The Canadian study of health and aging. *The Journal of Applied Gerontology*, 19(4), 389-404. *Gerontologist*, 39, 177-185.
- Opie, A. (1992). *There's nobody there. Community care of the confused older person*. Auckland, NZ: Oxford University Press.
- Ory, M.G., Hoffman, R., Yee, J., Tennstedt, S., & Shulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia caregivers. *The Gerontologist*, 39, 177-185.

- Ory, M.G., Yee, J.L., Tennstedt, S.L., & Shulz, R. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. In R. Shulz, (Ed.), *Handbook on dementia caregiving: Evidence-based interventions for family caregivers* (pp. 1-32). New York, NY: Springer Publishing Company.
- Padgett, D. (1998). *Qualitative methods in social work research*. Thousand Oaks, CA: Sage Publications.
- Parmar, J. (2014, April). Introduction and outline of the day. In J. Parmar (Chair), *Supporting family caregivers of seniors: Improving care and caregiver outcomes*. Symposium conducted at the meeting of Canadian Institute for Health Research, Lister Conference Centre, Edmonton.
- Parr, H. (2003). Medical geography: Care and caring. *Progress in Human Geography*, 27(2), 212-222.
- Parsons, K. (1997). The male experience of caregiving for a family member with Alzheimer's disease. *Qualitative Health Research*, 6(3), 391-406.
- Patel, M.K., Doku, V., & Tennakoon, L. (2003). Challenges in recruitment of research participants. *Advances in Psychiatric Treatment*, 9, 229-238.
- Pearlin, L.I., Mullan, J., Semple, S., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30, 583-594.
- Perel, V.D., & Hopkins, J. (1998). Psychosocial impact of Alzheimer disease. *Journal of The American Medical Association*, 279(13), 1038-1039.
- Petch, T. & Shamian, J. (2008). Tapestry of care: Who provides care in the home? *Healthcare Quarterly*, 11(4), 79-80.
- Pidgeon, N., & Henwood, K. (2004). Grounded Theory. In M. Hardy & A. Bryman (Eds.), *Handbook of data analysis* (pp. 625-648). Thousand Oaks, CA: Sage.
- Porter-O'Grady, T. (1996). Nurses as advanced practitioners and primary care providers. In E.L. Cohen (Ed.), *Nurse case management in the 21st century* (pp. 10-20). St. Louis, MO: Mosby.
- Posluns, L. (2014). *Harper government invests in national initiative to tackle dementia*. Retrieved from: <http://news.gc.ca/web/article-en.do?nid=883069>
- Pot, A.M., Deeg, D.J.H., & Van Dyck, R. (2000). Psychological distress of caregivers:

- Moderator effects of caregiving resources? *Patient Education & Counselling*, 41, 235-240.
- Press, D.Z. (2013). Foreword. In M.N. Allen, S. Dublin, & P.J. Kimmerly, *A look inside Alzheimer's: I know who I am today, but what about tomorrow?* (pp. ix). New York, NY: Demos Medical Publishing.
- Pretorius, C., Walker, S., & Malan Heyns, P. (2009). Sense of coherence amongst male caregivers in dementia. *Dementia*, 8(1), 79-94.
- Pruncho, R.A., & Resch, N.L. (1989). Husbands and wives as caregivers. Antecedents of depression and burden. *The Gerontologist*, 29, 159-165.
- Real, T. (1997). *I don't want to talk about it: Overcoming the secret legacy of male depression*. New York, NY: Scribner.
- Reeser, T.W. (2010). *Masculinities in theory: An introduction*. West Sussex, UK: Wiley-Blackwell.
- Reinhard, S.C., Given, B., Petlick, N.H., & Bemis, A. (2008). Supporting family caregivers in providing care. In Hughes, R.G., (Ed.), *Patient safety and quality: An evidence-based handbook for nurses* (pp. 1-23). Rockville, MD: U.S. Department of Health and Human Services.
- Renzetti, C.M., & Curran, D.J. (2003). *Women, men, and society (5th ed.)*. Boston, MA: Pearson Education, Inc.
- Rhodes, R., & Bodine, M. (1995). *Reasoning from the scriptures with the Mormons*. Harvest House Publishers. Eugene, Oregon.
- Ribeiro, O., & Paúl, C. (2008). Older male carers and the positive aspects of care. *Ageing & Society*, 28, 165-183.
- Ribeiro, O., Paúl, C., & Nogueira, C. (2007). Real men, real husbands: Caregiving and masculinities in later life. *Journal of Aging Studies*, 21, 302-313.
- Robinson, C.A., Bottorff, J.L., Pesut, B., Oliffe, J.L., Tomlinson, J. (2014). The male face of caregiving: A scoping review of men caring for a person with dementia. *American Journal of Men's Health*, 8(5), 409-426.
- Romanow, R.J. (2002). *Building on values: The future of health care in Canada- final report*. (Cat. No. CP32-85/2002E). Saskatoon, SK: National Library of Canada.

- Rowles, G.D., Oswald, F., & Hunter, E. (2004). Interior living environments in old age. In H.W. Wahl, R. Scheidt, & P.G. Windley (Eds.), *Aging in context: Socio-physical environments*. (Annual Review of Gerontology and Geriatrics, 2003) (pp. 167-193). New York, NY: Springer.
- Rudd, R.E., Moeykens, B.A., & Colton, T.C. (1999). Health and literacy: A review of medical and public health literature Volume 1 (pp. 1-41). National Center for the Study of Adult Learning and Literacy. Retrieved from: <http://www.ncsall.net/index.html?id=522.html>
- Rudd, M.G., Viney, L.L., & Preston, C.A. (1999). The grief experienced by spousal caregivers of dementia patients: the role of place of care of patient and gender of caregiver. *International Journal of Aging and Human Development*, 48(3), 217-240.
- Russell-Minda, E., Jutai, J., & Strong, G. (2006). Clear print: An evidence-based review of the research on typeface legibility for readers with low vision, module five. *Vision Rehabilitation Evidence-Based Review*. London: Canadian National Institute of the Blind. Retrieved from [http://www.cnib.ca/en/about/Publications/research/Documents/ClearPrint Full Review.doc](http://www.cnib.ca/en/about/Publications/research/Documents/ClearPrint%20Full%20Review.doc)
- Russell, R. (2001). In sickness and in health. A qualitative study of elderly men who care for wives with dementia. *Journal of Aging Studies*, 15, 351-367.
- Russell, R. (2007). The work of elderly male caregivers: From public careers to an unseen world. *Men and Masculinities*, 9(3), 298-314.
- Saad, K., Hartmann, J., Ballard, C., Kurian, M., Graham, C., & Wilcock, G. (1995). Coping by the carers of dementia sufferers. *Age & Ageing*, 24, 495-498.
- Sachs, C. (2006). Foreword. In H. Campbell, M.M. Bell, & M. Finney, (Eds.), *Country boys: Masculinity and rural life* (pp. viii- xi). University Park, PA: The Pennsylvania State University Press.
- Sandelowski, M. (1986). The problems of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37.

- Sanders, S. (2007). Experiences of rural male caregivers of older adults with their informal support networks. *Journal of Gerontological Social Work, 49*(4), 97-115.
- Sanders, S., & Power, J. (2009). Roles, responsibilities, and relationships among older husbands caring for wives with progressive dementia and other chronic conditions. *Health & Social Work, 34*(1), 41-51.
- Santos, C.D., Santos, V.A., & Goldman, A. (2011). Uncovering steady advances for an extreme programming course. *CLEI Electronic Journal, 15*(1), 2-2.
- Scharf, T., Phillipson, C., & Smith, A.E. (2005). Social exclusion of older people in deprived urban communities of England. *European Journal of Ageing, 2*, 76-87.
- Serow, W.J. (1987). Determinants of interstate migration: Differences between elderly and nonelderly movers. *Journal of Gerontology, 42*, 95-100.
- Schatzman, L., & Strauss, A.L. (1973). *Field research: Strategies for a natural sociology*. Englewood Cliffs, NJ: Prentice-Hall, Inc.
- Schneider, J., Murray, J., Banerjee, S., & Mann, A. (1999). Eurocare: A cross-national study of co-resident spouse carers for people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 14*(8), 651-661.
- Schroeder, B., MacDonald, J., & Shamian, J. (2012). Older workers with caregiving responsibilities: A Canadian perspective on corporate caring. *Ageing Int 37*, 39-56.
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association, 282*(23), 2215-2219.
- Shagman, J.Y. (2009). The many faces of dementia. *Radiologic Technology, 81*(2), 153-168.
- Shanas, E. (1979). The family as social support system in old age. *The Gerontologist, 19*, 169-174.
- Shanks-McElroy, H.A., & Strobino, J. (2001). Male caregivers of spouses with Alzheimer's disease: Risk factors and health status. *American Journal of Alzheimer's Disease and Other Dementias, 16*(3), 167-175.

- Sinha, M. (2013). *Portrait of caregivers, 2012* (Catalogue no. 89-652-X – No. 001). Ottawa, ON: Statistics Canada.
- Siriopoulos, G., Brown, Y., & Wright, K. (1999). Caregivers of wives diagnosed with Alzheimer's disease: Husbands' perspectives. *American Journal of Alzheimer Diseases, 14*(2), 79-87.
- Slack, K., & Fraser, M. (2014). *Husband, partner, dad, son, carer? A survey of the Experiences and needs of male carers*. London, EN: Carers Trust.
- Smetanin, P., Kobak, P., Briante, C., Stiff, D., Sherman, G., & Ahmad, S. (2009). *Rising tide: The impact of dementia in Alberta 2008 to 2038*. Risk Analytica.
- Smetanin, P., Kobak, P., Briante, C., Stiff, D., Sherman, G., & Ahmad, S. (2010). *Rising tide: The impact of dementia in Canada 2008 to 2038*. (ISBN 978-0-9733522-2-1). Toronto, ON: Alzheimer Society of Canada.
- Sorensen, E.S. (1994). Daily stressors and coping responses: A comparison of rural and suburban children. *Public Health Nursing, 11*(1), 24-31.
- Smith, B., & Hesse-Biber, S. (1996). Users' experiences with qualitative data analysis software: Neither Frankenstein's monster nor muse. *Social Science Computer Review, 14*(4), 423-432.
- Spears, R.A. (2005). McGraw-Hill's Dictionary of American Idioms and Phrasal Verbs. McGraw-Hill. New York, NY. DOI: 10.1036/0071435786
- Speechly, C.M., Bridges-Webb, C., & Passmore, E. (2008). The pathway to dementia diagnosis. *Medical Journal of Australia, 189*(9), 487-489.
- Stacy, J., & Thorne, B. (1985). The missing feminist revolution in sociology. *Social Problems, 32*(4), 301-316.
- Stanton, S.S. (2001, April). Alzheimer's disease: A family affair and a growing social problem. Proquest 2013 Retrieved from: <http://www.csa.com/discoveryguides/alzsa/editor.php>
- Statistics Canada. (2006). *A portrait of seniors in Canada* (Catalogue No. 89-519-XIE). Ottawa, ON: Statistics Canada.
- Statistics Canada. (2007). *Portrait of the Canadian population in 2006, by age and sex*,

- 2006 census (Catalogue No. 97-551-XIE). Ottawa, ON: Statistics Canada.
- Statistics Canada. (2011). *The Canadian population in 2011: age and sex* (Catalogue No. 98-311-X20110010). Ottawa, ON: Statistics Canada.
- Statistics Canada. (2012). *2011 general social survey: Overview of families in Canada*. (Catalogue no. 89-650-X) Ottawa, ON: Statistics Canada.
- Statistics Canada. (2013). *Spotlight on Canadians: Results from the general social survey. Portrait of caregivers, 2012*. (Catalogue no. 89-652-X No. 001 ISBN 978-1-100-22502-9) Ottawa, ON: Minister of Industry.
- Stern, P.N. (2007). On solid ground: Essential properties for growing grounded theory. In A. Bryant, & K. Charmaz, (Eds.), *The SAGE handbook of grounded theory* (pp. 114-126). Thousand Oaks, CA: Sage.
- Sternberg, S.A., Wolfson, C., & Baumgarten, M. (2000). Undetected dementia in community dwelling older people: The Canadian study of health and aging. *Journal of the American Geriatrics Society*, 48(11), 10-28.
- Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *The Gerontologist*, 29, 677-683.
- Stoller, E.P. (1990). Males as helpers: The role of sons, relatives, and friends. *The Gerontologist*, 30(2), 228-235.
- Stoller, E.P. (1992). Gender differences in the experiences of caregiving spouses. In J.W. Dwyer & R.T. Coward (Eds.), *Gender, families, and elder care* (pp. 49-64). Newbury Park: Sage.
- Stoller, E.P., & Miklowski, C.S. (2008). Spouses caring for spouses: Untangling the influences of relationship and gender. In M.E. Szinovacz, & A. Davey, (Eds.), *Caregiving contexts: cultural, familial, and social implications* (pp. 115-131). New York, NY: Springer Publishing Company.
- Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge University Press.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.
- Szala-Meneok, K. (2009). Ethical research with older adults. In D.M. Mertens, & P.E.

- Ginsberg, (Eds.), *The handbook of social research ethics* (pp. 507-518). Thousand Oaks, CA: Sage.
- Tapp-McDougall, C. (2004). *The complete Canadian eldercare guide: Expert solutions to help you make the best decisions for your loved ones*. Mississauga, ON: National Library of Canada Cataloguing in Publication.
- Thomas, C., Kelman, H.R., & Kennedy, G.J. (1990). The emergence of depressive symptoms in late life: The importance of declining health and increasing disability. *Journal of Community Health, 15*(2), 93-104.
- Thompson, E.H. (1997). *The gendered caregiving of husbands and sons and the social construction of men caregivers as deviants* (unpublished). Presented at the annual meeting of the American Sociological Association. Toronto, ON.
- Trigoboff, E., & Wilson, H. (2004). Cognitive disorders. In C.R. Kneisl, H.S. Wilson, & E. Trigoboff, (Eds.) *Contemporary psychiatric-mental health nursing* (pp. 234-259). Upper Saddle River, NJ: Pearson Education.
- Tuokko, H., & Hadjistavropoulos, T. (1998). Age-associated conditions affecting cognition. *An assessment guide to geriatric neuropsychology* (pp. 181-204). Mahwah, NJ: Lawrence Erlbaum Associates.
- Turner, D. W., III. (2010). Qualitative interview design: A practical guide for novice investigators. *The Qualitative Report, 15*(3), 754-760.
- Twigg, J., & Atkin, K. (1995). Carers and services: Factors mediating service provision. *Journal of Social Policy, 24*(1), 5-30.
- Ungerson, C. (1983). Women and caring: Skills, tasks, and taboos. In E. Gamarnikow, D. Morgan, J. Purvis, & D. Taylorson, (Eds.), *The public and the private*. London, England: Heinmann.
- University of Lethbridge Research & Innovation Services. (May 25, 2013). Retrieved <http://www.uleth.ca/research/ethics/human-subjects/forms>
- Vasunilashorn, S., Steinman, B.A., Liebig, P.S., & Pynoos. (2011). Aging in place: Evolution of a research topic whose time has come. *Journal of Aging Research, 20*(12), 1-6

- Verbrugge, L.M., & Wingard, D.L. (1987). Sex differentials in health and mortality. *Women and Health, 12*(2), 103-145.
- Vinick, B.H. (1983, April). *Elderly men as caretakers of wives*. Paper session presented at a scientific meeting of the Boston society for gerontological psychiatry, Boston.
- Wackerbarth, S. (1999). Modeling a dynamic decision process: Supporting the decisions of caregivers of family members with dementia. *Qualitative Health Research, 9*(3), 294-314.
- Wagenfeld, M.O. (2003). A snapshot of rural and frontier America. In B. Stamm (Ed.), *Rural behavioral health care: An interdisciplinary guide* (pp. 33-41). Washington DC: American Psychological Association.
- Waite, L.J., & Gallagher, M. (2000). *The case for marriage: Why married people are happier, healthier, and better off financially*. New York, NY: Doubleday.
- Walker, A. (1992). Conceptual perspectives on gender and family caregiving. In J.W. Dwyer, & R.T. Coward (Eds.), *Gender, families, and elder care* (pp. 34-46). Newbury Park: Sage
- Walker, A., Pratt, C., & Eddy, L. (1995). Informal caregiving to aging family members: A critical review. *Family Relations, 44*(4), 402-411.
- Ward, B. (2013). Rednecks, rig pigs, and cowboys: Rural masculinity in Albertan country music. *Spaces Between: An Undergraduate Feminist Journal, 1*(1), 1-20.
- Wenger, G.C. (1987). Dependence, interdependence, and reciprocity after eighty. *Journal Of Aging Studies, 1*, 355-377.
- Wenger, G.C. (1990). Elderly carers: The need for appropriate intervention. *Ageing and Society, 10*, 197-219.
- Wharton, A.S. (2012). *The sociology of gender: An introduction to theory and research* (2nd ed.). Malden, MA: Wiley-Blackwell.
- White, A., & Johnson, M. (1998). The complexities of nursing research with men. *International Journal of Nursing Studies, 35*(1), 41-48.
- Wickersham, J. (1994). *Hegemony and the Greek historians*. London: Rowman Littlefield Publishers.
- Wiles, J. (2003a). Daily geographies of caregivers: Mobility, routine, scale. *Social*

- Science and Medicine*, 57(13), 7-25.
- Wiles, J. (2003b) Informal caregivers' experiences of formal supports in a changing context. *Health and Social Care in the Community*, 11, 189-207.
- Williams, A.M. (Ed.) (1999). *Therapeutic landscapes: The dynamic between place and wellness*. Lanham, MD: University Press of America.
- Williams, A. (2002). Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Sciences & Medicine*, 55, 141-154.
- Williams, A.M., & Kulig, J.C. (2012). Health and place in rural Canada. In J.C. Kulig, & A.M. Williams, (Eds.), *Health in rural Canada* (pp. 1-22). Vancouver, BC: UBC Press.
- Wolff, J.L. & Kasper, J.D. (2006). Caregivers of frail elders: Updating a national profile. *The Gerontologist*, 46(3), 344-356.
- World Health Organization. (2012). *Dementia: A public health priority* (ISBN 978 92 4 156445 8). Geneva, Switzerland: WHO Press.
- Yiu, L. (2008). Community Care. In L.L. Stamler & L. Yiu, (Eds.) *Community health nursing: A Canadian perspective* (pp. 176-198). Toronto, ON: Pearson Prentice Hall
- Young, R.F., & Kahana, E. (1989). Specifying caregiver outcomes: Gender and relationship aspects of caregiving strain. *The Gerontologist*, 29(5), 660-666.
- Zodikoff, B.D. (2007). Gender differences in the community service use attitudes of older spousal caregiver-care recipient couples. *Home Health Care Services Quarterly*, 26(2), 1-20.

Appendix A

Comparison of Three Types of Grounded Theory

Table 1 Comparison of the three types of grounded theory			
	Classic	Straussian	Constructivist
Identifying the problem area	<ul style="list-style-type: none"> ■ Emergent. ■ No initial literature review. 	Experience, pragmatism and literature.	<ul style="list-style-type: none"> ■ Sensitising concepts. ■ Discipline-specific.
Conduct of research and developing theory	Laissez-faire theory generation.	Paradigm model theory verification.	Co-construction and reconstruction of data into theory.
Relationship to participants	Independent.	Active.	Co-construction.
Evaluating theory	Fit, work, relevance and modifiability.	Validity, reliability, efficiency and sensitivity.	<ul style="list-style-type: none"> ■ Situating theory in time place, culture and context. ■ Reflexive rendering of the researcher's position.
Coding	<ul style="list-style-type: none"> ■ Open coding. ■ Selective coding. ■ Theoretical coding. 	<ul style="list-style-type: none"> ■ Open coding. ■ Axial coding. ■ Selective coding. 	Line-by-line conceptual coding and focused coding to synthesise large amounts of data.

(Hunter, Murphy, Grealish, Casey, Keady, 2011, p. 8)

Appendix B

Recruitment Ad

**Does your wife have dementia? Are you taking care of her?
Would you be willing to talk about your experiences?**

If you live in rural southern or central Alberta and are willing to meet with me to talk about your experiences, I would appreciate you contacting me. Your participation is voluntary, and I expect we will spend no more than one hour together. For your time and information, I will provide you with a \$30.00 gift certificate to a local grocer.

I am a registered nurse completing my master's degree from the Faculty of Health Sciences. I hope to hear from you and I can be reached at:



Ryan Waldorf, RN, BN
ryan.waldorf@uleth.ca
(403) 332-4066 office
(403) 795-1825 cell



Appendix C

Informed Consent Document

(Insert Date)

Dear *(Insert Potential Research Participant's Name)*:

You are being invited to participate in a research study on male's perceptions of being in a caregiver role. In particular, I am interested in how men perceive their caregiving role in rural southern Alberta settings.

This research will require about 1-2 hours of your time. During this time, you will be interviewed about your perceptions of caregiving. The interviews will be conducted wherever you prefer (e.g. in your home), and will be tape-recorded.

There are no anticipated risks or discomforts related to this research. The person interviewing you, however, can give you the name and telephone number of some counseling and/or mental health services, if you wish this information.

You may also find the interview to be very enjoyable and rewarding, as many people who are in the role of a caregiver do not get to share their experiences with a skilled and nonjudgmental interviewer, as you will. By participating in this research, you may also benefit others by helping people to better understand what it is like to be a male caregiver, and how male caregivers cope with caregiving.

Several steps will be taken to protect your anonymity and identity. While the interviews will be tape-recorded, the tapes will be destroyed once they have been typed up. The typed interviews will NOT contain any mention of your name, and any identifying information from the interview will be

removed. The typed interviews will also be kept in a locked filing cabinet at the University of Lethbridge, and only the researcher and his supervisor (sworn to confidentiality) will have access to the interviews. All information will be destroyed after 5 years' time.

Your participation in this research is completely voluntary. If you decide to participate, you will receive \$30 cash for your time and trouble. However, you may withdraw from the study at any time for any reason. If you do this, all information from you will be destroyed, and you will be allowed to keep your \$30.

The results from this study will be presented in writing in journals read by health professionals, to help them better understand the experience of male caregivers. The results may also be presented in person to groups of male caregivers or health professionals. At no time, however, will your name be used or any identifying information revealed. If you wish to receive a copy of the results from this study, you may contact the researcher at the telephone number given below.

If you require any information about this study, or would like to speak to the researcher, please call Ryan Waldorf at (403) 332-4066 at the University of Lethbridge. If you have any other questions regarding your rights as a participant in this research, you may also contact the Office of Research Ethics at the University of Lethbridge at 403-329-2747 or research.services@uleth.ca.

I have read (or have been read) the above information regarding this research study on the perception of male caregivers, and consent to participate in this study.

_____ (Printed Name)

_____ (Signature)

_____ (Date)

Appendix D



Authorization to Reproduce Physical Likeness for Educational and Presentation Purposes

(where practical, attach a copy of the visual image approved by this authorization)

I hereby grant or do not grant

to the University of Lethbridge, including its employees, agents, assigns, or other third party as the University may authorize on its behalf, the nonexclusive right to photograph my home and rural setting where I reside.

I authorize Ryan Waldorf, a graduate student from the Faculty of Health Sciences, University of Lethbridge to use the designated photographs taken or to be taken on or about (insert date) _____ for the purpose of educational data collection and presenting at conferences and presentations on male caregivers in relation to NURS 6000 Master's Thesis distributed by poster presentation, and/or Power Point, and/or classroom in the period from December 01, 2013 through to December 01, 2017.

Full Legal Name: _____

Signature: _____

Date: _____

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Appendix E

Demographic Field Notes

Full legal name: _____

Age: _____ Ethnicity: _____ Culture: _____ Religion: _____

Siblings: _____ Parents: _____

Where raised: _____

Previous/Current Occupation: _____

Level of Education/Trade School Obtained:

Primary Residence: _____

Length of Time Residing in Current Residence: _____

Previous marriage/relationships: _____

Children: _____

Current marriage/relationship: _____

Community Engagment: _____

Length of Marriage: _____

Spouse legal name/Maiden Name: _____

Spouse Age: _____ Ethnicity: _____ Culture: _____ Religion: _____

Spouse Siblings: _____ Parents: _____

Spouse where raised: _____

Previous Occupation: _____

Level of Education/Trade School Obtained:

Spouse children:

Informal care providers/Type of care provided:

Formal care providers/Type of care provided:

Appendix F

Grounded Theory Interview Guide Questions

1. Tell me about how you came to be a caregiver for your spouse.
2. How would you describe the person you were then (at the time of spouses diagnosis)?
 - 2a. Could you tell me about your thoughts and feelings when your spouse was diagnosed with dementia?
 - 2b. How, if at all, have your thoughts and feelings about dementia changed since then?
3. If you are able to recall, could you describe what was going on in your life when your spouse was diagnosed with dementia?
4. How do you reconcile being a man in the role of a caregiver?
 - 4a. What was your gender role in the home prior to diagnosis?
 - 4b. What is your gender role currently?
 - 4c. Are male caregivers supported in their role as caregiver?
 - 4d. Do you identify yourself as your spouse caregiver, or as her husband?
5. Could you describe the most important lessons you have learned about being a caregiver?
6. How does living in a rural setting impact your role as a caregiver?
 - 6a. How would you describe the rural environment that you are living in? (symbolic to them?)
 - 6b. Have your thoughts about living in a rural setting changed since becoming a caregiver? 6c. If so, how have they changed?
 - 6d. If you had the option, would you rather be residing in a rural or urban setting?
 - 6e. What barriers/benefits are there to residing in a rural setting?
6. After reflecting on your experiences with caregiving, gender, and residing in a rural area is there something else you would like to add?
7. Is there anything you would like to ask me?

Appendix G

Safety Protocol

A. Remote and Rural Travel:

- researcher will provide supervisor with date, time and location for interviews conducted in rural and remote settings
- estimated return time will be given either via text or email to supervisor
- inclement road conditions will be monitored on Alberta Motors Association [AMA] website and Environment Canada weather reports will be monitored by researcher to decrease risk of travelling on or encountering poor road conditions related to seasonal weather patterns
- researcher will carry when travelling to rural and remote sites a charged cell phone and current membership to AMA if roadside assistance is required due to unanticipated vehicle failure

B. Intimate Partner Violence:

- intimate partner violence [IPV] is a pattern of assaultive behavior and coercive behavior that may include physical injury; sexual assault; psychological abuse including progressive isolation, neglect (refusal or failure to fulfill caregiving obligations), abandonment, deprivation, intimidation, and financial exploitation (illegal or improper exploitation of funds or other assets through undue influence or misuse of power of attorney). It can be experienced by both men and women in every community regardless of age, economic status, race, religion, ethnicity, sexual orientation, or educational background (The American College of Obstetricians and Gynecologists, 2012, p.1)
- if verbal disclosure of IPV of care recipient is stated or alluded to, researcher to remove self from setting and contact proper legal authorities to investigate
- acts of IPV displayed by the caregiver to care recipient observed by researcher will be communicated to the appropriate authorities
- interview participants will be informed at the beginning of the interview of the researcher's moral and legal obligation to report intimate partner violence

Adapted from:

Langford, D.R. (2000). Developing a safety protocol in qualitative research involving battered women. *Qualitative Health Research* 10(1), 133-142.

Appendix H

UNIVERSITY OF LETHBRIDGE INTERMEDIARY CONFIDENTIALITY AGREEMENT

Purpose of the Study: Discover how male caregivers understand their role as a caregiver in a rural setting in Alberta.

Project Title: How do informal male caregivers of spouses with dementia in rural southern and central Alberta come to understand their role as caregiver?

I, Lorrie Wittke the Intermediary, agree to:

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., laptops, USB sticks, transcripts, surveys) with anyone other than the Researcher(s).
2. keep all research information in any form or format (e.g., laptops, USB sticks, transcripts, surveys) secure while it is in my possession.
3. return all research information in any form or format (e.g., laptops, USB sticks, transcripts, surveys) to the Researcher(s) when I have completed the research tasks.
4. after consulting with the Researcher(s), erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher(s) (e.g., information stored on computer hard drive).

Intermediary:

Lorrie Wittke
(print name)

L Wittke
(signature)

January 10, 2014
(date)

Researcher(s)

RYAN WALDORF
(print name)

Ryan Waldorf
(signature)

January 11, 2014
(date)

**UNIVERSITY OF LETHBRIDGE
INTERMEDIARY CONFIDENTIALITY AGREEMENT**

Purpose of the Study: Discover how male caregivers understand their role as a caregiver in a rural setting in Alberta.


Project Title: How do informal male caregivers of spouses with dementia in rural southern and central Alberta come to understand their role as caregiver?

I, Gisele Woods, the Intermediary, agree to:

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., laptops, USB sticks, transcripts, surveys) with anyone other than the Researcher(s).
2. keep all research information in any form or format (e.g., laptops, USB sticks, transcripts, surveys) secure while it is in my possession.
3. return all research information in any form or format (e.g., laptops, USB sticks, transcripts, surveys) to the Researcher(s) when I have completed the research tasks.
4. after consulting with the Researcher(s), erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher(s) (e.g., information stored on computer hard drive).

Intermediary:

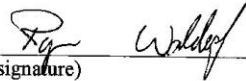
Gisele Woods
(print name)


(signature)

January 10, 2014
(date)

Researcher(s)

RYAN WALDOFF
(print name)


(signature)

January 11, 2014
(date)

Appendix I

CERTIFICATE OF HUMAN PARTICIPANT RESEARCH
University of Lethbridge
Human Subject Research Committee

PRINCIPAL INVESTIGATOR: Ryan Waldorf

ADDRESS: Faculty of Health Sciences
University of Lethbridge
4401 University Drive
Lethbridge, AB T1K 3M4

PROJECT TITLE: How do Informal Male Caregivers of Spouses with
Dementia in Rural Southern and Central Alberta come to
Understand Their Role as Caregiver?

INTERNAL FILE: 2013-078

INFORMED CONSENT: Yes

LENGTH OF APPROVAL: November 20, 2013 – November 30, 2014

The Human Subject Research Committee, having reviewed the above-named proposal on matters relating to the ethics of human research, approves the procedures proposed and certifies that the treatment of human participants will be in accordance with the Tri-Council Policy Statement, the Health Information Act, and University policy.

Susan Potts, Ethics Officer
Human Subject Research Committee

November 20, 2013
Date

Appendix J

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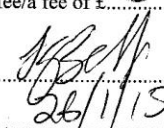
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