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Exploring the Lived Experiences of Daughters/ Daughters-in-Law Providing Primary Informal
Care to Their Mothers/ Mothers-in-Law with Dementia

by

Sarah E. MacFarlane

Wilfrid Laurier University, 2017

THESIS

Submitted to the Department of Kinesiology and Physical Education

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Finally, to the woman behind it all- Grams, this one is for you. I love you.

Abstract

Objective

As the senior population in Canada rises, more middle aged residents of Canada will find themselves taking on a caregiving role, often times for a parent with dementia. This research examines the lived experiences of daughters/daughters-in-law providing primary informal care to their mothers/mothers-in-law with dementia in order to understand the motivations, effects, and transitions within caregiving relationships.

Methods

Phenomenology was the theoretical orientation used to guide this research and captured individuals' lived experiences. Background questionnaires were administered initially, followed by one-on-one semi-structured interviews which were transcribed verbatim upon completion for data analysis. Field notes, member checks, and triangulation were used to further enhance the credibility of the study.

Results

From the analysis, four themes emerged: (1) "Master of none.": The many roles of informal caregivers; (2) The face of dementia; (3) "What a life!"; and (4) "Every so often you see a little bit of light.": The silver linings. All of the women expressed experiencing a multitude of both positive and negative effects as a result of their caregiving experiences.

Conclusions

Informal caregivers play an integral role in the Canadian health care system. This study provides a glimpse into the hectic lives of these informal female filial dementia caregivers. Their stories can provide strength and hope for individuals who have provided care for family members with dementia in the past, in the present, or will do so in the future.

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CHAPTER 1: REVIEW OF THE LITERATURE

1.1 INTRODUCTION

She is the working mom who everyday visits her older mother, only to sit in silence together. She is the middle aged woman who skips her own meals to feed her mother-in-law so she is not alone at meal time. The role of caregiving is one that people may not have expected for themselves, but often find themselves experiencing. With population aging, the demands placed on caregivers will continue to increase. Results from the General Social Survey (GSS) on Caregiving and Care Receiving estimated that approximately 13 million Canadians aged 15 and older provided informal care to a family member at some point during their lives. In the year 2012, 3.65 million Canadian's had provided informal filial care (Sinha, 2013).

She is the woman who is pacing up and down the hallway with her purse on her shoulder waiting for the ride that everyone else knows will never come. She is the woman smiling to every person who passes by, reintroducing herself to friends, family and strangers. Dementia is a progressive brain disorder that affects an individual's memory, thinking, language and problem solving (Alzheimer Society, 2015). Due to the progressive nature of dementia, many individuals will experience transitions within the disease and long-term care environments.

A caregiver paired with a senior with dementia is a caregiving dyad that often goes unrecognized for their ever changing relationship. As the senior population in Canada rises, more and more middle aged residents of Canada will find themselves taking on a caregiving role, often times for a parent with dementia. The concepts of dementia and caregiving will be described in turn.

1.2 MAGNITUDE OF PROBLEM

1.2.1 Caregiving Definition

There is no one definition of caregiving, as the concept has been examined by health professionals for decades and is still not fully understood (Ansello & Rosenthal, 2007). That being said, there are two main forms of caregiving identified, namely formal and informal. Formal care refers to “a range of home care and community support services provided to older persons (as well as to other groups such as children with complex continuing care needs) by a mix of providers, some who are contracted by Community Care Access Centres (CCACs) including personal support workers, nurses...” (Williams et al., 2010, p. 6), and is also provided with a monetary cost (Talley & Crews, 2007). Informal care refers to unpaid, untrained services usually provided by family members and friends. Although in most cases the two forms of care are provided simultaneously, formal care often provides mainly physical care for individuals, where informal care may range from emotional to instrumental support- tangible support such as transportation and childcare (Williams et al., 2010).

Within the informal caregiving context, there are varying levels and degrees of involvement. For example, a primary caregiver is an informal caregiver who is primarily responsible for an individual’s care (Barbosa et al., 2011), while a secondary caregiver is the individual who supports the primary caregiver and is not as involved in the direct care of the care recipient (Gaugler et al., 2003).

Although caregiving can occur for individuals across the lifespan, the Canadian government has noticed the shifts in population aging and the need for informal caregiving for the senior population. In 2002, Statistics Canada’s General Social Survey (GSS) changed their focus to caregiving and specifically the care provided to seniors. In past and current government

surveys, a senior has generally been defined as someone with a chronological age of 65 years or older (Cranswick & Dosman, 2007). As such, for the purposes of this study, a caregiver will be defined as a person who, during the most recent 12 months, provided assistance to an individual over age 65 with a long-term health condition or physical limitation (Cranswick & Dosman, 2007).

1.2.2 Defining Dementia

Dementia is an umbrella term for disorders with a set of signs and symptoms that affect the brain (Chertkow et al., 2013). There are many types of dementia including; Alzheimer's disease (50-80%), vascular dementia (20-30%), fronto-temporal dementia (5-10%) and Lewy body dementia (>5%) (Alzheimer Society of Canada, 2010). Although there are many forms, one common characteristic is the progressive nature of the disease, as signs and symptoms progress with increased brain cell damage (Alzheimer Society of Canada, 2010).

During an initial assessment, doctors ask questions revolving around symptoms, past illnesses, and family history. Physical examinations, including blood work to look for heart, lung, liver and thyroid problems, are also implemented to rule out other problems causing symptoms. Lastly, doctors typically conduct mental tests to measure individuals' sense of time and place, as well as their ability to remember, express themselves and perform simple calculations (Alzheimer Society of Canada, 2010). Diagnosing dementia clinically, using the Diagnostic and Statistical Manual of Mental Disorders 5th edition, requires an impairment of memory and at least one of the following domains: praxis, language, gnosis, or executive functioning (Chertkow et al., 2013). These impairments must not occur as a consequence of delirium or by another medical, psychiatric, or neurological condition. Other clinical criteria for dementia set by the National Institute of Aging, Alzheimer's Association (NIA-AA) include: (1)

symptoms that interfere with the ability to function independently at work or usual activities, (2) symptoms that represent a decline from prior levels of functioning, (3) symptoms that are not explained by delirium or major psychiatric disorder, (4) the cognitive impairment is detected and diagnosed with the combination of objective assessments and patient history and lastly, (5) impairment that involves at least two of the following domains, impaired ability to acquire and remember new information, impaired reasoning and handling of complex tasks, impaired visuo-spatial abilities, impaired language functioning and changes in personality and behaviour (Chertkow et al., 2013).

1.2.3 Dementia Caregiving Statistics

Informal caregiving has become increasingly important in Canadian society. According to the 2008/2009 Canadian Community Health Survey (CCHS), approximately 3.8 million Canadians were providing informal care to a senior with a short or long-term condition. These informal caregivers were generally aged 45 or older and were family and friends who provided unpaid assistance to a senior. Just over half of the informal caregivers for seniors in Canada were female (57%), and three-quarters of these individuals were middle aged (45 to 64) (Sinha, 2013).

As of 2011, there were 747 000 Canadians living with dementia, including Alzheimer's disease. Within long-term residential care in Canada, an estimated 45% aged 45 and older had a diagnosis of dementia (Wong et al., 2016). Statistics show that Canada hosts' large numbers of individuals living with dementia, and those numbers are also reflected financially. Economically, the sum of indirect and direct costs of dementia equals \$33 billion annually, and is estimated to increase to \$293 billion annually by 2040. Within the home, family caregivers spent 444 million unpaid hours caring for individuals with dementia, which is again expected to steadily increase

with time (Alzheimer Society of Canada, 2015). These numbers show the strain of dementia, and specifically within the home of informal caregivers.

Further, the Alzheimer Society conducted the *Rising Tide: The Impact of Dementia on Canadian Society* in 2008. *Rising Tide* estimated that the incidence of dementia in 2038 would be one new case every 2 minutes, and that the prevalence would be 2.8% of the Canadian population. Within this research, Alzheimer's disease and the other types of dementia were included, meaning that not only seniors over the age of 65 were included, but early onset dementia as well (Alzheimer Society of Canada, 2010). In short, as Western populations continue to age, and individuals continue to live longer but with increasing levels of chronic illness, impairments and/or disabilities, individuals providing informal care will be expected to meet the demands (Sinha, 2013).

1.3 GENDER AND CAREGIVING

1.3.1. Female Population Growth in Canada

Females comprise over half of Canada's population with 17.2 million females accounting for 50.4% of the total population. This female majority, although slim, has held for over three decades. Gains in life expectancy over the past century have benefited females over males, as lower mortality rates have contributed to the higher proportions of females in the Canadian population. These statistics are highest within our own backyard, with the largest female population residing in Ontario (39%). Like the rest of the Canadian population, the female population is aging. In particular, the baby boom cohort in 2010 was on the peak of becoming seniors at ages 45-64. The baby boom cohort in 2010 made up 28% of the overall female population that year, and more women fell into the ten year cohort of 45-54 than any other cohort. For the total Canadian senior population in 2010, 56% of the 65 years and older group

were females, 67% of the 85 years and older group were females, and 80% of the centenarians were females. By 2036, population projections estimate that one-quarter of the female population will be seniors aged 65 and older (Urquijo & Milan, 2015). The aging population in Canada, and in particular the percentage of females aging, is a statistic that is difficult to ignore. Over time, the distribution of the female population will shift to the older age group and directly affect individuals within the dyad caregiving relationship. The Canadian population will face an increasing number of females needing care and a declining number of females available to provide this care.

1.3.2 Females Providing Care

Neufeld and Harrison (2003) investigated the negative interactions of women providing care for family members with dementia. The purpose of the study was to describe females' experiences of non-support (i.e., with individuals who fail to provide assistance) and identify the varying types of non-support in their relationships outside of their caregiving relationships. Symbolic interactionism guided the longitudinal qualitative study, as interviews with a group of 8 women were conducted. These women were selected from a larger study of 20 women caring for relatives over the age of 60 with dementia, who self-identified as the primary informal caregiver. Each woman participated in open-ended interviews 3 or 4 times over 18 months. Results showed that caregivers reported "non-support" from unmet expectations, including unfulfilled or missing offers of assistance, unmet expectations for social interactions, helper incompetence, and mismatched aid. The second problem for the caregivers in gaining support were their negative interactions with family and friends, including conflict with appraising the health status of the care recipient, criticism and spillover of conflict from other surrounding issues. Lastly, support and "non-support" were found to coexist in the caregiving relationship,

whether this occurred over time or within specific isolated situations (Neufeld & Harrison, 2003). This study shed light on the limited research on women's caregiving expectations for support by investigating the "non-support" they experienced in their roles.

Stewart et al. (2016) investigated rural caregivers (N=231) of family members with dementia. The purpose of their study was to examine differences between rural family caregiver burden, the severity of distress that was related to the caregiver gender, and the relationship to the family member with dementia. Specifically, researchers examined the effects of generational relationships and gender on the level of caregiver burden and the severity of distress in filial dementia care. By comparing the four caregiver groups (wives, husbands, daughters, and sons) on severity of stress and caregiver burden, Stewart et al. (2016) were able to develop a causal model for these effects and test it using structural equation modeling. Results revealed that the gender effect found evident in literature was also evident in this rural-based study and that women reported more burden and severity of distress than men in like conditions. Researchers also determined that within the female results, adult daughters reported greater relationship strain and burden level than female spousal caregivers. The researchers hypothesized that wives did not necessarily perceive their role as caregivers in the same way adult children did, as wives believed it was part of their marital duty (Stewart et al., 2016).

A study by Hosseinpoor et al. (2013) used the 2004 World Health Survey (WHS) to study 48 low- and middle-income countries and their prevalence and determinants of caregiving. The WHS is a valid and comparable source of international health data, consisting of data from household and individual questionnaires of adults aged 18 and older. A final sample of 34, 289 respondents aged 60 years or above was utilized. Of these individuals, 14.8% provided care in the past year, consisting of activities such as supervision to household activities. Researchers

found that on a global scale the most important influence on becoming a caregiver was the female gender. Female caregivers were found to experience worse health outcomes when compared to male caregivers, as well as devote more hours to caregiving and experience greater long-term financial cost. This large, cross-sectional examination on the status of older caregivers contributes to the existing majority of caregiver research based in Western countries. However one limitation of this study was that the association between caregiving and health status was not investigated. As such, it was difficult to discern whether the healthier older adults were capable of being caregivers, whereas other individuals may not have performed caregiving duties as a result of compromised health from previous caregiving experiences (Hosseinpoor et al., 2013). The universality in caregiving prevalence, and the gender differences within, cements the need for further research in the field of gender specific caregiving, and the implications of an aging population on the Canadian society.

1.4 EFFECTS OF CAREGIVING

1.4.1 Negative Effects

Family caregivers of individuals with dementia are frequently deemed the “invisible second patients” (Brodaty & Donkin, 2009). Caregiving often requires prioritizing the needs of another individual above the needs of the caregiver themselves. Throughout the caregiving process, specifically for primary informal caregivers, negative effects may result.

For example, The Rising Tide study reported there was a ripple effect among caregivers, stating that family is the cornerstone of care for individuals with dementia but their own needs are often overlooked (Alzheimer Society of Canada, 2010). For example, caregivers reported high levels of psychological issues such as anxiety and mood disorders (40% to 75%) and clinical depression (15% to 32%). Caregivers were found to need various degrees of support

based on the stage of dementia of the individual in question. Specifically, 30% of individuals with mild/early dementia required informal care, whereas 88% of individuals with severe/late stage dementia required informal care (Alzheimer Society of Canada, 2010).

In a cross-sectional study by Cummings and Kropf (2015), caregivers (N=96) of older persons (age 55 and older) with severe mental illness (SMI) were investigated. The most frequent SMI included schizophrenia and schizophrenia-related disorders, bipolar disorder, major recurrent depressive disorder and personality disorders. Cumming and Kropf (2015) referred to this population as requiring a double demand for care (old age and psychiatric conditions), two issues to be addressed by caregivers. Participants also had to have provided instrumental or emotional support to their care recipients within the last month. Telephone interviews were conducted with participants and each lasted approximately 40 minutes. The depression dimension of the Brief Symptom Inventory-18 to measure caregiver depression was also utilized. Caregivers reported significant areas of distress within their caregiving roles, and 25% scored at or above the clinical cut-off for depression. Although there was great variation within the degree to which caregivers delivered assistance, all participants reported having to assist their family members with aspects of daily functioning. Caregivers also indicated that the most difficult characteristics of their care recipients were depression, being slow at completing tasks, lacking energy, being worried and having difficulty thinking- all common symptoms of individuals with dementia (Cumming & Kropf, 2015). Although caregivers of older adults with severe mental illness are a very unique population, there is some degree of transferability between this population, and those caregiving for seniors with dementia due to the common characteristics, complexity and challenges associated with this caregiving dyad.

Using data from the 2011 Canadian Work Stress and Health study, Glavin and Peters (2015) examined whether the frequency of workers (N=5 667) engaging in informal caregiving tasks was associated with mental health costs. Three hypotheses were constructed: (1) more frequent caregiving would be associated with depleted mental health, (2) work-family conflict would mediate the association between caregiving frequency and mental health, and (3) the association between frequency of caregiving and mental health would be stronger among women. Researchers examined psychological distress as a mental health outcome, and mastery as a personality trait, to identify caregiver strain. The researchers examined factors such as frequency of caregiving, work-to-family conflict, age, marital, status, children in the household, race/ethnicity, occupation, work hours, work sector and work shift, personal income, education and province/region. Results confirmed that a substantial number of Canadian workers had caregiving responsibilities. For example, just under half of employed women reported having to occasionally or frequently provide health-related care to a family member in the past 3 months, as opposed to men who were less likely to have provided care (Glavin & Peters, 2015). Additionally, many were frequently active. Both men and women who had frequent caregiving responsibilities reported higher levels of psychological distress than non-caregivers. Despite having similar work conditions with non-caregivers, caregivers reported higher levels of “Family-To-Work” conflict (the degree to which family demands hindered performance at work), and “Work-To-Family” conflict (the degree to which paid work demands interfered with the ability to meet family responsibilities) (Glavin & Peters, 2015).

1.4.2 Positive Effects

Despite the negative effects resulting from experiences, and in particular from primary informal caregiving, studies have also shown the positive aspects of caregiving. For example Lin

et al. (2012) investigated the positive and negative experiences of caregiving using data from the 2004 American National Long-Term Care Survey (NLTCS) (n= 1550 caregivers; 357 wives, 265 husbands, 649 daughters, and 281 sons). The primary advantage of the NLTCS was that it recruited caregivers of older adults with at least one functional limitation, even if an illness was not present. Negative caregiving experiences were measured by 12 items, including five items to measure interference, three items on strain, and four items assessing burnout. Positive caregiving experiences were gauged by two questions: (1) degree a caregiver felt good about him/herself and (2) degree a caregiver appreciated life more. Care recipients' problem behaviour, dependency, caregivers' involvement, reciprocal help from care recipient, family conflict and availability of other caregivers were also measured (Lin et al., 2012).

Results revealed that female and adult-child caregivers reported more negative experiences than male and spousal caregivers. It was also determined that male caregivers were more likely than female caregivers to find positive meaning from their caregiving duties, but this was only evident in male spousal caregivers. Lastly, caregivers who were wives were least likely to report positive experiences. Further, long hours of care provision was more stressful for males than females, and reciprocal help from care recipients, availability of other caregivers and low levels of family conflict were more beneficial for female caregivers than males. Overall, it was determined that both negative and positive caregiving experiences and their associated risk factors (i.e., care recipients' problem behaviours, dependency and hours of care provision) varied by both gender and relationships to care recipients (Lin et al., 2012).

Although research has found that caregiving can have negative outcomes, it has also been found that positive effects can occur simultaneously. Much of the current literature has focused

on the negative outcomes of the caregiving role and has not deeply investigated the potential benefits and motivations behind caregivers performing their duties.

1.5 FILIAL RESPONSIBILITY

When an individual becomes ill, a family member is often responsible for providing care. The term *filial responsibility* was coined by Hamon and Whitney (2003) to describe the sense of obligation one has to care for aging parent(s). Filial responsibility may consist of the many typical duties informal caregivers provide (e.g., emotional, financial and physical support and assistance) (Hamon & Whitney, 2003). Whether this filial responsibility is within a parent to child or child to parent dyad relationship, social norms show that family, in some capacity (Hamon & Whitney, 2003), take care of one another. Adult children are 4 times more likely to care for their parent rather than their parent-in-law, and 2.5 times more likely to care for their mother than father (Sinha, 2013).

The filial relationship was further explored by Santoro et al. (2016), who performed an ethnic multigroup analysis of patterns within filial caregiving. The purpose of the study was to examine interrelationships along perceptions of filial responsibility. A range of self-identified ethnicities participated, (White, Black, Hispanic, and Asian/Pacific Islander). Participants were asked to read a vignette regarding an older man needing medical care, and subsequently were to answer questions as if they were the man's son. Questions revolved around whether the participants would incorporate formal care, a health care advocate, for services related to their father's needs. Results indicated that for White, Black, Asia/Pacific Islander and Hispanic participants, the level of perceived filial responsibility by itself was not enough to make the decision to hire formal care. Santoro et al. (2016) concluded that results from this study do not reflect differences in cultural value systems, as for example white individuals were more likely

to hold individualistic cultural values versus Hispanic groups who were more likely to hold collectivist values. However, a limitation that may explain this finding is that participants were all residents of the United States, a country considered a cultural ‘melting pot’. To display differences between ethnicities and cultural levels of filial responsibility, participants could be selected from various countries where cultural values may be practiced more strongly and authentically. Ethnicity, related to filial responsibility has been disputed in the literature, and may therefore not be a strong predictor of filial responsibility when participants are extracted from a single country. When studying filial caregiving relationships and researchers have limited global resources or opportunities, ethnicity should not be considered a strong definitive influence (Santoro et al., 2016).

Literature has shown caregiving relationships occur outside of the nuclear family as well, particularly for in-laws. Strauss (2013) investigated the commonalities and differences caregiving for parents and in-laws. Using the MidLife Development in the United States study, individuals caring for a parent (n=77), individuals caring for an in-law (n=26) and noncaregivers (n=1 939) were analyzed. There were notable similarities and differences. Similarities included supporting the well-established view that caring for an ill parent or in-law might adversely affect the psychological and physical health of the caregiver. Notable differences included the types of tasks adult children performed for their parents versus in-laws, support from their spouse, and family strain. It was concluded however that all caregivers had similar experiences while they were found to be at different degrees. Limitations to this study included the effect of gender on the caregiver or care receiver and the influence of dementia (Strauss, 2013).

1.5.1 Daughters Caring For Their Mothers

Funk and Kobayashi (2009) describe filial caregiving as adult children providing assistance and support to their parental figures. To fully understand filial caregiving, one must move beyond the focus on the dichotomy between choice and obligation, as they are not mutually exclusive. The family caregiving experience is one that is difficult to define, as the complex realities of family care work are individualized (Funk & Kobayashi, 2009).

Krause et al. (1999) examined the experiences of 31 daughters who had a parent residing specifically in a Vancouver nursing home. The majority of participants were Caucasian, married with children, and employed either full or part-time (M= 48.19 years). The most common caregiving dyad was that of adult daughters caring for their mothers who had some type of dementia. Seven focus groups (ranging in size from 2 to 6 participants), exploring the stressful experiences of daughters, revealed eight major stressors including: sense of responsibility, role change, losses, realization of own vulnerabilities, facing the unknown, lack of family support, conflicting perceptions of parent's ability and the lack of appropriate facility care. Results illustrated that caregiving stressors did not simply evaporate when individuals moved into a nursing home, but rather the stressors actually became increasingly complex. Researchers suggested that this may be due to the trajectory of the changes in care recipients once institutionalized, including the fast paced timeline of the individuals personality altering or memory declining. These personal factors were found to be more consistent stressors than specific facility stressors and that once individuals were in formal settings, caregivers had a greater opportunity to focus on the actual care recipients rather than the tiring work of being caregivers (Krause et al., 1999).

Similarly Hollis-Sawyer (2003), investigated the changing mother-daughter eldercare relationship among 122 pairs (n=244) of caregiver daughters and their mothers. Daughters and mothers were interviewed individually to examine factors underlying positive, adaptive dyad caregiving relationships. Mother-daughter caregiver-care recipient pairs also completed parallel versions of a survey questionnaire, based on the pilot information from the unstructured interviews. Participants were asked to rate and explain the degree to which their experience caregiving and mother-daughter relationships had changed throughout their eldercare role. The quantitative and qualitative methods yielded four types of caregiving pairs: (1) positive (both mother and daughter had positive responses-38%), (2) negative (both had negative responses regarding their eldercare relationship-30%), (3) neutral (responses seemed to lack meaningful positive or negative responses-17%), and (4) mixed (there was a lack of correspondence between mother and daughter responses-15%). Further it was found that caregivers who were more open to the eldercare experience were better able to achieve personal growth. Also, caregivers who had open communication in their eldercare relationship were found to have stronger congruencies in the dyad role expectancies (Hollis-Sawyer, 2003). Further research into this relationship is warranted.

1.6 TRANSITIONS WITHIN CAREGIVING

In any relationship there are periods of transition. Within the caregiving relationship, transitions can occur as seniors move between community dwellings and the various formal care facilities, such as hospitals, retirement homes, and long-term care facilities. Pearlin (1992) first explored the concept of careers of caregivers by completing a longitudinal qualitative study of 555 caregivers of spouses or parents with dementia. As researchers expected, participants went through various transitions, namely that as individuals with dementia commonly follow an

upward trajectory of symptoms, varying levels of assistance had to be increasingly incorporated. At the time of the first interview, all caregivers were providing care for a senior in the community. However a year later at the second interview, the majority of caregivers had placed individuals in a formal care setting (67%), or for a small percentage of caregivers (27%), the senior had passed away. Researchers determined three stages that constituted the careers of caregivers: (1) residential caregiving, (2) institutional placement and (3) bereavement. Pearlin (1992) deemed the changes experienced within these transitions as the caregivers' careers. As the demands of caregiving altered between transitions, caregivers found themselves reshaping their self-concepts. Long-term caregiving turned into a career driven by the dynamic, evolving demands of the care recipients. In addition, as the caregivers moved through the various stages, the previous stage influenced their abilities to deal with the next and future stages (Pearlin, 1992). The study by Krause et al. (1999) reflected upon Pearlin's concept of the caregiving career. When participants were asked to talk about their experiences, they spoke historically about their past caregiving experiences. The career of caregiving helped to explain why participants described caregiving as a prolonged trajectory full of transitions and challenges rather than a fixed set of experiences (Pearlin, 1992).

The transition into caregiving for a person with dementia is one that is not heavily researched. Adams (2006) performed a phenomenological study based on 20 semi-structured interviews with spouses (n=16) and adult daughters (n=4) of individuals with mild dementia or a mild cognitive impairment. The participants (N=20) were equally divided between men and women, but among the men, all were husbands (n=10) as opposed to the mixture of adult daughters (n=4) and wives (n=6). Semi-structured individual interviews (approx. 1 hour) were conducted within the first year of the dementia diagnosis. The participants were simply asked to

tell the story of the initial signs and symptoms, how they came to seek assistance, and the progression up to the present day. Retrospective reflection allowed participants to acknowledge aspects such as the realization that early signs were ignored and the resulting guilt about not acting earlier, as well as singling out a traumatic event that forced them to seek help. Results showed that caregivers found themselves responsible for tasks that were once within the domain of the individual with dementia, including devoting more time to domestic and social tasks. The more the personality of the individual changed, the greater the tasks and roles the caregiver adopted, including decision-making and emotional cheerleader. It was also found that caregivers went through direct changes within their caregiving relationships, including protectiveness, concern, and loss of a confidant. Lastly, caregivers expressed thoughts about the future when reflecting on their experiences. Although the sample was a small and mostly Caucasian sample from a small geographic region, the voices of participants added to the personal accounts of caregivers and the transitions they experienced (Adams, 2006).

1.7 FEMALE CAREGIVING AND DEMENTIA: WHAT DO WE KNOW VS NEED TO KNOW

Although there is extensive research available on caregiving, including caregiving for seniors, existing literature does not cover all aspects of current Canadian caregivers. The population is aging, with women living longer than men and females more commonly being diagnosed with dementia. Further research has been presented to show that untrained female filial caregivers will most likely be expected to care for these individuals in the future.

Current literature does not have a strong focus on the most common dyad within the caregiving world: women informal caregivers and senior women. Statistics continue to show the growing number of female seniors with dementia, and the demand for informal care to be incorporated. Although the *who*, *what* and *how* of female filial caregiving have been investigated

(Hollis-Sawyer, 2003, and Krause et al., 1999), the *why* has not been heavily investigated, as to what makes a daughter take on and continue the caregiving role for her mother. Neufeld and Harrison (2003) investigated the areas of “non-support” female caregivers of seniors with dementia found within their experiences, and although results showed definite areas lacking support and negative consequences, no explanation to why women were still performing their duties was given. This has strong implications for the future. Understanding reasons females perform caregiving duties will potentially help the health care system put a focus on maintaining those incentives in order to uphold and establish strong informal care systems.

1.8 RESEARCH PURPOSE

The purpose was to explore the lived experiences of daughters/daughters-in-law in the primary informal caregiving role, providing support to their mothers/mothers-in-law with dementia. Within the research, three main research questions were addressed:

1. What transitions do daughters/daughters-in-law and mothers/ mothers-in-law go through within the caregiving relationship?
2. Why do daughters/daughters-in-law provide care for their mothers/mothers-in-law with dementia?
3. What are the effects of caregiving on the mother/mother-in-law and daughter/ daughter-in-law relationship?

Implications for this research include recognizing the valuable contributions female primary informal caregivers make to our Canadian health care system, as well as ensuring supports are in place to sustain the health and well-being of this specific population.

CHAPTER 2: METHODOLOGY

2.1 PARTICIPANT RECRUITMENT

In order to gain rich information about the lived experiences of primary caregivers, individuals had to be experiencing the phenomenon firsthand (Patton, 2015) to participate in the study. I recruited 10 female primary informal caregivers of mothers or mothers-in-law with dementia. For recruiting participants, purposeful sampling allowed for personal connections to be utilized within a small city in South-Western Ontario. Snowball sampling was also employed whereby participants were asked if they knew any female primary informal caregivers of mothers or mothers-in-law with dementia (Patton, 2015). Lastly, criterion sampling ensured participants recruited met the criteria of the study (Patton, 2015). As the primary researcher, I knew all of the participants to varying degrees going into the interviews. Overall, knowing the participants added to the integrity of the research and led to an increase in rapport and degree of information shared.

The criteria for the female caregivers was as follows: (1) had to begin caregiving between the ages of 45 and 64; (2) must self-acknowledge themselves as the primary caregivers for their mothers or mothers-in-law with dementia; (3) had to be untrained and unpaid for their services; and (4) must have had some degree of contact with their mothers or mothers-in-law with dementia weekly; (5) must have not had any debilitating disease or disability that directly interfered with their abilities to perform caregiving duties. The criteria for the senior females consisted of the following: (1) 65 years or older; (2) had to be formally diagnosed with dementia after age 65; (3) dementia had to be primary condition; and (4) for seniors who passed away, caregivers must have performed caregiving duties for the seniors within the past year.

2.2 RESEARCH TOOLS & PROCEDURE

2.2.1 The Qualitative Methods

Qualitative research methods were employed in order to obtain a thorough understanding of the lived experiences of female caregivers of seniors with dementia. Patton (2015) described qualitative research as being able to illuminate meanings, study how things work, and capture stories to understand people's perspectives. Specifically, this methodology is grounded in a constructivist paradigm in which the nature and reality of a phenomenon are always relative to one's experiences and environment (Creswell, 2013). I believe qualitative inquiry with a constructivist paradigm base allowed the stories, experiences, and emotions of female caregivers to be heard and valued.

Specifically, the theoretical orientation used to guide my research was phenomenology, which examined "the meaning, structure, and essence of the lived experience of this phenomenon for a person" (Patton, 2015, p. 98). Patton (2015) described the approach as "a focus on exploring how human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning (p. 115)." In short, this means that participants had "lived experiences" rather than "second-hand experiences" (Patton, 2015, p. 115).

2.2.2 Ethics

All tools and procedures were approved by the Wilfrid Laurier University Research Ethics Board before the study began. Before participation, individuals read and signed an informed consent statement. Participants were also encouraged to ask any questions throughout the study if clarification was needed, as well as request for the interview to be stopped or paused at any time.

2.2.3 Background Questionnaire

Prior to the interview each participant was asked to complete a background questionnaire [Appendix A] which consisted of: (1) demographic information (e.g., date of birth, ethnicity, education, employment, marital status, children); (2) questions regarding personal health; (3) questions regarding the health of their mothers and; (4) descriptions of their relationships with their mothers or mother-in-law. The information obtained from the background questionnaires allowed for context to be established before the interviews and as a means to begin establishing rapport with participants.

2.2.4 Interviews

Ten participants took part in a one-on-one semi-structured interview conducted by myself, the primary researcher (Sarah MacFarlane). Interviews were arranged at a time and place convenient for participants. All of the interviews were conducted in person, and were audio recorded for further analysis. The amount of detail provided by the women influenced the length of the interviews. On average, the interviews were 72 minutes and ranged from 39 to 94 minutes in length. Each interview was digitally recorded, transcribed verbatim, and stripped of identifiers with pseudonyms in place of participant names.

In order to capture the full story and lived experiences of these primary informal caregivers, I asked 20 open-ended questions [see Appendix B]. The beginning of the interview consisted of background questions and demographic information to capture the lives of the caregivers. The interview then moved into the caregiving experiences, including describing the types of tasks they performed at different stages of their mothers or mothers-in-law lives, their knowledge of dementia, the influence of dementia on their experiences, and their mothers or mothers-in-law disease progression. In the next part of the interview, I asked the caregivers about

the transitions they experienced within their roles, their relationships, and any barriers or challenges they experienced. I then directed my questions towards how their caregiving experiences influenced different aspects of their lives, and how they found themselves in the roles. The interview came to a culminating close with questions regarding how they would define caregiving and if there was anything they would change about their experiences, or any advice they would give to others as a result of their own journey's. I used probes throughout the interviews to allow the women to elaborate on their points, and to redirect any tangents that began. Ending with self-reflective and abstract questions allowed for the emotionally charged interviews to generally end on a positive, neutral note.

Upon completion of each interview, I transcribed the data verbatim and continued to analyze. Interviews were conducted and transcribed, creating a total of 179 pages (single spaced) until I felt saturation had been met. I felt saturation was met after interviewing ten participants, and no new information was acquired (Patton, 2015). At this point I determined that further interviews would not enrich the quality of the data as suggested by Patton (2015).

2.2.5 Field Notes

Throughout data collection, I took field notes to coincide with each of the interviews. Before, during, and after each interview field notes were taken to record participants' emotional reactions, body language, and environmental cues (Patton, 2015). These field notes were used to create an even greater context to the experiences explained throughout the interviews. Upon completion of the interviews, I took field notes to reflect on my own thoughts and emotions that I monitored throughout the interview process. This process was known as journaling, as I recorded any reflective thoughts that occurred to further minimize bias (Janesick, 1999). The field notes

complemented the transcripts by allowing contextual references to assist in determining themes and subthemes.

2.2.6 Member Checks

Upon completion of transcription, participants were provided copies of their interviews to review. Participants were able to “correct, amend or extend” (Lincoln & Guba, 1985, p.236) any information within their transcripts. Member checks also reinforced the trust within the researcher- participant relationship, and ensured that participants had control over which of her words could be used in future research papers and presentations (Patton, 2015). Alongside the transcript I also asked questions on points that I felt needed further explanation or clarification. I asked participants to return transcripts within a 2 week period. If a member check was not returned within this time period, the interview transcript remained the same. All of the participants returned their member checks without changes, and those who were asked further questions provided answers. This process added to the overall relationships with participants, as well as added to the trustworthiness of the data (Patton, 2015)

2.3 CREDIBILITY

Patton (2015) stated that credibility depends on four elements: (1) systematic, in-depth fieldwork that yields high quality data; (2) systematic and conscientious analysis of data with attention to the issues that lie within credibility; (3) credibility of the inquirer, including training and experience and; (4) readers’ and users’ philosophical belief in the value of qualitative research. Credibility measures were used throughout this study, including the previously mentioned concepts (i.e., field notes, member checks, and triangulation). These methods established and reaffirmed the researcher-participant relationship, and allowed for open communication and the collection of quality data. As the primary researcher, I was an integral

tool in the qualitative research process. To help establish my credibility, I completed a qualitative research course and extensive literature search in the topic area in question. Having witnessed and lived this phenomena with my own family, I also had personal experience with the population of both female informal primary caregivers and senior women with dementia. Lastly, I truly value qualitative data and the contributions it makes to the world of research. I firmly believe that qualitative research is a useful tool to establish a voice and gain insight into the personal experiences of individuals. I do not feel that this quality of information could have been attained from this specific group without the use of qualitative research.

2.3.1 Transferability

Lincoln and Guba (1985) described transferability as the ability to apply findings of a specific work to varying contexts. To do so, a “thick description” of the topic at hand was obtained. For the current study, transferability was maintained by ensuring that high-quality data was obtained. This was done by ensuring all participants were information-rich cases, meaning that my specific inclusion and exclusion criteria were followed. By employing this method, theoretical saturation was met, resulting in enhanced integrity and transferability of the data (Lincoln & Guba, 1985).

2.3.2 Confirmability

Confirmability is the degree of neutrality within a study, or how participants and their responses, as opposed to the motivations of the researcher, shape the data (Lincoln & Guba, 1985). Lincoln and Guba (1985) stated that to establish confirmability, field notes and triangulation are integral to the process. By utilizing these methods of confirmability, participants and their lived experiences were able to shape the data used in the current study.

2.3.3 Triangulation

Creswell (2013) contends that the purpose of triangulation is to utilize a variety of information sources to substantiate and legitimize findings from the analysis phase of the research. Triangulation was used in my study in order to increase credibility. Data triangulation (Patton, 2015) was utilized to increase the study's credibility through the combination of multiple data methods including background questionnaires, field notes, one-on-one semi-structured interviews, and member checks. Investigator triangulation (Patton, 2015) was also utilized by having my supervisor and I evaluate all transcripts throughout the process. Further, a group of qualitative MKin/PhD students were a part of the data analysis and interpretation process which added to investigator triangulation by reviewing some of the first transcripts produced. Using two methods of triangulation, the credibility of the study increased (Patton, 2015).

2.4 DATA TREATMENT

2.4.1 Qualitative Analysis: Phenomenology

The theoretical orientation that was used to guide my research was phenomenology. Van Manen (1990) described phenomenology as the “explication of phenomena as they present themselves to consciousness” (p.9) with consciousness further explained as “the only access human beings have in the world” (Van Manen, 1990, p. 9). Patton (2002) described phenomenology as:

“how human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning. This requires methodologically, carefully, and thoroughly capturing and describing how people experience some phenomenon- how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others” (p. 104).

As this research examined the lived experiences of females providing primary informal care to their mothers/mothers-in-law with dementia, phenomenology was the most appropriate theoretical orientation to use as it allowed the phenomenon (i.e., filial caregiving) to be examined and understood through the investigation of qualities and intricacies of the phenomenon in question (Van Manen, 1990).

Information gathered from my data collection tools such as the background questionnaires provided context for the interviews and provided me with direction throughout the interview process. During the analysis phase of research, the background questionnaire allowed me to reference specific living transitions noted, as well as details regarding children, family and other pertinent information. Every participant became emotional during the interviews, therefore the field notes were very useful in noting when and how females became emotional. Being able to give context, and add emotion to the transcripts, the voices of the participants were able to shine through the data. The incorporation of field notes allowed for the stories of these primary caregivers to be conveyed as realistically as possible.

For the purpose of data analysis, I began by collecting the background questionnaires, interview transcripts, field notes, and member checks. I read, and re-read transcripts multiple times, highlighting and noting any reoccurring statements, emotions, and experiences that led to the eventual emergence of themes and sub-themes. Specifically, I completed a step-by-step analysis of the data, generally based around the framework of Moustakas (1994). First, I actively refrained from judgement when viewing my data. Due to my personal experiences with dementia and many personal connections with the informal caregivers, I purposefully wanted to set aside any pre-existing biases or opinions regarding this group. I continually journaled throughout the thesis process, noting my own experiences as well as the connections and pre-existing

information I knew about the informal caregivers. This helped me to “set aside” my own views of the data as much as possible and not bring in my own opinions or preconceived knowledge of some of the experiences, allowing purely the primary caregivers perspective to be shared. This was tested in some instances within the interviews when caregivers would leave out information they believed I already knew about their experiences. These instances were addressed within member checks and kept in mind during analysis. In addition, throughout the one-on-one interviews, I did my best to interact with the informal caregivers in a neutral manner with non-verbal communication that allowed the women to know I was listening. Many of these informal caregivers also knew about my own experiences with this phenomenon, helping build rapport with participants, and inviting them to feel comfortable with me. However, I did my best not to relate their experiences to my own or voice my experiences with them throughout the interview, keeping the focus on their unique experiences. As I followed through the stages of analysis, I first highlighted positive and negative experiences, as well as the tasks conducted by the caregivers. Throughout the interviews I noticed how basic and recurrent the information was, and decided to treat it as the first organizational step in analysis. I then created a chart categorizing the positive and negative experiences, noticing the trend of effects regarding health, social life, and financial. As I began to discover more themes and subthemes, I read through transcripts multiple times in detail to highlight and colour code specific quotes that best portrayed the experiences. These verbatim quotes were then picked from the transcripts and condensed to their most basic form, as many of the women had lengthy quotes and stories. I brought these quotes and emergent themes to my supervisor for discussion, as well as a few to the qualitative lab group (investigator triangulation), in order to contribute to the study’s credibility. This form of analysis was both inductive and deductive in nature. Deductive analysis

was utilized when developing themes based on existing literature and tailored interview questions; however, inductive analysis was also used as patterns, categories and themes were found within the data (Patton, 2002). By utilizing both of these methods with the rich information gathered, a variety of concrete themes and subthemes were able to be constructed.

CHAPTER 3: RESULTS

3.1 INTRODUCTION TO PARTICIPANTS & THEMES

The purpose of this study was to explore the lived experiences of primary informal daughters or daughters-in-law caregiving for their mothers or mothers-in-law with dementia. Ten informal female caregivers participated in one-on-one semi-structured interviews. Women ranged from age 52-67, and were all married with adult children. Education levels varied from high school (n=4), college (n= 3), and university (n=3), and all caregivers were employed throughout their caregiving experiences. Women explained their own health as ranging from good to excellent, and did not report any illnesses that deterred their abilities to perform their caregiving duties (Refer to Table 1 & Table 2 in the appendix). Eight of the individuals reflected on the experiences of caregiving for their mothers, while the remaining two reflected on the caregiving experiences for their mothers-in-law. Daughters-in-law considered their mothers-in-law to be their second mothers, with longstanding close relationships. Five of the interviews were retrospective in nature as their mothers had passed away within the previous year, while the remaining five were caregiving at the time of the interviews. All women generally had similar experiences, which resulted in the emergence of four major themes: (1) “Master of none.”: The many roles of informal caregivers, (2) The face of dementia, (3) “What a life!?” and (4) “Every so often you see a little bit of light.”: The silver linings. The first theme delved into the many roles of informal caregivers. The second theme provided a detailed picture of dementia and what

caregiving for individuals with the disease entailed. The third and fourth themes addressed the negative and positive effects associated with dementia caregiving. The themes and their respective subthemes, summarized in Table 3, will be discussed in turn.

3.2 “MASTER OF NONE.”: THE MANY ROLES OF INFORMAL CAREGIVERS

The first theme that emerged from data analysis examined the roles of caregiving. All primary informal caregivers were mothers, wives, employees at one point, and daughters or daughters-in-law. All women wore different hats every day, and had many separate responsibilities associated with caregiving, in addition to encountering many transitions within their caregiving experiences. The three distinct subthemes of this theme included: a) “You’re a mom, you’re a daughter, you’re an employee, but you’re not being very good at anything.”: Challenges with role conflict and reversal, b) “This is the new normal.”: Role acceptance, and c) “Everyone’s lives are busy.”: Role within the family unit.

3.2.1 “You’re a mom, you’re a daughter, you’re an employee, but you’re not being very good at anything.”: Challenges with role conflict and reversal

Within this sub-theme, caregivers expressed a loss of their own identities throughout the caregiving process, and felt conflicted by their roles as informal caregivers. For example, Lucy, who is her mother’s primary caregiver, found the transition between daughter and caregiver emotionally overwhelming

It takes over your life. You lose your independence. You almost lose who you are, because you’re so consumed with what you have to do.

Lucy, whose mother had recently moved into long-term care facility, but previously lived with her, explained how this role was not something she had ever envisioned for herself.

Never growing up did I ever realize that I would be looking after my mother in the capacity that I was (choked up). You work hard, you, ya know, you save your money, you try to make the best for your children, and then you end up having to you know, take time

away from them to look after your mother. You have to take time away from yourself to look after your mother.

As an informal caregiver, Lucy felt conflicted and overwhelmed as a result of her caregiving role.

Jenna, a registered physiotherapist, found conflict between her formal occupation and her informal role as a caregiver. She explained how she would compartmentalize her two roles in order to help her cope. The following quotes explain how Jenna found and dealt with conflict between her formal and informal caregiving roles.

It was very easy to rationalize and take a step back and wear my physio hat, as opposed to my daughter hat sometimes. And trying probably to intellectualize stuff a little too much, but uh I guess that's the nature of the beast sometimes.

So I sought out.... from my clinical brain as opposed to my daughter, stress brain...I don't know if that just kind of gave more opportunity and facilitated that part of my personality. It was one more thing that I could plan and schedule. It gave some, external structure to it so it was easy to get focused on, on the details and not the circumstances that required the planning to some degree.

I think it also allowed me to take a step back and I could wear my clinical hat, and that allowed me to have a little bit of maybe, uh, I don't know that separation is the word but um compartmentalize. I do that a lot I think (laughs.)

Similarly Connie, a registered occupational therapist (OT), cared for her mother-in-law and found she struggled with the “in-law” relationship as well as her formal role as an OT.

They [her children] were letting her live there alone when they knew she couldn't see, when she was cognitively impaired, and she definitely was not living in a hygienic situation. None of them wanted to cross her! And so I said, so I called my college. And I was legally informed that “yup, you're right, you could be, you could lose your license over this if she does hurt some other person or family.”

Caregivers talked about the transitions between their roles as daughters or daughters-in-law and caregivers. The tipping point for most females occurred when they took over caring for their mothers or mothers-in-law's personal hygiene. More specifically caregivers felt conflicted between their roles during their transitions between being family members and hands-on

caregivers. For example, Rachel shared the following about the role conflict she felt with her mother-in-law when assisting her with toileting and hygiene.

....one of the biggest things is, um, I need help with my mother-in-law's hygiene. Because what has been happening over the past six months is typically I would try and help her shower a couple of times a week. Did I want to do it? (Shrugs) No. I, I really could do without my mother-in-law naked, but, I did it. Because I love her. And she was okay with me doing it!

At the time of the interview, Rachel was looking to hire a personal support worker, because she found she could no longer assist her mother-in-law with the level of personal hygiene necessary. She explained "hitting" a point where she knew she needed to seek and accept formal care.

This is beyond what I can, even if I have the time, it's beyond what I can give anymore. And no, I don't, I don't want to give some, you know. I kind of got to that place where I just, it just, there's help out there to do that, we have to get help now. I can't do it all.

When the caregivers moved through the transition of role conflict, and found themselves immersed in their informal caregiving roles, they experienced another challenging transition. Each caregiver discussed the role reversal that occurred in their caregiving experiences. This role reversal involved caregivers shifting into a "mother role" and their mothers or mothers-in-law into a child role. All caregivers found this change influenced the dynamics of their relationships.

But, just as I had that transition with what I took over for her, the roles shifted right? To me, (pause) um from me being the daughter, to shifting and, and being in care, caregiving of her. And mothering her, yeah. - Penny

So, it was like, I was the mother, she was the daughter. (Pause) and that's, I would say that. A very big role reversal. Like I made all the decisions for her, I did a lot for her. Yeah. Yeah. It's, completely reversed. - Julie

It's definitely still a mother-daughter [relationship] although it's like (laughs) yeah you know, maybe is it almost like I'm the mother kind of thing, I mean, obviously I'm taking care of HER. - Annie

It switched. Because I was like the mom. Because she'd say "you're pretty God damn bossy", I'd go "well Ma, you gave me the role of being the mother, you're the daughter" and she'd laugh. - Carly

Similarly Jenna explained the current nature of the relationship between her mother and herself as one that “completely flipped”. Jocelyn, who also experienced the challenge of role reversal, explained the sadness and reality behind the transition.

I guess it was a matter of, it was like having a child again. Yeah. It was like having a child again. The only difference is that your child you know is going to grow up. But when you see her declining, then you know it's (pause and tears) and that's what it's like.

Annie also found that within this role reversal, she came to feel like a teacher for her mother, trying to remind her to do things she did before the onset of dementia.

I have to remind her to be positive though, but fair enough, fair enough, but I have to remind her you know “mum, you ALWAYS used to have something positive to say about something, so let's, okay let's try and find something positive!” you know, so, it's like I'm her teacher, but yeah. You know?

Abbie summed up the challenges of the role of informal caregiving.

I understand what that term [sandwich caregiver] means now. That you are caught in the middle. You're a mom, you're a daughter, you're an employee, but you're not being very good at anything. When you're in that kind of situation. Master of none. So it was tough.

All of the caregivers experienced challenges with their informal caregiving roles. Role conflict occurred throughout transitions in the caregiving roles, when individuals had formal health care roles outside of their informal roles, and when the numerous roles in their lives collided. Role reversal was also challenging within the specific context of informal filial caregiving and dementia.

3.2.2 “This is the new normal.”: Role acceptance

Despite the challenges in caregiving, caregivers eventually came to accept their roles. Participants discussed how they learned to accept their roles, even though they may have experienced challenges throughout their caregiving journeys.

Proximity to care recipient played a role in every caregivers abilities to provide care and their rationalization behind them being deemed primary caregivers. Also, caregivers indicated

their female gender and their mother's female gender contributed to them assuming the primary caregiving roles

.... obvious to me is I was one of four children and I was the only daughter. And it was for me to do. There was no doubt in my mind. I didn't want the boys --- they didn't need to do that, to take care of mom's physical hygiene like I did. I don't think that a son should have to do what I did for a mother. It was just my place. – Abbie

Annie, who also had brothers who lived locally, explained her role acceptance due to her female gender.

(Blows out air and laughs) because I'm the only daughter!.... Boys are boys... So (shrugs and pause) then there's something different. There is something completely different between a mother daughter relationship too, and a son and mother relationship. They're all amazing, but in very different ways.

Jenna also found that birth order within the family played a role alongside gender.

Being the oldest daughter and POA and um for both my brother and I are, for finances it's the 4 of us, for health it's my brother and I because we're more local. Um, but in reality um I've been doing most of it.... Well I'm the oldest daughter and I think that sort of, there's a natural tendency to do that.

Some caregivers explained their roles as being natural, almost as if taken on subconsciously.

I guess I just sort of stepped into the role. You know, no one really said "hey can you do this?" I guess as a, as a mom, and you know I consider my mother-in-law to be like a second mom to me and a friend and I just, I saw the needs and I just sort of yeah (smiles and shrugs). I just sort of stepped into it I guess. – Rachel

...., I just took it on! I just, took it on. I thought, it's gotta be done. My evenings were free. I didn't work shifts at the time, so I could be there at certain time. Most of my weekends were off so, I just did it. I just, it wasn't a question of who is going to do it. I just took it on. – Julie

But it's like (shrugs) I don't think about it, it's not like (pause) I think I should, I have to do this! It's, it's not like that, it's just like, part of life, here we go, part of the process of living and dying. We're all going to. - Annie

Other caregivers found their caregiving roles were expected by their mothers or mothers-in-law.

And when she was hospitalized, she just relied on me keeping everything straight. You know, the doctors would ask her questions, and she might answer but then she would look right at me. And so my sisters would be 'okay well just wait until Penny gets here' and yeah. So, she pretty much handed all of that over to me (laughs). - Penny

[CCAC would] call and (laugh) say "your mother locked us out!" And I'd just say okay and have to go in myself... I'd go in and I'd say "Ma, you've gotta have a bath!" and she said "well I'll let you do it!" and I'd say "okay, I'll give ya a bath" (heavy sigh). - Carly

Most caregivers accepted their roles because of lifelong positive relationships with their mothers, or lasting strong relationships with their mothers-in-law.

It just was a natural thing for me to do for mom. And I wanted to! She was a lovely lady. It was because of our relationship. It wasn't like I was asked or felt I had to do it, it was just natural. It was what I had to do. It was my, step up to the plate. It was my pleasure. It was, it was my pleasure. - Abbie

Because she's my mom! She's done enough for me! – Annie

Connie, although not having a lifelong relationship with her care receiver, still found that her existing relationship with her mother-in-law predetermined her role acceptance.

She always said to me, "you're good to me Connie". When she was you know, ill, and I would go, and "uh yeah, okay well yeah I hope so (laughs) you were always good to me" you know!?

Caregivers also found themselves accepting their roles as informal caregivers to protect the dignity of their mothers or mothers-in-law. Participants found they were able to provide a specific level of care and comfort that formal care could not, or did not, provide. Additionally, in some instances care recipients were not ready or willing to accept formal care. Rachel's sentiments are depicted as follows:

.... I think there was probably a time when people thought you know I was just trying to do everything on my own but I was really, I was really protective of my mother-in-law's dignity too. And I didn't feel she was ready. She just seemed too aware, for somebody to be coming in to help her shower. Even though she would walk around with the greasiest looking hair, my father-in-law before I stepped in to sort of takeover, she probably went weeks without a shower.... I didn't feel like she was, I thought that she just still was too aware! And I would say to her 'mum do you, would you want somebody to come in and help you?' And she'd be like (scrunches up face) 'umm' (pause). Now! Now it's like

'mmm okay, that'd be, that'd be good'. So, I knew that I would know when the time would be right.

Julie found that she applied the golden rule to her caregiving experience, as she wanted to treat her mother the way she would want to be treated.

I, I wanted to treat my mother the way I would have wanted to be treated.... if anything happened to me. Like, so that was my mindset. You know what, I want to be cared for when I can't do it anymore, and I want them to do it gently and be considerate and courteous and you know, that's how I did with my parents.

Similar to applying the golden rule to caregiving, Carly found there was no question in how individuals should be treated.

Yeah just pull your socks on and you've gotta go it. And you have to treat them with respect. You know, you have to. You can't, you can't do it any other way.

Annie explained how her role as her mother's caregiver was the new normal.

This is the new routine. This is the new life... This is the new routine. It's just normal! It's normal. You know, I go to mum's a few times a week and call her every night and say goodnight and then yeah, what's going to happen when that's gone! So you do look forward to it, in a bizarre way (laughs and tears up) it is bizarre.

Rachel talked about love as her motivation for continuing her caregiving role.

I just found it got to be where, and of course I would come home tired sometimes from work and think 'hmm' (makes sad, exhausted shrug) 'I'm really not up for this'. But I would do it, of course, because I love her, and it has to be done.

Individuals accepted their roles due to love, obligation, and expectation or based on the established relationships prior to the dementia. This role acceptance experienced by women was another transition within their roles as primary informal caregivers of their mothers/mothers-in-law with dementia.

3.2.3 "Everyone's lives are busy.": Role within the family unit

Participants found themselves being pulled in multiple directions as a result of their numerous roles: caregiver, employee, daughter, wife, and mother. Many caregivers found their

siblings did not support them in the way they wished they would, or needed them to do so.

For example, Jocelyn's two brothers did not give her the support she needed while she was not only caring for her mother with dementia, but also her father with dementia. She found they acknowledged that she was overwhelmed, but they did not step into caregiving roles to assist.

He would say "Jocelyn you can't go on this way", but it was never, "I can do it, I can help", it was more of a, from both of them actually, was, it wasn't um you know "lets spread the duties here" it was more "you're doing too much, you gotta take care of yourself."

This one day my one brother called the other brother and said, on his phone message and said "it's your turn". Well, he didn't like that. And he called here and he just kind of (moves hands in a 'blow up' motion), and I kept saying "it wasn't me that said that!" and it was at that point, and that's all resolved, but it was at that point I felt, I'm not appreciated. To have somebody screaming at me. I just thought, no. I'm not, I'm not appreciated for everything I do for them. And they, they think I do too much, they, and that was really painful. I carried that for a lot of years. It's gone now, because you know, we've all of us, with mom passed, we became really, really close like we always were. But I think sometimes the caretaker feels that way. That you know your siblings love you very much, and you know they care about your health, but (pause) sometimes you just think (shrugs). Everybody's lives are busy, and I know their lives were busy, I, I know that. They had grandkids that they had to take to hockey and dance and all of this but, yeah. Everyone's lives are busy.

Penny's mother lived with her throughout her caregiving experiences. She explained that she completed the majority of caregiving duties not only due to immediate proximity but also because her family did not "step up" to assist willingly.

And I know that my sisters, they were there if I needed them for anything. But on a day to day basis, there wasn't, they weren't involved that way.

Both Annie and Carly came from big families, but felt isolated and alone in the majority of their caregiving duties. They explained how frustrating the dynamic was.

Frustrating because of, because it's just, she's got six kids, and it's me. That's where it's like, frustrating with the siblings sort of thing. They're into their own world for whatever reason and everybody has their own problems and (heavy sigh) and I'm the, I don't

know, I'm just the best (laughs) one to take care of them, the most stable, I'll put it that way maybe, to take care of. - Annie

I tried to get the sisters and brothers to, if every one of us pitched in, one night a week, and just spent time. And nope, nope, nope, nope, busy. Okay (sigh) well, there was really a lot of family dynamics in our family, from how they were raised to how mom was acting so they just gave up on mom. - Carly

Rachel, was providing care for her mother-in-law who had three grown sons. She too felt isolated in her role and not supported by any members of the family, particularly the other daughters-in-law in the family dynamic.

I do sometimes get resentful. That (pause) you know, not everybody is all in. I get resentful that, how come, you know, if it's a day off for me, and it's not that I, and they're only fleeting thoughts! But sometimes I think "ok it's my day off". You know, my sister-in-law is probably on the golf course, the other one is probably at a workout training thing, nobody is, nobody is thinking geez, I wonder if my mom has had a shower you know. They just don't think. Things are just done.

Jenna found that her husband did not support her.

Oddly my husband wasn't[supportive].... he thought that we should have put mum in the nursing home much earlier and I don't know whether that's um because he felt it was, my time was being used up... That's been something since that point I've struggled with in our relationship. Yeah, he wasn't supportive, really at all.

Although many of these caregivers had siblings who could have provided assistance with direct caregiving duties, women found they did not. One woman stated that "actions speak louder than words" in relations to intentions to assist, versus physical actions of assistance.

Informal caregivers experienced many different roles in their caregiving experiences. This theme explored role challenges (conflict and reversal), role acceptance and role within family and substantiated the challenges associated with caregiving for mothers and mothers-in-law. Before and after role acceptance, caregivers experienced challenges within their roles particularly during periods of transition. The role of family members added another layer of complexity to situations that were already arduous.

3.3 FACE OF DEMENTIA

Throughout the course of the interviews, participants described dementia as a ruthless but fascinating disease. The face of dementia aimed to capture an image of caregiving for individuals with dementia. Within this theme there were four subthemes: a) Personality changes, b) “You’re thinking for two”, c) “I know her as my mother, but she’s not.”: Loss (While living), and d) “I felt I lost God.”: Questioning faith.

3.3.1 Personality changes

Caregivers reported two types of personality changes among their care recipients. Essentially, there were those whose personalities changed drastically and those who changed only slightly. Informal caregivers spoke about how these personality changes seemed to coincide with the progression of the dementia.

Some individuals noted changes in personalities that were for the worse. Caregivers noted their mothers became angrier which was in opposition to their personalities prior to the dementia onset.

Yes, she became very bitter. Very, very mean. Um, just the way she yelled at us (pause, tears up) um, yeah. She, she became a very bitter, and mean woman (begins to cry), totally opposite to what she was. Yeah! And we knew what, we knew why it was, but, it was hard to see. Yeah, she was a cranky old lady (Laughs and tears). – Julie

We found that was, with the dementia, her, the way she talked to people was terrible. It was awful. Like MEAN. So, yeah I would say the dementia made her meaner. And angrier. -Carly

In addition to anger, Lucy described her mother as becoming violent as the disease progressed.

... the rest was like a slow progression, um so it didn't really affect me as severely as my mother becoming violent. With my mom being a stay at home mother, she never swore, she was never aggressive, my father was always um the one that disciplined us as children. My mother would not. And there was a point where I went in to get her out of bed, and she was swearing and it just seemed to progress, from there.... And then it got to where she was biting or kicking or scratching um and swearing and um that lasted, I'm gonna say, up until where um she started losing her speech. Um, and as her, she lost her

speech, she started just making noises and more screaming and then when she went into the nursing home, by the time she went into the nursing home she was basically just making noises.

At the time of the interview, Annie's mother was in the beginning stages of dementia. Although Annie did not describe her mother as becoming angry, she was starting to see her mother as not being as positive as she was before the cognitive impairments. She also lost interest in hobbies that she once enjoyed.

She certainly isn't as positive. She used to, it doesn't matter what it was, she would look on the bright side, see the bright side (hums happily) she would be humming ALL the time, she used to always hum just "hmm mm mm mm", whether she was truly happy or not right, that made her happy. If you look good, you feel good type of thing! So, no, now I think she doesn't know even. I don't know that the brain is registering (pause) happy. Like, "what would make you happy mum?" She has no idea. You know, food doesn't interest her (shrugs and shakes head no) "meh", gardening (shrugs and shakes head no) "meh", no, nothing. She'll just sit and sort of stare at the TV. And again, I don't even know that her mind is registering what she's, what she's watching sometimes. It's just on because it's keeping her company sort of thing.

Connie discussed how her mother-in-law did not have a drastic personality change, but rather a slight change, as she had always had anger within her. These quotes reflect the anger Connie's mother-in-law displayed throughout their caregiving relationship.

So that's, that's hard. And with his brothers and sisters too, if anyone picks at her she blames me... you gotta remember it's not her. That is the disease. And I said then she was angry long before you or I ever were around. And it's true! So we just bear the brunt of it that's all. You just have to remember. You know, she's just, oh and when she was in the hospital when she was like an animal I was like this is fight or flight! She didn't know who she was. And it didn't matter who we were! You know, she's lost that. We've just got to take care of her, it's all we do.

With the dementia, I think she's always been angry. She's been angry for long before even my husband was born.

I find with any dementia individual, if you're an angry person and you get dementia, I think that that part of the personality stays there. Until it gets to the point where um they can't, they can't articulate it.

Amidst their various degrees of personality changes, caregivers also found their mothers/mothers-in-law living in the past.

Since the nursing home... her mental attitude or her place, she was back in the day of I'm going to say 1960, 1970, 1980 because she referred to everything to that time in her life.
– Carly

Individuals also found that as the disease progressed, caregivers lost the reciprocity of their relationships with their care recipients. Caregivers stated there was more give than take, particularly with conversations and quality of the visits. As depicted in the next few quotes, Abbie expressed struggling with the quality of her visits that had been eroded by dementia.

It wasn't a two way visit, she stopped asking me how my day was. It was like she forgot to ask about it, or she (pause) I don't know (tired laugh) it wasn't like I got mad at her but I'd say "well what about me mom!?"

I used to think "okay here I am mom, I just worked 10 hours today, and then I'm coming to see you instead of going home to my family, and I'm exhausted, and here you're worried about other people but not a thing about how MY day was". But I think it was just, the relationship we ended up having, she knew that I was able to take care of myself and I could, I could handle it. Because she raised me! She raised me to handle more than one thing at a time. But that's when I, not that it hurt me, but it exhausted me some days.

Jenna contended how the dementia and associated personality changes in her mother, negatively affected the quality of her visits with her mother:

I found myself, I wasn't going up as much. And I don't know whether part of that was (pause) um, I'm worried that it's because at that point she wasn't recognizing me and it was difficult to have you know, the conversations.

She sleeps a lot during the day and sometimes she doesn't wake up when you go to visit. Um, it's, it doesn't seem like there's any more quality to a visit if you're done there doing anything because she's not getting any benefit from it. So I tend to kind of spend the time with her in her room. So (shrugs shoulders).

Two participants, who had both parents with dementia, described the struggle of caring for two individuals, and watching their parents/ relationships change as a result of dementia.

And my dad, loved the day she came. He was beginning to, he adjusted there, and he wanted my mom. Just, ugh (sigh) whenever it was like, the sun would shine. My mom at

that point my mom wasn't as affectionate to him, I think she burned out, I think she burned out caretaking for my dad that she just was, tired. And I think when they did get together, she would just probably felt again, "I'm back taking care, I'm back burning out", however! As, as a family, we got together, the boys and I, and said we can't do this, maybe putting them together, and maybe even in the same room, they would, you know, fall in love again and adjust (big smile and shrug)! - Jocelyn

But mom, when she was in the hospital and the home, we'd take dad to go visit her, and all she'd do was yell at dad... and he doesn't even know what she's talking about because he was in his dementia by then right?.... she just yelled.- Julie

Caregivers described the different personality changes in their mothers or mothers-in-law. These personality changes had great effects on the caregivers' experiences as the changes affected the tone and reciprocity of the relationships.

3.3.2 "You're thinking for two."

Since dementia is a cognitive disease, many caregivers compensated for the mental gaps in their mothers/mothers-in-law. Penny, whose mother lived with her, described her experience of "thinking for two".

My son used to say to me all the time, 'well mom' if I was tired or something he'd say 'well you're thinking for two!' (laughs) 'You're her brain, you're her memory. You finish all of her, anything she can't remember she turns to you and says 'what was that Penny? Who am I thinking about?' 'Well just a minute let me see! (laughs)'.

I had to be her brain. And um, keep things straight for her. So that was, it was exhausting. And it could be very, it can be very frustrating sometimes.

Annie described having similar experiences, despite her mother being in the beginning stages of the disease.

It's funny because she has bouts of really, real confusion, where she'll call and say 'hunny, I need ya, they just, ugh, I'm out of' and I can just see her just trying so hard to think of the word. 'It's, it's on my hands, it's for my hands'. Lotion. She couldn't come up with lotion. And it's like oh (pause and winces). It comes and it goes. Things like that I have to, almost speak for her. And she'll say 'oh she's my eyes and my ears and my brain this one' and it's like (laughs) yeah! Yeah.

Annie also described having to also attend medical appointments with her mother as she was not able to retain information provided by health professionals.

I have to be there for that [medical appointments], because she doesn't get half of the, she doesn't get most of the conversation, A because she doesn't hear and B she just isn't, can't retain it. So I have to be there for every little thing.

Lucy described an interesting story related to her mother's declining memory. She found that as the forgetfulness increased, she had to step in and make executive decisions for the safety of her mother.

She was smoking she progressed I took away her cigarettes and I don't even think she realized that she had been a smoker! Just one day, she had burned a hole in her chair, and I took her cigarettes away and we just went on as usual. And nothing ever became of it!

Julie also found that as her mother began forgetting to do things, she had to compensate for the activities no longer being done.

So it started at home. Because she would think that she was up, she would think that she had got up and had breakfast and made lunch, whereas they didn't eat all day. And, she couldn't figure out why, like, dad was hungry and stuff like that. She'd say 'oh I fed him, we made this and this and this' and nothing was (nods head no), and 'oh I had a bath this morning' and no mom you haven't bathed in a week. So it started at home. But we saw more, of the deeper personality change once she was at the (nursing) home.

Although most informal caregivers described assisting or compensating for their care recipients, caregivers did not find they were trained or qualified to do so in some cases. For example, Abbie found that she improvised with how she handled her mother's memory deficits.

At first, I didn't know how to take it. I'd say 'well no, mom, no, you didn't cook supper for dad remember he' and she'd say 'oh I know that, why did I say that, that was silly'. And then she'd get very quiet. So I think it scared her. It scared me too! I think there was a level of fear there, that we knew that she was starting to (pause) not lose grasp of reality but she was starting to slip away when it came to the present.

Caregivers found that with their mothers or mothers-in-law dementia, and the associated memory deficits, they had to make decisions, speak, and think for them. Care recipients described this

task as “thinking for two”, a further issue which contributed to the challenges of caregiving for individuals faced with dementia.

3.3.3 “I know her as my mother, but she’s not.”: Loss (While living)

Caregivers expressed loss as a result of the devastating effects of dementia. This loss was not something that was only found in the individuals whose mothers were deceased, but was described among women caring for their mothers or mothers-in-law who were still alive. This theme dealt with loss while living.

That uh that part of it is very, very hard. Because she’s not my mother anymore. I know her as my mother, but she’s not. (choked up again). - Lucy

It was heartbreaking to see a strong woman like my mom go into somebody that depended. - Carly

And you know it’s not our mother, it’s not our mother, it’s the disease. - Carly

Many individuals found they lost their mothers/mothers-in-law when they could no longer interact with them as they had been able to previously. Both Jocelyn and Abbie expressed the moments when they “lost” their mom’s.

“You couldn’t get conversations out of mom. So I guess, it was during that time that I (voice goes soft), I kind of lost my mom.” – Jocelyn

It started to become really hard to have a conversation with her. And that’s when I started to notice, the role, my role really changed. I was losing my mom. And it was becoming this senior person that I was (tears) visiting and helping to take care of. - Abbie

Abbie further provided several quotes to reflect this issue.

I think, I grieved my mother, she passed away last August...but I grieved the loss of my mother a year and a half before that. Because of the dementia. She wasn’t there anymore.

The relationship changed, and I felt very guilty for feeling differently about her, but it was about this body that was sitting in front of me, my mom was already gone.

I guess I wish I had the opportunity to say goodbye to mom before she wasn’t mom.

No I guess just that you know, caring for my mom wasn't a negative experience, but it was an experience of losing my mom before my mom was actually gone. And even though you're prepared for your parents to age, you're never prepared for the situation of that parent not knowing who you are...this just takes your mind away and leaves you as a shell.

Individuals also expressed losing not only their mothers or mothers-in-law, but one of their confidants.

So basically for the majority of my life I have seen my mother every single day. And, just as with her going into the nursing home, I don't see her every day, I see her several times a week, a majority of the week, but um but we're not living together. And, we can't socialize anymore, I can't talk to her about things that are on my mind. I can't tell her the good things in my life, I can't tell her the bad things in my life.... emotionally it took a toll because I didn't have uh I had my husband, but I didn't have my mother. My mother was my sounding board a lot of times. Um, and I could talk to her about anything. So, I, you know that was a void in my life. . -Lucy

(Long pause) well (pause, talking through tears) and uh sorry, she's uh, I'm having some really significant relationship challenges now and I don't have a mum to go to for help. – Jenna

I couldn't have a mother-daughter talk. I couldn't ask her for advice. I couldn't tell her about my day and expect a response. - Abbie

Further Jenna acknowledged the lack of support from her husband while she was experiencing loss while living.

I wish that my husband had a better understanding of what it's like to see a person still alive, but not there. And not themselves. And not, they're just kind of the body and not the soul. And recognize what that does to children (tears up and nodding).

Those currently providing care for their mothers or mothers-in-law with dementia explained how they welcomed death, as they viewed death as a “release of the body” for the soul had already departed. Lucy reflected on this issue as follows:

But, now that my mother has progressed to the state she's in, um, it, it is really hard, it's depressing. Um, and without trying to sound cruel, um after I've seen her when I go to bed sometimes I pray that God takes her before the morning comes (pause). I know that in my heart if my mother knew the state that she was in, and the life that she was living, she would not want it.

She's still my mother (smiles and shrugs, eyes well up). And I know in the back of my mind when she does pass away, it will be devastating um (choked up) but I don't know what is more devastating, going and seeing her every day or her passing.

Abbie explained her conflicting thoughts regarding her mother's passing.

...I got so I would ask God to take her. As much as I didn't want her to go. And then I'd feel guilty for asking that (talking through tears) but it was hard to see her suffer and she clearly was. It was hard for her not to, for me to see her not recognize me when I walked in. That her eyes were just sort of glazed over and I was just another person that was uh, coming in to look at her or put the blanket on her.

Jenna even went on to discuss Physician Assisted Dying and dementia.

It was sort of discouraging when they had the um Physician Assisted Dying legislation come into place that they, um, as it stands right now, that uh the dementia is not on the list, or end stage Alzheimer's. I mean I think that that will change. But that's, I, I don't want to, I wouldn't want to have my last five years of my life like my mother has had.

Throughout dementia's progression, Carly explained how her mother expressed being ready to die.

She says 'I really don't wanna live no more', I'd go 'Maaa, don't talk like that! I still need you!' (Heavy sigh) I said 'what's going on in your head', and she said 'you know, sometimes it's like a radio, all that static up there, and you know how sometimes you tease me about the bird flying, yeah. I know I'm forgetting.'

She gave up. Wouldn't think anymore. Slept most of the time. And then it got to be where she didn't know us. She knew me! But, but the rest of the kids she didn't uh (pause) she just wanted to die.

Individuals found they lost their mothers or mothers-in-law before they had passed on, as the dementia turned them into individuals who were unrecognizable. Additionally for those caregivers whose mothers/mothers-in-law has passed on, individuals found themselves grieving for a second time. Caregivers expressed loss in numerous capacities and how these losses contributed to their relationships and overall caregiving experiences.

3.3.4 “I felt I lost God.”: Questioning faith

Although I did not include religion in my inclusion criteria or background questionnaires, during the interviews many caregivers disclosed their religious beliefs. Individuals found themselves questioning their faith, and teetering on the edge of belief as the disease progressed.

Tell me there's a God you know? How can you tell me there's a God? That's when you really shake your faith.... WHY are you doing this to this woman? - Annie

Um, it made me question. It made me (pause) I stopped going to church for quite a while. - Abbie

Also, Abbie discussed how her mother's beliefs and faith- a lifelong devoted Christian- also began to waiver.

It was tough. Spiritually it was tough. Even for mom, all the faith that she had, she did question why she was still hanging on.

That's when I felt fear. When she started to say “I'm not too sure why I'm here”, “I don't know why the Good Lord won't take me, I'm ready” so it was a tough time to watch. Mom didn't deserve that kind of time she had to spend there. She deserved to be able to go to Heaven and be with dad.

At one point in her caregiving experience, Jocelyn felt she lost God.

There was a period there, when my dad passed away, and I felt I lost God. And it wasn't like I was BLAMING him I just, ‘where are you? Why do I feel this black hole? Why can't I get out of it?’ I mean I prayed all my life and I had good spiritual life of feeling presence and knowing what the next move should be, and it was gone.

However, Jocelyn did find that although there was a period of darkness in terms of her beliefs, she was able to also find strength through God.

It did bring me closer uh until dad passed away, closer to God spiritually because I depended every day on strength to get me through this.

The face of dementia included individuals questioning their faith and belief systems. Although most caregivers expressed their faith wavering, individuals also expressed how their faith saved

them at times. The face of dementia, and the positives and negatives associated with the theme depicted a clear picture of the disease and how it affects caregiving.

3.4 “WHAT A LIFE!?”

“What A Life” is a theme that encompassed the lives of the primary informal caregivers, and specifically the negatives associated with their roles. Within this theme there were five subthemes: a) Battling negative emotions, b) “It’s curtailed my job.”: Financial & career effects. c) “I put myself in last place.”: Health effects, d) “My social life is dead.”: Social effects, and e) “The challenge is to fit me into my own life.”: Balancing act. Each sub-theme will be discussed in turn.

3.4.1 Battling negative emotions

Many individuals found themselves experiencing negative emotions as a result of their caregiving roles and responsibilities. For example, women experienced guilt when they could not accommodate their mothers or mothers-in-law as they wanted to or wished they could.

Additionally, caregivers expressed feeling guilty for taking “a breath” from their caregiving duties or not being there to visit and be with their mothers or mothers-in-law.

I came home and it was just like ugh, I couldn't, I just couldn't, I thought I can't go back there again, I'm gonna have to ignore the phone. But oh my God? I can't ignore the phone, you know? I mean, the guilt is crazy! Guilt is crazy. - Annie

I'm starting, I'm feeling guilty that I don't go up as much as I should. And that I will regret that because the times to visit are going to be less and less. – Jenna

Penny, a full-time worker, recalled not being able to take her mother every place that she wanted to go, after her mother lost her license.

So when that happened and she stopped driving, then she missed it a little bit but not that much. But then that meant that I then needed to ensure that she got out. Um, so there were times when I, when I was working full time that I felt badly that I couldn't take her all of the places that she would normally go.

Abbie described moments when her mother's dementia erased her visits almost instantly, and that her mother constantly wondered where she was or tell her siblings that Abbie had not been to visit her for a long time. Instances such as these made Abbie's challenges with caregiving even more taxing and stressful.

She'd ask where I was, some days she'd say "oh your sister hadn't been up for a couple of days" well I had just been up earlier that day. And that made me feel bad. That she didn't remember that I had been there. Because it made me feel bad that she, was missing me, that I didn't, that she didn't think I was there that day.

Women also felt guilt after transitioning their care recipients into long-term care. Some of this guilt arose as a result of promising their mothers before the onset of dementia they would not move them into long-term care and they would take care of them.

*I felt guilty about leaving her. Because when she first got diagnosed with Alzheimer's, um she, her and I had a long talk about it. Um, so I made her a promise that I would look after her as long as I could. And I tried my best. (started to tear up). So when I go see her, I'm getting choked up now (wipes eyes and pauses, laughs). - **Lucy***

*She ALWAYS, always made my sister and myself promise 'don't ever put me in a home'. I said 'okay, okay, Ma, we'll promise" she said 'I've got a silver bullet for the first one that puts me in'. - **Carly***

Carly eventually had to break her promise to her mother and transition her into long-term care.

The following quotes depict the angst she endured as a result of her broken promise.

I think by putting my mom in the home, in the beginning I think with me was a little bit of a letdown, because I thought I could take her in but, I couldn't. I couldn't.

I'd say that would be the biggest [emotion], a failure. Because (shrugs) I wanted to take care of her like she wanted to take care of me. Guilt! Guilt is a big one.

Abbie was emotional reflecting on moving her mother into a nursing home. The first nursing home was not a good fit; however long-term care beds were so rare to find that her family did not feel they had a choice.

To this day, I feel SO (begins to cry) see I'm getting upset. I feel SO guilty for moving mom into that nursing home. Because it was NOT a nice place. The floor she was on was

(pause and crying) not the floor she should have been on, but it was the only room that was available.

Prior to her mother's move into long-term care, Jenna explained she found herself checking the local newspaper obituary section to see what openings would be available based on deaths in the community. When explaining her actions, she almost seemed to catch herself and realize how strange and sad the idea sounded.

We gradually came to the decision, like we knew from the get go I mean ultimately we were going to have to go long-term care, I think that it was um (heavy sigh) once we had thought "okay we're getting to that point we need to be" and um I started, started watching obituaries to see (slight laugh) what the openings were going to be like, which is just, (pause and shakes head).

On top of the guilt she felt for moving her mother into long-term care, Carly also found herself feeling guilty about having to spend time away from her husband, as a result of her caregiving.

And I say that with my husband, is, is I would feel guilt because I'm torn between my parents and then torn between my husband because my parents were taking a lot of my time. But he would always say "we've got lots of time", you know, so I would feel guilty about having to, being pulled in opposite directions, but I never blamed my mom for that.

When providing care for their care recipients, caregivers also expressed fear as they questioned whether they were getting a glimpse into their own futures. Some individuals expressed fear of the future with long-term care in general.

Which, again, it really affects how we think, us caregivers as what are we gonna do hunny when we have to go somewhere? You know what, HOW pfft you know, mom is only surviving because when her father died he left her a little bit, and she collected interest on it and things like that... What if we both have to go into care! Like just one of you is, and that's right now, it's like \$2 800, 3 grand, but for one of you! What if you both have to have care! I just don't know how its, HOW, yeah. - Annie

Caregivers also experienced fear towards hereditary aspects of the disease and how that would affect the people caring for them in the future. Carly expressed thinking about her own senior care, "now I worry if I'm going to have it. And have to put my kids through it". As a result of her

caregiving experiences, Jenna explained how she was actively trying to prevent and prepare for any negative cognitive outcomes she may experience in the future.

There's a strong family (pause) history... But, so I, I start to think you know hmmm. And so in retirement, like I'm making a conscious effort. Like I started piano lessons, I'm doing art, I'm trying to keep the brain busy. I mean I don't, the evidence is not really great that it makes a big difference for brain exercises and stuff like that, but you know just trying to keep active that way.

Caregivers were fully immersed in their experiences and viewed the effects of dementia firsthand. Individuals saw the devastating effects of the disease and expressed fear of the future, their own aging processes and their risk of dementia development.

Resentment and frustration were also negative emotions expressed throughout the interviews. Annie's mother, who was in the very beginning stages of dementia and was relatively stable physically, had not moved into long-term care as of the interview date. When discussing long-term care and the future of her mother's care once she was no longer supported within assisted living, Annie reported she was already resenting and dreading the transition.

Well, we toured them and it was like (shocked sigh) you know what, she's just gonna have to come and I'll sleep on the couch, she's going to live with us, like I don't know what we're going to do, but I would not put my parents in any places [nursing homes], those places are pretty scary, scary looking.

Women also expressed their feelings of frustration, particularly with the health care system and long-term care. Annie reflected her frustration with the long-term care facility.

The nurses whoever is on duty is doing it, then they get busy so say the laundry just sits in the dryer for hours and hours and hours, then they return it to her and her pants were SO wrinkled I was like "are you kidding me!?! That you ACTUALLY returned this to them like that!?" And they thought nothing of it. They just said "yup! That's the way it is" kind of thing. And (heavy sigh) and that's the other thing, you don't want to say anything to upset the apple cart because she's in their hands! When I'm not there, who knows what's going on! That's probably the hardest part, because what's really going on there when I'm NOT there let alone, you know, just the little things that I see happen when I AM there.

Abbie was constantly frustrated when her mother was in her first nursing home; however, her mother did not verbally express any frustration. Abbie noted being frustrated for two individuals- for herself and her mother.

There were people, screaming on the floor at all times. Yelling for help. Yelling to get out. Yelling at each other. And, poor mom was agitated by that and, you know, but AGAIN not a “get me out of here” not an “I don’t want to be here” not a negative word. She just (shrugs and tears) with her grace and dignity would stare out the window and say “oh isn’t that a beautiful tree? Oh look at that pretty sky”. She would always come up with something that, you know, would comfort US. She always thought about what would make US feel better. But she declined quickly in that atmosphere.

Many women discussed their issues with long-term care being a business, and not being as empathetic and warm as caregivers/families wanted and felt their care recipients deserved. Carly, who worked in housekeeping in a long-term care facility, found herself seeing both sides of the system and being frustrated with it all.

The people that work in these facilities, these administrators, open your eyes to the appearance. Because I’ll tell ya, they can snow ya. They’re the meanest people going.... It’s a business. And it shouldn’t be a business. Our folks deserve better.

On top of the facilities and the environment of long-term care, caregivers found themselves being frustrated with doctors who treated their mothers or mothers-in-law. Annie explained in detail an experience she had with her mother and having to advocate for her to the doctor and staff within the assisted living facility. When Annie’s mother became ill, she had to take matters into her own hands and take her to the emergency room as could not rely on the in-house care that was supposed to be provided.

This week it was, she’s had a cough, this chesty cough, for over a week, and I called LAST week to say “okay couldn’t the doctor take a look at her because this cough just doesn’t seem to be going away”, well, no, nothing ever happened! They never pass on the, yeah. So I picked her up the other day and it was um a nice day “let’s go for a drive mum”, started going out of town and it was like “hmmm mom”, it was overcast now supposed to be sunny, “do you really wanna go for a drive or (deep sigh) do you wanna go sit at the clinic, because I think we need to get this cough looked at, I mean God knows when he’s going to see you, it’s gonna be at LEAST next week”, so we went, and

sat in emerge forever, and ever, for HOURS and eventually they did the x-rays and yup, she's got pneumonia starting! So had I NOT taken her, you know!?

As a result of feeling like she could not rely on the in-house care, Annie expressed feelings of distrust, frustration, and being overwhelmed.

To say "yeah we should have that looked at" or "while he's [the doctor] here" like it's two minutes, the building is not a big building to have him go look at this. So, yeah, that's, I'm finding really, really hard. So therefore I have to constantly be, right, there's my mind is ALWAYS like okay mum, okay did she sound funny today?

Likewise, Jenna expressed feeling frustrated with herself and particularly for not noticing the onset of her mother's dementia.

I'm frustrated that I didn't pick up sooner on some of the stress that he [dad] was feeling as a caregiver, with her.

I guess I was just, I guess you know you can't see the label from the inside of the jar right? So I think I was kind of rationalizing and stuff, and then it became more and more evident.

Individuals expressed frustration with the disease itself, its ruthless nature, and their feelings of helplessness as a result.

*Ugh (sigh) I wish I could just, make it go away. Make it better. Do SOMETHING. Yeah.... It's, exhausting. It's emotionally draining is what it is. That's probably more, again because your mind is just constantly, that's always a concern right, she's always going to be the concern. And you feel sorry too, it's like, oh God can I do SOMETHING, isn't there something I could do to, and there isn't! Just be there for her and you know, (pause) yeah, and yes, it is rewarding, but I'm saying first and foremost obviously its (blows out air and deflates on couch) overwhelming. It's overwhelming. - **Annie***

*It's, the unkindness of Alzheimer's. It's ruthless. It's a terrible way to exist. I'd rather have a disease like, well not that I'd want cancer, but I'd rather have a physical disease that at least you can try to fight and have hope and do something with. - **Abbie***

Overwhelmed, frustrated, helpless, and guilty are emotions caregivers expressed feeling throughout their journeys with dementia and its progression. As unique as individuals personal experiences were, the multitude of negative emotions experienced were a common thread.

3.4.2 “It’s curtailed my job.”: Financial and career effects

All caregivers were employed full or part-time at one point during their caregiving experiences. Women discussed the financial effects of caregiving as related to their careers. Annie, who worked part time in sales, expressed how her caregiving tasks and experiences had filled up her schedule to the point of not being able to imagine working full time.

I said I just need to know when the doctor is going to be there next week for example because I need to book it off, I’ve got to you know I, do you think we just say “hey yeah I’ve gotta leave for a few hours” and then you go back to work? Like, it doesn’t work that way! And part-time, I don’t get paid for days off! You know (sigh). So that’s the most frustrating. And working full-time, there’s no way. I just can’t do that.

Connie, also employed full-time, found her informal caregiving role restricted the trajectory of her career opportunities.

Yeah! It’s curtailed my job, my job! I could never do, I could never take on a full time position somewhere or take on an administrative position anywhere, because I just couldn’t. And I couldn’t be in charge of people, I could never return to being a manager of anything, I just didn’t have the time between that and the kids and here.

Jenna, who is a retired registered physiotherapist, was thankful for her job flexibility as she found her schedule revolving around her mother’s weekly needs.

Um, but I’m not, it, um, you know I, I guess at work near the end I had to make sure that if I, because I usually went over and had lunch with mom there near the end, so I’d have to kind of structure my schedule at work a little bit to make sure that happened. Or, made uh if it was a meeting or something that I couldn’t get at it, I would have to make sure that someone else could cover. Um, I’d be leaving work right away to get on the days that were mine to you know, go and do meals and stuff, and we had a routine that you know I took her for her hair appointments on Friday and then we went and got her groceries and stuff and spent some time with her.

Abbie found herself relying on her work for structure, distraction and control in an otherwise uncontrollable situation.

I never missed a day of work, and I don’t call in sick, and some days I think I should have because I needed a mental health day to put me back. But if I called in sick I wouldn’t have been taking that time, I would have been cleaning the house or going to visit mom, so, I just thought being in the routine was the best way to, to make it all work.

Connie also relied on her job to help guide her through the caregiving experiences.

It impacts, everything! How you feel about, it makes you question yourself. I'm thinking "I'm not in left field" because you say "leave it alone, this isn't your business" (sighs and laughs) what do you mean it isn't my business!?! How can I sit back to the point where I'm calling my college saying "okay, like I'm feeling a little like this is my business. And I'm going to lose my licence because I'm, I'm, a professional I have to report things that I feel are not, people are not being taken care of". "You're right, you are! Regulations speaking, you are very well within, you've earned your right to feel like you are and this is what you have to do". But I'm constantly seeking, you have to, you have to look for um reassurances.

Many caregivers found themselves spending money they would not have spent if they had not been caregiving. Abbie discussed the financial effects and realities of caregiving as she found herself paying for her mother's necessities out of her own pocket and not reimbursing herself from her mother's funds. She justified her actions by explaining the financial immensity that is long-term care.

I took on some expense myself because I always worried about certain things for mom, yes she wasn't buying her food but she was having to pay this horrendous amount of food at the homes that she was eating very little of. So I would buy her Depends and do stuff like that without having mom reimburse me. So it did affect us financially, also from the point I mean it seems small but it wasn't, where I didn't have time to come home and cook so we would grab more meals out than we normally would, or I'd bring food home um you know, I didn't hire a cleaning lady, I probably should have, but we put that money into hiring somebody that would, we could pay to feed mom for one meal a day. And that worked out. So financially yeah it was a concern and affected me a bit, but more of a concern for mom, that she could continue to live in these homes as long as she did.

All women interviewed were employed at one point during their caregiving experiences, and found they experienced financial effects as a result of caregiving. Some caregivers experienced direct financial consequences, while others experienced indirect financial effects associated with their career restrictions as a result of their caregiving responsibilities.

3.4.3 "I put myself in last place.": Health effects

All women expressed experiencing physical health effects as a result of their caregiving.

The overwhelming, 24/7 nature of their roles had immediate effects on various aspects of their health. For example, caregivers expressed how their roles physically aged them due to the stress they felt.

It ages you! It really does. It takes, it just, emotionally and physically it drains you... It's like because stress, you know, the number one of everything! It's like, my hips hurt, my back hurts my ugh! So yeah, I'm quite sure it has (laughs) as I said I feel like I have literally aged 10 years in the last 2. - Annie

It has aged me traumatically (nodding). It's aged me because I have given up my life between working and providing care for my mother. - Lucy

Additionally, caregivers noted the lack of sleep they had due to constant thoughts in their heads about their schedules, responsibilities, and worries as a result of their caregiving.

Can you tell (points to face) I was awake again all last night? Yeah. I don't sleep a lot.- Annie

As I said I tend to be a bit of a worry wart and kind of review the day in my head and you know, what are the things I need to do tomorrow? But at the same time, just by age as you know, perimenopause and then menopausal, so there's all of the sleep disturbances that are part and parcel with that right? - Jenna

Most caregivers noted the significance of the phone, and the immediate emotional response associated with the phone ringing.

I found I didn't sleep well. Because you never knew whether you were gonna get a phone call or not. - Carly

I'd be lying awake thinking what do I have to do next, like, or waiting for a phone call! Like, thank goodness we're not going to have those morning phone calls anymore. But, yeah (tears up) every time the phone would ring (grabs tissue), because um long-term care facilities are very good about calling you when things are happening, but its EVERYTHING (exasperated sigh) and you can think "oh my goodness what is it now?" - Julie

Julie, whose mother had passed away at the time of the interview, continued to describe her emotional responses of the phone ringing even after her mother had passed.

... Oh my goodness, like I had to change my ringtone on my cell phone because I had one specific for the nursing home, and my stomach would turn every time it would go off! So I changed my ringtone, is no longer on my phone at all, like so I don't have it!

Lucy, who moved into her mother's apartment to provide care, related her sleep quality as similar to the sleep patterns she experienced after having her first child.

I mean, I would, when I would put her to put at night I would leave my bedroom door open, listening for her in case, you know, something happened. So my sleep, um, for you know, for the past 2 or 4 years has been disrupted. Um, it was kind of like the sleep you get when you have your first child, you know, you put your child to bed at night, and you lay there and you listen, um I remember when I had my first, my daughter, I had her in a bassinet beside my bed. And sleeping at night, I would listen for her breathing, terrified to fall asleep just in case. I mean with my second it wasn't so severe. But with my mother, putting her to bed I was always worried she would get up or she would fall or something would happen. So my sleep was always, um, disrupted. So that took a toll on me physically, I felt that I was always tired.

Another health effect was weight gain. Abbie found that she gained weight throughout her caregiving experiences which she attributed to stress, poor eating habits, and routines as a result of a busy schedule.

I put on weight, which sounds silly as a physical effect but it was. I think it was stress. Um, I'd have little meltdowns once in a while on my own because I didn't think I could keep everything going, full time work was stressful and because I have a stressful job. Sometimes running over to see mom on my lunch for 5 minutes when I was really worried about her, so didn't eat well if at all.

I put myself in last place, because it just was expected! And I wasn't boo-hooing about it, I just, I had a full-time job that I had a responsibility for, I have a husband and two children that I had the responsibility for.

Negative health outcomes and physical effects were experienced by all caregivers. Their caregiving roles and associated duties created stress and lifestyle changes that resulted in a myriad of negative health consequences.

3.4.4 "My social life died.": Social effects

Alongside the emotional, financial, and physical effects were the social effects of

caregiving. All women found all facets of their lives were affected by their caregiving experiences, and particularly did not view their social lives with family and friends as a priority.

Impacted with regards to relationship with your husband, with your kids, with your friends, your family. Everything. It impacts everything you do. - Connie

The 24/7 nature of their caregiving roles, resulted in their social opportunities being negatively affected.

Yeah, I couldn't go out as much. No, because I was either tired or I had to be someplace with mom.... my social life died. - Julie

I haven't had an independent outside life. Any extra time I had was always spent with her. So I stopped socializing with friends, um to the majority, I stopped going out, um I was trying to split my time between my husband, my son, my mother, and my work, and I was being pulled in all directions. - Lucy

Carly found that her mother's diagnosis and her caregiving role had direct effects on her family stating that "it broke the family up." Connie also found her family was affected.

....impacted with regards to relationship with your husband, with your kids, with your friends, your family. Everything. It impacts everything you do.

Abbie described that although her social life with friends declined, her family became her social outlet. Everything revolved around her mother, including her social life.

Basically just did family things because mom was the centre. So when we get together with my family we'd all get together at one person's home, but it was always to talk about "okay what should we do for mom here, would it be easier if we did this?" So it was nice we had everybody to talk to, but we didn't go out with friends, we stopped kind of doing that. Um, to be honest everything was geared around family. And in the moment. We didn't do anything. We didn't go out with friends, we didn't travel. We were afraid sometimes to take a weekend away in case something happened to mom. I felt very responsible to always be on call to be there for her.

Caregivers also expressed their free time being restricted. Many caregivers found themselves spending their days off filled with their mothers scheduled appointments, and rarely had the opportunity to complete their own schedules or social activities.

It's a nice day, I just want to sit on the patio and have A beer, just have A drink! Just sit and, but I know I can't do that because if I have more than one, what if that phone rings and I have to go. So your whole life is totally changed! It really is. -Annie

Individuals stayed in close proximity to their mothers and mothers-in-law and expressed fear of going away in case anything happened and while they were out of town.

It's like always now you're just, everyday you're thinking 'we shouldn't go too far because what if', but that's just the way life is now. – Annie

It impacted my days off, but if we were going away or there was something going on, you know, my sister would come for the weekend like there was always a plan B. - Jenna

Caregivers expressed in detail how their social lives were put on hold, delayed, or ceased to exist as a whole as a result of their caregiving duties. Individuals experienced negative social effects with both their families and friends as a result.

3.4.5 “The challenge is to fit me into my own life.”: Balancing act

Caregivers expressed the balancing act of caregiving life. This “life” included coordinating responsibilities, and having to be accountable for various individuals. Rachel found she had to balance arranging her mother-in-law’s appointments and social life, all while maintaining her own commitments.

(Deep sigh) so I spend so much time, with appointments, they're calling me “she didn't show up for this”so between like working, and my own appointments, and things, you can't just give them an appointment, because she can't remember now. So you have to have the reminder appointments, and I have to remember to do them (laughs)! It's a gong show!

Lucy was fully immersed in her caregiving role before her mother moved into long-term care.

....still trying to work full time, and still trying to look after my mother full time, I moved out of my home and into my mother's apartment. Where I would get her up in the morning, and help her shower.... brush her hair, brush her teeth, give her her medication, I would make her breakfast, I would turn the TV on, I would get her set, I would work, I would come back upstairs, luckily I worked downstairs, I would come back up, I would give her lunch, I would check on her periodically. I would go back to work, I would come back up, I would give her dinner, I would sit with her to give her company.... I tried to um take her for walks almost every day in the evening....I had my, my second

husband living at home with my son, who was still at home, while I was living at the, my business with my mother. I did that for 3 years.

Connie discussed the balancing act of taking care of her own home and all of her mother-in-law's caregiving duties. She felt her family did not acknowledge all of her caregiving responsibilities, in addition to her immediate family responsibilities.

I don't think anyone, unless they do this, recognize how much of that has to happen... I've been vacuuming, cleaning, and canning and doing laundry at 1 o'clock in the morning! Or setting my alarms so I can get back up to put the wash in the dryer so it's dry for 6 o'clock when I know somebody needs it! But I wanted to sleep and not wait for the hour and a half it took for the wash or you know? It's stupid, and my husband will roll his eyes and walk away, because they figure now what the hell are you putting yourself through that for? Well, who else is going to? The tooth fairy isn't going to do it? (Laughs) like can you believe that? And I just think oh my God people, I hope they recognize. I hope they recognize.

Individuals found they were struggling to fit themselves into their own lives. The following quotes depict Annie's experiences with the balancing act of caregiving.

You know, the challenge is to fit me into my own life. (Long pause and tears up) mmmm. Even for me to see a doctor right, it's like, well mum's got to do this so. But yeah, it's fitting me in there.

You have to work at it again with your relationship with your husband or whoever you're living with, but you gotta fit you in there! You still have to fit you, that couple thing going. That individual you thing going. That mum thing.

Well right now actually I'm, this morning was like a million phone calls again, appointment out of town that I have for me, and there's one in town, and it was like okay, let me book all this stuff around her schedule. It's like having a baby, her schedule is first! Her schedule is more important!

Jenna related balancing her numerous responsibilities to juggling balls.

Just trying to you know, juggle all the balls and still managing the medical practice and all of the stuff for the year and the accounting and then taking over all of mum's finances and stuff. So there were a lot of balls in the air.... It was kind of always there [scheduling] in the back of your mind.

Abbie described the family consequences she experienced trying to balance her responsibilities.

So I do feel that families suffer when somebody has this kind of situation. And, and me as the main caregiver, along with the professionals, um, I felt a responsibility to be there ALL the time, but I also was caught between being here. You're caught in the middle.

Education wise, none of these women had full formal training to prepare them for their caregiving duties. They had been self-taught and learned the majority of their skills through direct experiences. Almost all of the caregivers discussed not being fully supported by Alzheimer resources, and having to take matters into their own hands when it came to training.

I mean we had talked. I have talked to the Alzheimer's Society and meh I don't know if they have a, it's funny, there were some courses sort of thing, but who had time to go to them for one thing! But again it's just, I found it easier, or better or more logical to figure it out on my own. Like, I know what she needs, I know what she, you know, she's my mother. I just know her. As opposed to "well some will want to do this, and some will want to do that" and I just know what she wants and (pause) well I think (tears up). Yeah, I do. - Annie

Caregivers experienced difficulty balancing all of their responsibilities as informal primary caregivers with other facets of their lives. All women reported that caring for their mothers/mothers-in-law and their families were the priorities. Their own needs always came last.

There were a multitude of negatives associated with informal dementia caregiving. This theme delved into the negative emotions experienced by caregivers, as well as the financial, health and social effects associated with the balancing acts of the role.

3.5 "EVERY SO OFTEN YOU SEE A LITTLE BIT OF LIGHT.": THE SILVER LININGS

Despite all of the negatives associated with caregiving for individuals with dementia, all caregivers found silver linings in their experiences. Women continued to provide care with one stating "we wouldn't have traded it". Every individual spoke of positive experiences regardless of whether their mothers/mothers-in-law were alive or deceased. For instance, when describing their caregiving experiences the following series of quotes epitomize the positive aspects of caregiving.

It was fulfilling. Because I really do feel like that with my mother-in-law I'm a lifeline and that makes me feel good. - Rachel

Joy, sadness, struggling, and rewarding. Because I know she's there, rewarding, I know she's there (holds hands to heart with tears in eyes) - Jocelyn

More recognition of the need for enjoying each day and living in the moment. – Jenna

I don't regret one minute of what I did for my mom. Not one minute. Because you know? You learn. – Carly

Honour, it was my privilege to take care of mom, it was with utmost love. -Abbie

Penny, who had chronic fatigue syndrome, found her mother's disease and the demands associated with caring for her, forced her to set aside some of her symptoms.

Um, one of the benefits when I was sick of having mom in the house was I had to get up for her. I had to keep her routine, because I had her to look after. So when I was really sick, and could have slept 23 out of 24 hours, I had to, I had someone I had to look after. So I had to get up. That was one of the benefits to me, personally. That she was there for that.

Further individuals learned a great deal about themselves and in various strengths in their characters. Caregiving for their mothers or mothers-in-law with dementia served as a method of self-discovery. Jenna explained, "I learned that I need to be more patient". Julie also expressed life lessons with regards to patience and strength.

Oh! Man. (Tears up) I've become more tolerant. Um, more patient and understanding. I, I don't take anything as an insult, like especially working at the retirement home now, I understand where they are coming from, so I don't take offence when they get mad at me or if they say something, say "well, it's ok! You know, you're entitled!" And just walk away from it. I've become more tolerant I would say. Yeah. Um, yeah, it's opened my eyes to a lot of, when I was a kid you would have called them the crazy old lady down the street, now you know, there was things that were bothering them, so yeah. I, I would say my tolerance level has gone way up.

(Pause) um yeah. I became stronger. Um, (pause) did things I didn't know I could ever do. (Long pause, tears up) I'm trying to think of the word. (Pause with tears) I found out how much I loved my mother.

Abbie expressed learning about herself, but also caregiving in general.

I didn't find it easy. Although I do believe it made me grow as a person, um it made me understand family situations a little bit better um and I didn't understand really what a burden it can be on the family, and on you personally.

I think it made me a stronger person. More caring. I think it made me a more patient, caring person. Because boy it really tested your patience.... And it's just such a sad way for people to (pause) to move into that part of their life where they don't remember all the good things that they had. It's such a sad way to end your life. But it taught me tolerance. Taught me to be brave. Taught me to be more involved. Taught me to be not afraid to (pause) advocate for her. So it made me a stronger person I think.

Caregivers also gave credit to their support systems, which included their other siblings who were involved in some capacity.

Thank God for my sister, because we're each other's rock. She depends on me, I depend on her. - Carly

Many individuals also gave credit to their spouses.

He was, he's fantastic... He'd be my sounding board.... With my husband, I walked on eggshells a lot on how to approach him and say that my folks needed me. And like I said, he, he was just excellent about the whole thing. And when he did say "let's move", I was the happiest woman in the world. - Carly

.... my husband, like he was wonderful, I couldn't have asked for a better husband because of all the times I got called.... during the night to go to the hospital, stay in the hospital seven hours at a time waiting with them, um, he was always, he never EVER ever got mad.- Jocelyn

For individuals whose mothers or mothers-in-law had passed away, they found they were thankful for their experiences. Carly described how "it was my way of 'thank you mom'. Because I'm the person today because of my mom".

During the interviews, many women used humour to neutralize their reflections and expressed using humour as a way to shield emotions throughout their caregiving journeys. Individuals used this method to not only cope with dementia symptoms, but also bring joy to their experiences.

We'd say "Ma! The hamster must have fell off the wheel up there!" "Oh I'm repeating!" So we'd do funny things like that so that she wouldn't feel uncomfortable. - Carly

Laugh! You just have to look at those horrible situations and it's just, you have to make, you don't want to say make light of it, but yeah, you just can't take it too seriously you know what I mean? If you don't laugh you'll cry. You HAVE to laugh. - Annie

And I just think life goes on. Like, laugh at it and go on. It's not the end of the world. Yeah, definitely. It's, it's made me believe that live now while you can, because you don't know what's going to be thrown at you later in life. - Julie

All caregivers laughed and cried throughout their interviews. They would light up and laugh when talking about happy moments with their mothers or mothers-in-law, but also found aspects of joy amidst the sad moments.

Women who were caregiving at the time of the interviews, and those whose mothers or mothers-in-law had passed away, both expressed they would not have changed their experiences. Penny described how “we wouldn't have traded it”, while Lucy stated “it's um, it's really tough. Would I change it? I don't think I would. Would I tell others to? Definitely”. Many women acknowledged caregiving, like aging, was simply a natural part of life. They expressed these views as a positive and not in a negative tone.

It's part of the journey of life. But within that journey don't lose yourself. Even the small things, because it affects the whole way, just don't lose yourself in that journey, don't forget that you're important too....just take 20 minutes and walk around the neighbourhood and get fresh air. Leave your work behind so you can transition better to your family time and your caregiving time. - Abbie

Part of life. Part of life as we get older. We have to treat them, these people are gold. – Carly

All women described various silver linings associated with dementia caregiving. Connie described the perspective she gained from her caregiving experiences with her mother-in-law.

Recognize that cleaning, and canning, and laundry and all that shit, they're not going to remember that. They're not going to remember that your house was a mess, they're going to remember that you loved them, I'll put it that way. I think that's, that's the, you know?

Annie explained how her role allowed for extra time to be spent with her mother, time she would not trade.

I spend a lot of, I spend a LOT of time with her! Right, I see her all the time, talk to her all the time, we go out all the time. She's always "oh hunny you have to take me ugh you're wasting your day doing this" and uh hello! We're out together! It's our day together! So we get to chat and keep her from just being this you know, alone, quiet lonely person. Um, and funny stories! You know, she'll, especially when you know family is together, she enjoys, SO enjoys all of that. Having everybody together and laughing and all that fun stuff. Um, and again, the big thing, is because I get to spend a lot of time with her.

Women also learned a lot about how they wanted their end of life care to occur based on their own experiences.

I don't want my kids, I don't want to be a burden to my kids. So, I want them to know that when I do get like that don't be sad, that you have to put me in a home. Just come and visit me, and love me. That's all that I ask. – Carly

My daughter at one point, when I was really struggling with mum and you know her being stubborn and not wanting to accept I said "you know one of these days I'm going to write a letter and the letter is going to say 'when I start saying these things that I'm hearing my mother say', you just give me the letter and then that will be the cue, that will be the cue". – Jenna

Jenna described that despite the negatives and unknowns of the disease, she was able to continue to find motivation to continue her caregiving role and all its associated duties.

You have to step back in realizing that you're hopefully doing it because you care about the person, but often times they're at the times where they're not able to necessarily acknowledge and be appreciative of the care aspect from the practical and the emotional. And so there's that bit of a dual role of being a caregiver.

One day at a time and just learn to appreciate whatever the interaction that you have with that person on that day.

The silver linings were summed up by Jenna who stated "every so often you see a little bit of light."

3.6 SUMMARY

The purpose of this study was to explore the lived experiences of daughters or daughters-in-law in the primary informal caregiving role, providing support to their mothers or mothers-in-law with dementia. Ten individuals were recruited for the study and took part in one-on-one semi-structured interviews. Four themes emerged from the analysis: (1) “Master of none.”: The many roles of informal caregivers, (2) The face of dementia, (3) “What a life!?” and (4) “Every so often you see a little bit of light.”: The silver linings. While each experience and circumstance were unique to the individual and her family, themes emerged that were consistent across each of the experiences.

The themes and subthemes highlighted the various aspects of the primary informal caregiving experiences. Caregivers found themselves gradually able to come to terms with their caregiving roles after definite transition periods. The harsh, ruthless nature of dementia was displayed through the caregivers’ numerous stories and recollections. Women also reported effects of their experiences in various aspects of their lives, unfortunately primarily negative. That said, although there were definite moments of darkness, caregivers shed light on learned life lessons and self-reflections as a result of their caregiving journeys.

CHAPTER 4: DISCUSSION

4.1 A CHORUS OF VOICES

Predicated on the narratives of women caregiving for their mothers/mothers-in-law with dementia, this research uncovered the presence of four major themes discussing the many roles of informal caregivers, how dementia affects the caregiving process, and the positive and negative experiences of caregivers found within each unique experience. Although every woman shared personal stories, there were collective experiences among each of the women.

Previous research has shown how caring for individuals with Alzheimer's disease poses threats to sense of self and loss of identity (Skaalvik et al., 2014). A study by Goldsteen et al. (2007) also found that caregivers felt pressure from all their new roles and struggled with their new identities as a result of caring for family members with dementia. These struggles with identity between family members and caregivers lead to difficulties and misunderstandings with responsibility surrounding care recipients. Similarly, caregivers within the current study found they struggled with their identities during transitions prior to the onset of the disease and after disease onset. For examples, women talked about performing tasks prior to disease onset associated primarily with age-related changes (e.g., groceries) versus tasks that became more onerous as the disease progressed (e.g., assisting with personal hygiene).

As caregiving duties progressed to include tasks that were more personal in nature, caregiving roles "transitioned" into activities deemed more "parenting" in nature, and mirrored tasks they would have completed for their children. Caregivers noted since these tasks were for seniors - whether mothers or mothers-in-law - women expressed a reversal in their relationships and subsequently questioned their new identities: parent vs. child? This "role reversal" was associated with their care recipients' loss of independence, an issue that was emotional for caregivers and care recipients alike. Women described this role reversal as being driven by dementia which exacerbated age-related declines, and added to the burden experienced by caregivers. Although role reversal in the context of dementia care was not found within the literature, role reversal associated with aging has been investigated. Mottram and Hortascu (2005) explained how adult daughters caring for their aging mothers often experienced role reversal when their mothers were widowed and had physical health declines. Given that the role

reversal associated with age-related changes, in addition to dementia, appeared to add another layer of complexity to caregiving, more research is warranted in this area.

The current study shed light on the motivations behind caregiving for seniors with dementia. All individuals expressed eventually accepting their roles at various stages of disease progression. Many women expressed how role acceptance appeared natural and was facilitated by lifelong positive relationships with their mothers. Daughters-in-law caring for their husbands' mothers articulated how these women had been mother figures in their lives for so long they naturally accepted their caregiving roles. The strength of the positive relationships seemed to establish the foundation for their caregiving roles. Even with disease progression and the diminishing of relationships, caregivers' roles continued to be accepted, in spite of the lack of reciprocity in the relationships. This finding was supported by Spector et al. (2016) who reported that pre-existing relationships can strongly influence role acceptance for caregivers of individuals with dementia and mental illness. Funk and Kobayashi (2009) aimed to delve further into the motivations of caregiving, specifically examining choice vs obligation. These were not found to be isolated concepts, as psychological ambivalence occurred with the complexity of filial relationships. Motivations within the current study followed suit and did not emerge as simply one or the other. Women did not explicitly acknowledge or express their actions within their caregiving roles as being due to choice or obligation, but a multitude of emotions and circumstances.

All individuals expressed how their roles within their family units shifted and were affected by their caregiving duties. Women reported how isolating the role of caregiver was, despite having siblings and their own family units. Further, women found negative sibling interactions occurring regarding division of labour, and expressed numerous instances of unmet

expectations of siblings or spouses. Similarly Neufeld and Harrison (2003) revealed female caregivers of their family members with dementia experienced two moments when they felt unsupported: when they had unmet expectations of support, and negative interactions with family members. The current findings also revealed families being “divided” as a result caregiving responsibilities and lack of support, which was reaffirmed by Peisah et al. (2006) who termed dementia the “great family divider” especially when cracks in family solidarity were already evident. Health providers need to advocate for open communication between family members throughout the dementia caregiving process in order to alleviate burden on the primary caregiver and other caregivers.

Female caregivers continuously referred to dementia as a harsh, cruel disease, which involved personality changes among their care recipients. Dementia, in all of its forms, transformed kind, soft-spoken women into bears, strong, independent women into mice, and others simply shells of their previously lives. Williams et al. (1995) examined carer-rated personality changes associated with “senile dementia”. Seniors whose personalities became senile were found to be more neurotic, less extraverted, and less conscientious. These personality changes were found to have a direct effect on caregiver morale even more than physical burden and effects of caregiving (Williams et al., 1995). The women in the current study also expressed how drastic personality changes in their mothers or mothers-in-law affected their morale and taxed their already difficult visits, one way conversations and relationships in general. These personality changes associated with dementia further complicated the arduous tasks of caregiving and decreased opportunities for enjoyable social moments to the point that caregivers expressed having to talk themselves into visiting care recipients at times. Strategies to prepare individuals for this lack of reciprocity in the caregiving relationship could include family

counselling, education on the disease or expressive arts workshops to try and form other alternative methods of communication.

Undoubtedly, dementia results in cognitive impairments. Caregivers in the current study found themselves “thinking for two” at many times in their roles. Women had to make decisions for their mothers or mothers-in-law, attend appointments, and essentially be there for any moment when important information was being shared. Many women were also the Power of Attorney and therefore held legal responsibilities as well. Although some women had jobs within the health care system, all were deemed informal caregivers as they were caring for their mothers/mothers-in-law as daughters or daughters-in-law and not as formal caregivers. None of these women felt they were educated to handle all of the dynamics of their roles and found themselves improvising and adapting throughout the caregiving process. Literature by Berry (2014) complemented these findings and identified how caregivers tried to reduce family members’ moments of confusion and disorientation through improvised cognitive support work. He explained how individuals unconsciously moved through three stages in cognitively supporting their family members: (1) caregivers discussed triggers with the person with dementia and how to avoid these triggers, (2) caregivers lost the ability to collaborate with the person with dementia and began unilateral attempts to minimize confusion, and (3) caregivers learned and accepted that the person with dementia had reached a level of impairment that could no longer be tackled with reduction techniques. Dementia and the cognitive impairments associated with the disease, undoubtedly exacerbated the caregiving experience. Better understanding the added cognitive demands on caregivers who are “thinking for two” will allow for structured supports to be implemented to further alleviate stressors. Additionally, one-on-one family counselling to increase sibling communication could assist caregivers in establishing duties between siblings.

Alzheimer's and other dementias are diseases that "strip the soul" from the body and caregivers are left caring essentially for shells of former people they knew. Women in the current study expressed having lost their mothers/mothers-in-law when dementia had taken away the women they once knew. Further, some women said they welcomed death as an end to their mothers or mothers-in-law suffering. Although half of the women in the study were currently providing care, while the other half had already lost their mothers/mothers-in-law within the most recent year, all expressed having experienced grief and loss. It is important to note that this loss came with the progression of dementia and not exclusively with the passing of the individual - meaning that individuals grieved for the life lost even prior to death. Pre-death grief in the context of dementia caregiving is an emerging concept that has been investigated in existing literature. Lindauer and Harvath (2014) explained that witnessing changes and losses in family members with dementia could lead to pre-death grief. Viewing profound psychological and physical changes in family members with dementia is perceived as a loss for caregivers. This concept of pre-death grief is associated with burden, depression, and poor coping mechanisms for caregivers (Lindauer & Harvath, 2014), and is an important aspect of dementia caregiving that is not discussed in detail within the literature. This study adds to the current literature on pre-death grief and serves as a means to increase awareness of the concept. When someone passes away, family is typically provided with forms of assistance to cope with loss. However, what happens when the loss is experienced before death? Health care professionals need to be educated about provision of support for individuals who experience losing someone to dementia before and after death, in order to help caregivers throughout the process.

Many women in the current study expressed wavering faith as a direct result of their mothers or mothers-in-law disease. All of the women were Caucasian, living in a rural

community and were practicing Christians or had profound faith. Many disclosed their Christianity within the interviews, and how their mothers or mothers-in-law diagnosis affected their faith, even though the concept of religion was not directly asked about in interviews. Existing literature has examined spiritual well-being and caregiver burden in a sample of 150 family Alzheimer's caregivers (Spurlock, 2005) and found caregivers frequently use prayer to alleviate caregiver burden; however, Spurlock (2005) also found an inverse relationship between spiritual well-being and caregiver burden. The current study supports this as none of the women in the current study acknowledged having increased spiritual well-being as a result of their caregiver journeys. The current study gathered experiences from a range of circumstances and women at varying points in their spiritual journeys with dementia. Women viewed their mothers or mothers-in-law as undeserving of the disease and found themselves blaming and questioning God's means and methods. Some women found peace after their mothers or mothers-in-law had passed away; however, they still acknowledged the wavering faith as a result of dementia. This seemingly novel finding shows the need for spiritual guidance for caregivers, particularly those of Christian faith, and how supports could be established for individuals addressing their loss of faith. The time frame of the current study should be noted as all of the individuals were providing active care within the year. For women whose care recipients had passed, caregivers were still struggling with their transitions out of caregiving and immersed in other tasks that needed completion (e.g., planning funeral, settling estate, going through personal effects). Participants of different faiths or individuals years passed their caregiving experiences may have different reflections and experiences with faith.

Caregivers expressed experiencing a multitude of negative emotions. Previous research by Sarabia-Cobo et al. (2016) examined decisions at the end of life made by family members of

patients in long-term care. Caregivers were found to have unresolved emotional needs resulting from both the disease and the institutionalization of their family members. Informal caregivers expressed feeling uneducated and unprepared to make end of life decisions for their family members with dementia (Sarabia-Cobo et al., 2016). Similarly in an analysis of caregiver's stories of nursing home placements, Kellet (1999) revealed five shared meanings: experiencing a loss of control; being disempowered; feeling guilt, sadness and relief simultaneously; possessing a sense of failure; and having to make forced, negative choices. Caregivers in the current study also felt guilt, conflict, and frustration with long-term care and having to make the decisions to move their mothers or mothers-in-law into long-term care. The emotional trauma experienced by informal caregivers during transitions into long-term care is an important piece in caregiving for individuals with dementia. The current findings complement caregiving research on family caregiver's experiences of nursing home placements and the associated transitions (Kellet, 1999; Sarabia-Cobo et al., 2016). The current study contributes to existing literature and provides further evidence of the need to better understand the emotional well-being of primary informal caregivers and to provide assistance if required. Dementia affects the family unit, not solely individuals afflicted with the disease. As such, treatment should address the resulting issues incurred by caregivers, as well as the individuals with dementia.

Throughout the caregiving process, women undeniably placed their own needs second to care recipients, which subsequently led to compromised financial, physical and social well-being. All of these effects of caregiving have been discussed at length in existing literature, among caregivers for seniors with various age-related changes and/or diseases, including dementia. For example, Horell et al. (2014) found that providing care for a loved elder (not necessarily dementia) came first over career. In particular, caregivers experienced physical health effects

such as lack of sleep, weight gain and stress in both the current study and existing literature (Richardson et al., 2013). Further, Horell et al. (2014) also found that caregivers gave lowest priority to the maintenance of their own health and balanced life. A myriad of negative effects were reported by the current caregivers, namely, fatigue, unexpected financial deficits, and compromised social life. Understanding not only the effects but the corollary of these effects on the lives of caregivers is imperative for maintaining the fragile balance between reliance on formal and informal care in the Canadian health care system.

Existing literature provides evidence of dementia caregivers who experienced strains from general worries and uncertainties, balancing multiple demands and feeling overwhelmed with caregiving duties (Bookman & Kimbrel, 2011; Sanders, 2005). Similarly women within the current study found themselves balancing multiple demands such as their mothers/mothers-in-law appointments, work obligations, and duties within their own homes. Balancing multiple demands led one woman to call caregivers “masters of none”, displaying evidence of the need for more support for this population. Caregivers who provide more care than they can manage, will face their own repercussions, resulting in caregiver burnout which would have the potential to directly affect the care recipients.

Fear of the future as discussed within the current study was also evident in the work by Chappell et al. (2015). Researchers found caregivers were more likely to note having fears of the future when they had chronic conditions themselves, even if they had only been caregiving for a short time period. Individuals who worried about their own loss of communication in the future were more likely to live in smaller geographic areas, be caring for someone who had fewer ADLs and exhibited verbal agitation. Also, caregivers who had lower self-esteem were more likely to worry about their own future personality changes (Chappell et al., 2015).

Understanding individuals' fears of the future can provide information for structuring programs to educate and prepare caregivers and other family members, and prepare for the associated changes in themselves and/or other family members.

While conducting the interviews I continually asked myself, "why do these women continue to provide care?" These women were emotional and opening up to me about their lives, their struggles with caregiving and their absolute despair with losing their mothers/mothers-in-law to dementia, yet, they continued to care on the worst of days. All women were able to see the silver linings in their everyday experiences and hang on to those special moments, no matter how few and far between. They were able to reflect on their experiences, even if they were still immersed in caregiving, and explained how they would not trade any of it for the world. This theme emerged as unique and was expressed on its own as these filial female caregivers explicitly described the positive aspects of their roles without probes. Throughout their journeys caregivers voiced silver linings they experienced while providing care to their mothers or mothers-in-law. These findings complement Sanders' (2005) work who examined 85 caregivers, and found 81% reported both strains (e.g.,) and gains (e.g., spiritual growth, personal growth, and feelings of mastery), while only 19% reported only experiencing only strains associated with caregiving. Further, caregivers in the current study expressed growth in their physical capabilities with respect to caregiving, but also as human beings. Growth in skill set and personality traits within this female dementia dyad is relatively void within the literature, as are positive aspects of dementia caregiving in general. Families need to be reminded during their experiences with dementia caregiving to search for the "silver linings" in spite of the turmoil dementia creates. Caregivers in the current study would contend that light exists amidst the darkest days of dementia caregiving.

Throughout the current study, women both laughed and cried while reflecting on their experiences. I did have personal connections with many of the women interviewed which may have increased the level of comfort and ability to express various emotions throughout their interviews; however, I still feel their use of humour was authentic despite the personal connections. The women expressed using humour as coping mechanisms, communication tactics and overall tension diffusers. Previous literature has shown that individuals used humour when describing their roles, and specifically instances of role reversal with aging parents (Bethea et al., 2000). Bethea et al. (2000) contends that humour was used as a way to diffuse discussing uncomfortable topics such as forgetfulness, incontinence, and other issues with ADLs. In the current study, caregivers used humour as a communication tool throughout their dementia experiences. Individuals supporting dementia caregivers need to know they are not alone in using this tactic and that it is alright to bring humour to a devastating situation in order to cope effectively.

4.2 LIMITATIONS

This study examined the lived experiences of female informal caregivers caring for their mothers or mothers-in-law with dementia. Women within the study were Caucasian, from a small rural community, married, employed throughout their lives, and middle class. Although examining this particular female dyad created an in-depth look into a very relevant, specific geographic, the findings may not be representative of other dyads (e.g., male/male, spousal). Experiences of single, divorced or widowed individuals may also have differed and added another dynamic to the caregiving experiences financially, physically, and socially. Additionally, caregivers discussed their experiences as retrospective reflections which may have limited their recall of their experiences. Completing longitudinal research tracking caregivers throughout the

process of dementia (prognosis to death) would provide a more holistic view of this specific female caregiving dyad.

4.3 IMPLICATIONS

This study provides substantial contributions to literature surrounding informal caregivers of family members and in particular those caring for parents with dementia. As the aging population continues to increase so will the reliance and need for informal caregivers. Informal caregivers play an integral role in the Canadian health care system and acknowledging this selfless work is the first step in assisting this population. A shift in health care policies should be made to first, better support caregivers of seniors with dementia. By valuing our elders and their respective informal caregivers, and increasing assistance services, quality of life can potentially be enhanced in order to match quantity of life.

Further, in order to decrease the stigma associated with long-term care through education, improving the LTC physical environments and investing more resources in LTC, care recipients (and caregivers) may be more willing to accept placing their care recipients into facilities earlier. As a result the lives of informal caregivers' would be enhanced by giving them peace of mind knowing their care recipients are receiving the best care.

Filial dementia caregiving is emotionally laborious work that can be isolating for primary caregivers. Knowing this, caregivers need to realize their needs are just as important as care recipients. A person cannot pour from an empty glass. Each person must fulfill him/herself in order to continue to provide optimal care for the care recipient and complete other duties (e.g., family, children, and occupation). It is anticipated that this research will reach families who are in need of support and prepare as a family for caregiving responsibilities in order to best serve the needs of the care recipient and the family unit as a whole. Findings of this study will allow

caregivers to realize and take comfort in knowing that they are not alone in their experiences, as isolating as it may feel at times.

4.4 FUTURE DIRECTIONS

Currently, much of the existing caregiving research is focused on aging parents. Research needs to continue in this vein, but increase the information concerning dementia caregiving. Being able to draw comparisons and differences between caring for an aging parent and one diagnosed with dementia could identify specific areas requiring attention. Further, as previously mentioned longitudinal research could follow informal adult child caregivers into their own senior years to follow any latent effects of health behaviours adopted during their caregiving roles. Tracking these caregivers and viewing how their past experiences shape their own experiences as care recipients could add greatly to the area of caregiving research.

Future research could also benefit from more voices within the family caregiving experience being heard. Interviewing secondary caregivers (i.e., caregiver spouses), tertiary caregivers (i.e., caregiver children) or the care recipients themselves could create a fuller picture of the family unit experiences. Also, many of the senior women in the current study were widowers; however, future research could investigate the experiences of spousal caregivers and the effects of such caregiving on aspects such as physical health and their marriage.

It is of utmost importance that research in the field of caregiving continues to be investigated using both quantitative and qualitative methods. Qualitative methods give voice to a population that does not feel they are heard.

4.5 REFLECTIONS OF THE RESEARCHER

Most children grow up dreaming of becoming an astronaut, firefighter, or something extraordinary. I, however, was the child who wanted to be a pharmacist. I do not think it was so

much the profession I wanted, rather the woman it represented in my life. I wanted to be just like my grandma.

My grandma was kind but feisty, soft yet strong. She lived her life with grace, honesty, and dignity. Growing up she was the woman who would watch us when we were sick, and would spoil us on weekends. As I turned the corner into my adult life my grandma became my friend. She was my sounding board and I gained a new respect for her as a person.

During the completion of my undergraduate degree, my grandma's physical and cognitive health started to steadily decline. The once resilient, powerfully soft-spoken individual had been beaten down by her body to an almost unrecognizable woman. During this time, I watched my mom step into a primary informal caregiving role.

Unfortunately, with many age-related changes come the realities of loss of bodily function. My mom had never had a strong constitution for environments such as long-term care homes. Nonetheless, I would see her psyching herself up for what she would have to do that day as she walked down the long hallway to my grandma's room. "*You can do this*". She would take a deep breath, walk in, always greet my grandma with a smile, and begin the motions. I would frequently go with my mom to visit my grandma, and as a team, I would visit while my mom cleaned her room. She would organize the closet, tidy up the pantry, or clean the bathroom. My mother was always completing at least five tasks simultaneously at every stage of my grandma's transitions with her disease and movement through formal care institutions.

At the time, I did not know why my mom did not easily sit back and enjoy these visits with her mother. Maybe she did not want to sit down and face the fact that her mother was turning into someone unrecognizable. Maybe she was scared that if she did not clean up, nobody would. Maybe, at the end of the day, the cleaning and the tidying were things she could control

in an uncontrollable situation. I know now from this research that she, like many other primary informal daughters/daughters-in-law caring for their mothers/mothers-in-law with dementia, was stepping up and doing the best she could. She was improvising, and bringing whatever skill set she had to her informal role. She was running with the punches, and trying to do so all while maintaining her mother's dignity in an undignified environment.

After completing my study, I acknowledge how much these female caregivers persevere, modeling the caring, nurturing behaviours their mothers exhibited when raising them. My caregivers modeled the methods they experienced throughout their relationships, even after their own mothers/mothers-in-law no longer recognized them. One quote that resonates with my caregiving research is "be kind, for everyone you know is fighting a hard battle". These women are the backbones to our health care system, performing labours of love in order to provide their mothers and mothers-in-law with the best care possible.

What does dementia mean to me now? To grieve the loss of a soul before the body has left the world. The acceptance of a new person in a familiar shell. The battle of past and present. I now feel better prepared for my own inevitable caregiving journey for my parents and in particular my mother. I have watched her persevere with strength and positivity that not only allowed her relationship with my grandma to thrive, but also her career, social life, health, marriage, and her ability to be an outstanding mom throughout the entire process.

During this research, my grandma peacefully passed away at age 91. As a religious person, I now believe that my grandma's soul was welcomed into Heaven with open arms. However, I also believe that her soul lives on in my life today. My mother is my grandma. I am my grandma. Outside of our own faults, we emulate her light, her compassion and her ability to love. I do not know whether these traits were something I was born into, or whether I learned

them from two of the greatest role models in my life. Throughout the thesis process one of my caregivers said it best, simply stating: *Caregiving? Is love. It's unconditional love.*

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Appendix A

Table 1: Caregiver Information

Primary informal caregivers	Age	Number of children	Current Employment	Highest level of education	Marital status	Perceived health status	Current health conditions
"Connie"	57	4 + 2*	Occupational Therapist	Undergraduate degree	Married	Good	None
"Jocelyn"	62	2	Retired	High School**	Married	Good	None
"Rachel"	57	2	Furniture Sales	College	Married	Excellent	None
"Jenna"	60	2	Retired Physiotherapist, Medical Practice Office Manager	Undergraduate degree	Married	Excellent	None
"Carly"	67	2	Retired LTC House Keeping	High School	Married	Excellent	None
"Julie"	57	2	Dietary Aide	College	Married	Excellent	None
"Penny"	52	1	Children's Services Caseworker	Undergraduate degree	Married	Good	Yes***
"Lucy"	57	2	Harley Davidson Sales	High School	Married	Good	None
"Annie"	58	3	Retail Sales	High School	Married	Good	None
"Abbie"	57	2	Assistant Bank Manager	College	Married	Good	None

* Step Children

** Plus University & College courses for employment training

*** Chronic Fatigue Syndrome

Appendix B

Table 2: Care Recipient Information

Primary Informal Caregivers	Care recipient relation	Care recipient status	Care recipient health status in last year of life	Care recipient most recent living arrangement
“Connie”	Mother-In-Law	Living	Declining	Nursing Home
“Jocelyn”	Mother	Deceased	Declining	Nursing Home
“Rachel”	Mother-In-Law	Living	Steady	Own Home
“Jenna”	Mother	Living	Declining	Nursing Home
“Carly”	Mother	Deceased	Declining	Nursing Home
“Julie”	Mother	Deceased	Declining	Nursing Home
“Penny”	Mother	Deceased	Declining	Caregiver’s Home
“Lucy”	Mother	Living	Declining	Nursing Home
“Annie”	Mother	Living	Declining	Retirement Home
“Abbie”	Mother	Deceased	Declining	Nursing Home

Appendix C

Table 3: Themes and subthemes of the lived experiences of daughters providing primary informal care to their care recipient with dementia.

Theme	Subthemes
1. “Master of none.”: The many roles of informal caregivers	i. “You’re a mom, you’re a daughter, you’re an employee, but you’re not being very good at anything.”: Challenges with role conflict and reversal ii. “This is the new normal.”: Role acceptance iii. “Everyone’s lives are busy.”: Role within the family unit
2. The face of dementia	i. Personality changes ii. “You’re thinking for two” iii. “I know her as my mother, but she’s not.” : Loss (While living) iv. “I felt I lost God.”: Questioning faith
3. “What a life!?”	i. Battling negative emotions ii. “It’s curtailed my job.”: Financial & career effects iii. “I put myself in last place.”: Health effects iv. “My social life died.”: Social effects v. “The challenge is to fit me into my own life.”: Balancing act
4. “Every so often you see a little bit of light.”: The silver linings.	N/A

Appendix D

Background Questionnaire

Please fill out the following questions in the space provided or by choosing the most appropriate answer. You may choose not to answer any questions.

1. What is your date of birth (MM/YYYY)? _____

2. With which race(s) or ethnicity(s) do you self-identify? _____

3. What is the highest level of education you have completed? Please check one.

- | | |
|--------------------------------------------|-----------------------------------------------------|
| <input type="checkbox"/> Elementary School | <input type="checkbox"/> Undergraduate degree |
| <input type="checkbox"/> High School | <input type="checkbox"/> Masters or Doctoral degree |
| <input type="checkbox"/> College | <input type="checkbox"/> Other: _____ |

4. Are you currently:

- Employed full time (please specify occupation): _____
- Employed part time (please specify occupation): _____
- Unemployed
- Leave of absence
- Other (please specify): _____

5. What is your current marital status? Please check one.

- | | |
|------------------------------------------------|----------------------------------|
| <input type="checkbox"/> Married or Common-Law | <input type="checkbox"/> Dating |
| <input type="checkbox"/> Separated | <input type="checkbox"/> Single |
| <input type="checkbox"/> Divorced | <input type="checkbox"/> Widowed |

6. Do you have any children?

- No
- Yes

If yes, please complete;

	Date of Birth (MM/YYYY)	Gender	Where does child currently live? (With you, on own, at school, etc.)	Do you consider child dependent on you? Yes/No
First Child				
Second Child				

Third Child				
Fourth Child				
Fifth Child				

Other:

The following questions are about *your health*:

6. How would you currently describe your health? Please check one.

- Excellent
 Fair
 Good
 Poor

7. Do you currently have any illnesses/conditions/impairments that affect your ability to complete your daily activities?

- No
 Yes (please specify):

The following questions are about *your mother's health*:

8. How would you generally describe your mother's physical health within the most recent year? Please check one.

- Steady
 Variable
 Declining
 Improving

9. Does/did she have any illnesses/conditions/impairments, besides dementia, within the most recent year?

- No

Yes (please specify):

The next questions are regarding *your relationship with your mother*:

10. Please complete the following table, addressing the following issues:

	Type/ Location (Home, Retirement Home, Nursing Home, etc.)	Your Caregiving Involvement During This Time (Absent, Minimal, Moderate, Substantial)	Number of Months/ Years
1			
2			
3			
4			
5			

Thank you for taking the time to participate in this study.

Appendix E

Interview Guide

1. Before we get into your caregiving experience, I want to hear about you. Can you tell me about yourself?
 - > Education
 - > Work life/career
 - > Upbringing
 - > Lifestyle

2. Now let's talk about your family.
 - > Partner? (Occupation, relationship, health)
 - > Children (Age, education, relationship, health)
 - > Parents (Occupation, relationship, health)

3. Please describe your mother before she was diagnosed with dementia?
 - > Personality
 - > Living situation
 - > Lifestyle

4. What, if any, care did you provide to your mother before her diagnosis?
 - > Types of tasks
 - > Duration
 - > Assistance of formal
 - > Community versus institution

5. Can you tell me what you know about dementia?
 - > Have you had formal education about the disease?
 - > Have you cared for anyone in the past with dementia?

6. Can you now describe your mom during and after her diagnosis?
 - > Personality
 - > Living situation
 - > Lifestyle
 - > Who provides care to her? Gender, number, network.

7. Can you describe the care you provide and have provided to your mother since her diagnosis?
 - > Types of tasks
 - > Duration
 - > Assistance of formal (CCAC)?
 - > Community versus institution

8. What, if any, role has dementia played in your caregiving experience?
 - > Positive?
 - > Negative?

> Transitions

Next, I am going to ask you questions regarding transitions within your role.

9. What, if any, transitions have you gone through within your caregiving role? Describe.

- > Who were your support systems through the transitions?
- > Did you cope; resources utilized?
- > What was the most significant transition for you? Why?

10. How would you describe your relationship with your mother?

- > Before her diagnosis
- > During her diagnosis
- > After her diagnosis
- > Current day
- > Through various living arrangements
- > Give me one word that best describes the relationship with your mother at each of the stages above

11. In what way, if any, has the relationship of mother-daughter changed throughout your caregiving experience?

- > Explain the relationship
- > Positive?
- > Negative?

12. What, if any, barriers or challenges have you had to being a caregiver?

- > Constant/ changing?
- > Fears

13. Do you feel your caregiving role has influenced or directly affected any aspect of your life? Please explain.

- > Positive
- > Negative
- > Effects on emotions?
- > Of your family's life?
- > Of your mom's life?

14. Can you tell me how you became a caregiver?

- > What are the reasons why you continued to be a caregiver?
- > Why are you caregiving, current day?

15. Is there anything you would change about caregiving? Please explain.

- > Within your own family experience?
- > Within Canada?

16. Can you define caregiving for me?

- > Has your definition changed throughout this discussion?

> What does caregiving for your mom mean to you?

17. With the experience that you had, if you were given three wishes tomorrow, what would they be?

18. Do you have any advice for others as a result of your caregiving experience?

19. Can you describe and talk me through, using phrases or words, your journey up to this point. Now, what is the one word or phrase that overall describes your caregiving experience, what do you take away from it?

20. Is there anything else you would like to add or ask me?

Thank you for taking the time to participate in this study.