The ‘One Way Journey’: How men experience, navigate, and conceptualize the process of being a caregiver for their wives who have dementia

by

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Author’s Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Background: The health care system relies heavily on unpaid caregivers, or family, for people living with dementia. As demographics and gender norms shift, more older men will be providing care than ever before. Caring for someone with dementia within the home comes with challenges and health impacts (including stress, depression, sleep difficulties, and anxiety) and the needs of the caregiver are easily hidden. Specifically, research on men is limited to small, homogenized samples resulting in an oversimplification of their experiences and limits the understanding of a broad range of experiences.

Research Question: What are the experiences of husbands who care for their wives with dementia?

Method: Using a constructivist grounded theory approach, this research explores the experience of caregiving for husbands when their wife has dementia. Semi-structured interviews were conducted with 11 men aged 61-88 who have a wife with dementia. Interviews were transcribed and analyzed using the constant comparative method through an iterative approach. The method was not used to develop a theory; rather, the systematic process grounded in the data provides a robust analysis of their experiences.

Findings: Three major themes were identified from the study; *Becoming a Caregiver*; *Navigating and Managing Changes in Relationship*; and *Organizing, Planning, and Re-evaluating the Future*. Becoming a Caregiver involved learning to be a caregiver, what it means to be a caregiver, and experiencing changes in self. Navigating and Managing Changes in Relationship involved navigating loss and grief; managing and avoiding conflict; and maintaining intimacy. Organizing, Planning and Re-evaluating the future involved and planning and making the decision for long-term care; reconceptualizing values, and meaningful gender-specific supports. Men navigated and negotiated their sense of self. Their experiences impacted their view of themselves and compelled an evaluation of their values. Within all aspects of this journey was a negotiation of what it means to be a man in a caring role, with masculinity presenting as a dynamic process.

Discussion: This thesis identified practical and conceptual components to the caregiving experience for husbands; 1) How men provide and conceive care, 2) How men construct their sense of self and their relationship, 3) How they navigated and managed their evolving relationship, and 4) What men find supportive as a caregiver. Men in this study perceived caregiving as both physical and emotional which can limit their self-identification as a caregiver if men did not provide personal care. Men navigated their circumstance and their changing reality by actively re-constructing their sense of self and their marital relationship. Men in this study found supports that are specific to them, that are not centralized on caregiving, and that utilize purposeful recruitment to be the most effective strategy to engage them.

Conclusion: The experience of husbands caring for a wife with dementia is complex. This thesis identifies both practical and conceptional elements and provides new insight into the complex and dynamic nature of being a caregiver as a man. More research is needed to further understand the variance in experiences.

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Dedication

To the men who taught me what true enduring love looks like.

Descending into Dementia

Dementia is a downward staircase
The first step is very wide, well lit, and almost imperceptible
From it, one can see the world and all it's wonders
But the step has been taken, and cannot be taken back.

Each successive step goes farther down
Until at some point, the descender realizes the unpleasantness of it all
And those on the landing above begin to notice
Disturbing changes, never seen before.

The staircase is narrowing now
No longer well lit or inviting
And each tread becomes rough under foot
Bringing pain to all.

So much is lost along those stairs
Memories, talents, bodily functions
A blurring of everything
Into perpetual vagueness.

Banisters begin to appear
In the form of family, friends and caregivers
At first rejected, the descender reaches out
To grasp all handrails until the very end.

With the long awaited last step
The descender finally rises up
No longer earthbound
But free at last.

~B. Richardson Corbett, in memory of Shirley Maxwell Whitcher/Ross 1916-1996

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Chapter 1

Literature Review

1.1 Caregivers for Persons Living with Dementia

The Canadian healthcare system relies heavily on unpaid family caregivers and will increasingly do so to support the rising number of individuals living with dementia (Zwaanswijk et al., 2013). In Canada and the United States, an estimated 60-80% of caregiving for someone with dementia occurs at home (Canadian Institute for Health Information, 2018; Centre for Disease Control, 2019). Caring for someone with dementia at home creates unique challenges for family members and contributes to invisibility of the caregiver's needs. Research suggests that family caregivers experience high levels of stress and burden due to the requirements of caring for someone with dementia (Macleod et al., 2017; Ashley & Kleinpeter, 2002). These feelings of burden often increase as their loved one's health deteriorates and the severity of dementia progresses (Ashley & Kleinpeter, 2002). The increasing requirements of providing care for someone with dementia may also contribute to poor mental and physical health of the caregiver as their health needs may be neglected with the development and adjustment into a caregiving role (Shanks-McElroy & Strobino, 2001; Macleod et al., 2017; Ashley & Kleinpeter, 2002). They may experience several negative health consequences as a result of caring; these include but are not limited to, increased experiences of stress, neglecting one's own health, sleep disruption, exhaustion, increased blood pressure, depression, and anxiety (Macleod et al., 2017; Ashley & Kleinpeter, 2002; Shanks-McElroy & Strobino, 2001; Robinson et al., 2014).

Specifically, when an older individual is caring for their spouse who is living with dementia the physical demands of the required care may involve significant effort and can include assistance with eating, using the bathroom, bathing, dressing, and the need for supervision (Shanks-McElroy & Strobino, 2001). This can become emotionally and physically taxing, reducing the caregivers overall functional capacity and limits their ability to take care of their own needs (Shanks-McElroy & Strobino, 2001). However, these health outcomes can be mitigated in part by the provision of appropriate support systems. Supporting family caregivers can improve health outcomes for both the caregiver and the care recipient and allows caregiving to remain at home for longer periods of time (Macleod et al., 2017).

1.2 Caregiving Trends in Canada

Historically, women have provided most caregiving, but with changing demographics and cultural shifts, a rise in men as caregivers is expected (Lauderdale & Gallagher-Thompson, 2003). The proportion of men as caregivers is increasing due to societal shifts in caregiving duties and expectations. In Canada, approximately 40% of caregivers for older adults are men[1] (Robinson et al., 2014; Frederick & Fast, 1999) and is anticipated to increase in the coming years (Poysti et al., 2012). As such, the proportion of older spouses providing care is expected to increase due to greater longevity of partners and a general preference to “age in place”; the notion of aging in one’s own home (Hong & Coogle, 2016). In addition, the dynamics of families are changing. Previously, caregiving responsibilities tended to fall on daughters; however, this responsibility is transitioning to husbands more frequently due to families having fewer children to rely on, which suggests that more caregiving will fall on husbands (Shanks-McElroy & Strobino, 2001). Knowing this, more men will need support in their role as caregivers than in previous generations.

1.3 Experiences of Men Caring for a Spouse with Dementia

Consequentially, a particular area of concern is the experience of older husbands who provide care for their spouses who have dementia. There remains a lack of understanding of the experience of men, their needs, and their perceptions of caregiving and support services. What we currently know about caregiving relies on research with women caregivers, or research on men as caregivers that involves relatively small, homogenized samples of middle-class white men (Calasanti & King, 2007; Simpson et al., 2018). However, the experiences of men may differ from their women counterparts, in part due to the socialization of gender roles and the

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[1] As of 2018, 46% of caregivers in Canada are men (Statistics Canada, 2020), although this is not specific to older adults.

performance of masculinity[2]. Some research has suggested that the current cohort of older men as caregivers understand gender roles from their upbringing in the 20th century where men were strongly socialized to perform traditional masculinity, and as a result, construct caregiving in a way that protects what it means to be a “man” (Robinson et al., 2014; Hong & Coogle, 2016; Schwartz & McInnis-Dittrich, 2015). Within this context, masculinity refers to the norms performed by men, such as power relations and control, as well as dominant characteristics of masculinity that include stoicism, competition, and self-reliance (Connells, 2005; Robinson et al., 2014). However, caregiving is a feminized role and not traditionally performed by men. This may mean the men who become caregivers for their spouses are entering into a new role, requiring them to adapt to being a caregiver, navigate a traditionally feminized experience (Hellstrom et al., 2017), and may struggle with this transition.

The current understanding of caregiving by men within the dementia context suggests that men adopt work/task oriented caring, as opposed to the relational and emotional coping strategies typically adopted by women (Robinson et al., 2014). The existing perception suggests that men construct caregiving for their wives with dementia as a task or as “men’s work” (Hong & Coogle, 2016; Greenwood & Smith, 2015; Calasanti & King, 2007), adopting managerial roles and problem solving in their caregiving to alleviate strain (Hong & Coogle, 2016). However, some literature suggests that categorizing men’s work as “managerial” may miss many men’s experience in caregiving if they do not participate in managerial roles (Calasanti & King, 2007). This is an example of an oversimplification of the experiences of men and misses the potential variance within an entire gender. Occupational metaphors for care work may still fit with men’s experiences but may need to expand beyond “managerial” metaphors (Calasanti & King, 2007). This understanding may not suit all men and only offers a one-dimensional understanding of their experience which disserves the needs of men who do not conform to this construction of caring.

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[2] Within the context of social construction, the performance of masculinity depends on the individual and the situation and is measured against the dominant ideology of masculinity (or hegemonic masculinity) (Migliaccio, 2009). This refers to how much a man conforms to ideals of masculinity.

The ideals of masculinity can help identify strategies to serve men but should not define a prescribed experience for all caregivers who are men. Although the traditional and dominant view of masculinity is pervasive, the embodiment and compliance with it vary considerably between men (Robinson et al., 2014). Further exploration of their experience is warranted to better understand their perceptions and needs, as well as provide an understanding of caregiving that captures role structuring beyond assumptive metaphors. Men's experiences vary and the adoption of multiple perspectives and experiences is necessary in order to properly serve their broad needs.

1.4 Impact on Health for Husband Caregivers for Spouses with Dementia

As discussed, caring for someone with dementia can be challenging and is associated with higher levels of stress, burden, and the development of depression (Robinson et al., 2014). Caregiving for someone with dementia is often all-encompassing, with the dual challenge of attending to physical needs, such as activities of daily living, and the psychological components of care that may require 24-hour supervision, especially as dementia progresses (Robinson et al., 2014). This impact on health is exacerbated in the experiences of men due to the lack of understanding of their needs, experiences, and the availability of appropriate services (Macleod et al., 2017).

1.4.1 Stress

The research on stress in caregiving for someone with dementia has mostly focused on the experience of women, but the experiences of men differ and should also be considered. Previous literature in stress and coping in men as caregivers for persons with dementia suggest that men find stress not necessarily in the care itself, but rather in the perception of whether it was done well (Hong & Coogle, 2016). Men may also have "cushioning effects" in terms of their experience and stress that protect them from negative experiences. Socially, they may have relative freedom from a socialized responsibility or expectations that their women counterparts may face when providing care for a spouse with dementia (Calasanti & King, 2007). They may also experience more praise for their care work, which may act as a protective mechanism in experiencing stress (Calasanti & King, 2007). These findings should be interpreted with caution as the literature is scarce and other studies have suggested that stress is not a function of gender necessarily, but on the level of care needed by their spouse (Hong & Coogle, 2016; Sun et al., 2008).

1.4.2 Depression

Experience of depression differs between genders and is expressed in ways that may not be obvious. Some studies suggest that women experience higher levels of depression and greater burden than men when caring for someone with dementia (Greenwood & Smith, 2015; Sun et al., 2008). However, other studies suggest that this may not be the case and an inaccurate depiction of their experience may be represented in the literature. For example, depression is higher in women in the general population, and consequently, a higher proportion of women experiencing depression in caring for their spouse with dementia may be a reflection of the general trend rather than a consequence of their coping (Ford et al., 1997; Sun et al., 2008). Additionally, men are less likely to admit negative feelings or mental health problems which may hide their true experiences, especially when self-reporting (Hong & Coogle, 2016; Houde, 2002; Robinson et al., 2014).

1.4.3 Physiological Impacts

Physical symptoms can allude to the actual experience of stress and depression that men experience when caregiving for someone with dementia. Although men report fewer depressive symptoms and less distress generally, their biomarkers and symptomology suggest otherwise. In one study, men caring for someone with dementia experienced sleep disruption and higher circulation of coagulation biomarkers representing biological implications of stress on the body (Robinson et al., 2014). Physiological responses can help provide insight into the true experiences of stress in men as caregivers.

Additionally, comparing women to men may not show the actual experience of depression for men and a different approach may provide a more complete picture. Studies comparing non-caregiving men to caregiving counterparts found significantly higher scores for depression and poorer physical health (Ashley & Kleinpeter, 2002). Men caring for spouses with dementia reported greater difficulty sleeping, respiratory symptoms, and more medication use than in non-caregiving men (Ashley & Kleinpeter, 2002). Another study reported that men who cared for a spouse with dementia were six times more likely to develop dementia themselves (Robinson et al., 2014). Given the evidence of physiological reactions, and men's tendency to underreport stress and depression, the experience of men caring for someone with dementia requires further investigation and critical assessment. Due to the gender-based socialization of men and the preference for stoicism when dealing with stress and depression, understanding the depth of experiences of men as caregivers can help identify strategies to address these issues in men.

1.5 Coping and Help Seeking Behaviour in Men as Caregivers

Men tend not to self-identify as caregivers, nor do they experience stress or depression in the same way as women do, which results in help seeking behaviours that do not align with the current service provision for caregivers for someone with dementia (Greenwood & Smith, 2015; Hong & Coogle, 2016; Robinson et al., 2014; Calasanti & King, 2007; Poysti et al., 2014; Macleod et al., 2017). Help seeking behaviour is understood in this context as a purposeful action to receive help and support from family and friends or from services. Help seeking behaviours within dementia care are influenced by a myriad of factors, including family closeness, cost of services, availability, knowledge, and past experiences (Robinson et al., 2014). Often, caregivers only sought help after experiencing a critical event or change in functional status of either the caregiver or care receiver, requiring action (Brown & Chen, 2008). For example, an unexplained change in behaviour or other critical experience can be a turning point for seeking help (Brown & Chen, 2008). Understanding the experience among men as caregivers in how they perceive and understand support can help identify methods to increase their help-seeking behaviour before reaching a critical point.

1.6 Methodological Issues in Studying Men as Caregivers

The current literature on men as caregivers, specifically for those caring for their spouse with dementia, is sparse and implications drawn from these studies should not be presumed to be applicable to the experience of all men. As discussed above, when studies have included men as caregivers, it is often with a small sample (Houde, 2002) or when comparing men to women, the ratio of participants is often skewed, with most studies having a significantly higher proportion of women in their sample (e.g. Pillemer et al., 2018 = 77% women; Macleod et al., 2017 = 67% women; Shanks-McElroy & Strobino, 2001 = 56% women; Sun et al., 2008 = 77% women; Ford et al., 2010 = 66% women). This may mask the true picture of the experiences of men in these studies and creates inaccurate depictions of their needs.

This disproportionate sample translates into the development of biased tools used to assess and measure perceived stress and other health impacts for caregivers of someone with dementia (Lauderdale & Gallagher-Thompson, 2003). An assessment of the current tools used to measure health outcomes found that the assessment questions were developed using a sample composed predominately of women and may not accurately depict the experience of men as caregivers (Lauderdale & Gallagher-Thompson, 2003). This suggests that the current measures used to assess stress may be problematic in fully understanding the true experience of stress for men due to flaws in the tools themselves.

Research recruitment strategies for men as caregivers in dementia care also affect the reliability of the research. A review of methodological issues in caregiving studies within dementia care identified that the sample of men who typically are included in the research are often not representative of the population due to recruitment strategies only utilizing support organizations (Houde, 2002). As mentioned earlier, men tend to under-report their distress or need for support and under-utilize support organizations. Research focusing solely on those who engage with services may not give an accurate representation of the experience of the majority of men as caregivers (Houde, 2002). Recruiting research participants exclusively through service organizations obscures the data, favouring those who demonstrate support seeking behaviours, and overlooks those who are not active with support organizations. Researchers may need to evaluate their sampling strategies in order to purposefully engage individuals who would otherwise be difficult to reach, in order to gain a full understanding of their experiences.

Chapter 2

Study Rationale

The research has consistently acknowledged that men are underrepresented in the dementia caregiving literature, or when included, the methodology used limits their voice. The current literature focuses predominantly on the differences between men and women in caregiving but fails to recognize the range and variability within the experience of men. By categorizing into two broad groups of men and women the experiences of men as caregivers may be lost. This study addresses this lack of research on the experiences of men by specifically interviewing men as caregivers. Focusing specifically on one gender allows the research to acknowledge the existence of gendered differences while pursuing a more nuanced understanding of men as caregivers that may have previously been overlooked. This research explores the experience of men, specifically husbands whose wives have dementia, to gain a better understanding of their experience, how they provide care, and how they construct their sense of self and their role. This research delves into the multiple and varied experiences of men as caregivers. Using a constructivist grounded theory approach, this research is exploratory and evolved as themes were identified, allowing further inquiry into new insights. The overall purpose of this thesis was to contribute to the knowledge and understanding of the experiences of men caring for their spouse with dementia, increasing awareness of their perceptions and experiences.

2.1 Research Questions

This research seeks to address the following question(s):

What are the experiences of husbands who care for their wives with dementia?

a. How do they provide care?

b. How do they manage/construct their sense of self and their role?

Chapter 3

Methods and Methodology

This research used a constructivist grounded theory approach to develop an understanding of the experiences of husband caregivers whose wives have dementia, how they provide care, and how they construct/manage their sense of self and their role. This chapter includes an overview of Grounded Theory and its paradigms; the study design and rationale; inclusion/exclusion criteria; data generation activities and procedures, approach to data analysis; strategies for rigour; and the role and positionality of the researcher.

3.1 Introduction to Grounded Theory

Grounded theory is an inductive qualitative research method used to generate knowledge on behaviour and the meanings of constructed social interactions (McCallin, 2003; El Hussein et al., 2014). It was originally conceived by Glaser and Strauss in 1967 in their seminal text, *The Discovery of Grounded Theory: Strategies for qualitative research*. The purpose of the method was to provide a means of discovering the concerns of groups of people, and how they manage those concerns and experiences. The method is exploratory, using patterns and variables to explore a social process and integrate it into theory. In grounded theory the research problem is determined by those who experience the situation rather than imposing a predetermined context. This is particularly appropriate when there are many unknowns (McCallin, 2003).

3.2 Paradigms, Ontology, and Epistemology

Since its original conception, grounded theory has diverged into different ontological and epistemological paradigms. These paradigms include what some call “Straussian Grounded Theory”, developed by Strauss and Corbin, and constructivist grounded theory developed by Charmaz (Mills, Bonner & Francis, 2006). A paradigm is a world view or propositions that explain how the world is perceived, informing the way a researcher interacts with data and the relationship with their participants. A specific paradigm can be broken down into ontology, epistemology, and methodological approaches. Ontology focuses on the nature of and what can be known about reality. Epistemology asks what the relationship is between the researcher and the researched and what can be known. Methodology refers to how the research should be undertaken in relation to the researchers ontological and epistemological stance (Annells, 1996).

Traditional or classic grounded theory can be considered post-positivist and objectivist (Mills et al., 2006). This conception of grounded theory is based on symbolic interactionism and focuses on “the nature of reality”, of which Glaser strongly advocates that there exists a real reality and maintains a purist stance on the original grounded theory (Annells, 1996; Thronberg, 2012). Adaptions of the original grounded theory are reflective of the evolution of the philosophical paradigms over the past quarter century. Strauss and Corbin developed a version of grounded theory in which they advocate for a conditional matrix and have some constructivist intent (Mills et al., 2006). A conditional matrix is an analytic tool to assist the researcher in considering conditions, interactions, and consequences of a phenomenon in the development of a theory (Corbin & Strauss, 1990). A student of Strauss, Kathy Charmaz, further revised grounded theory with the development of constructivist grounded theory.

3.3 Constructivist Grounded Theory

The constructivist paradigm views the nature of reality as time and context specific (Annells, 1996). In constructivist grounded theory the researcher co-constructs knowledge through a process of inquiry that acknowledges the role of both the researcher and the participant in the development of the interpreted work (Annells, 1996; Charmaz, 2014). Constructivists believe that the interaction between the researcher and the researched is precisely what creates the data, and thus, the constructivist grounded theory approach is one of data generation rather than data collection. As a method, constructivist grounded theory requires reciprocity in the research relationship, reflexivity in the potential power dynamics within the participant and researcher interactions, attempts to reduce these imbalances, and a clear articulation of the positionality of the author. The approach required the author to reflect and discuss underlying assumptions, awareness of biases, and discuss how these impact the data (Mills et al., 2006).

3.4 Research Method Rationale

This research study employed constructivist grounded theory methods to explore the experiences of older husband caregivers whose spouses lives with dementia. This research approach was chosen to provide a structured form of inquiry to explore diverse perspectives and allow the men interviewed to express their experiences with being a caregiver. Grounded theory explores a social process within a specific context (Starks & Trinidad, 2007), which lends itself well to explore being a caregiver (social process) as a husband (specific context).

The method allows for exploration of a phenomenon without imposing a specific outcome on the research (McCallin, 2003), which provides space for information that may have been missed in earlier studies by opening opportunity for dialogue that removes unintentionally biased considerations. This may help address the limited understanding of the experience of men in the current literature. With the goals of expanding our knowledge about the experience of men as caregivers for a spouse with dementia, constructivist grounded theory allows for a deep and rich description and for variance to be explored. Constructivist grounded theory was selected specifically because a constructivist lens aligns with the research questions and the epistemological and ontological stance of the researcher. Constructivist grounded theory provides a systematic way to examine concepts, constructs, and relationships between them to provide an explanation of a phenomenon (Carmichael & Cunningham, 2017).

3.5 Theoretical Orientation, Social Constructionism, and Gender

Constructivist grounded theory has strong connections to a social constructionist approach with the acknowledgement of research as a construction of meaning that includes the social reality of the participants as well as the position of the researcher (Charmaz, 2014). The key tenet of social constructionism is that our understanding of the world is a product of thought and not an external reality (Burr, 2015). Consequently, people’s positions within discourses provide their perspective of the world. Social constructionism’s epistemological position is relativism, which means that there exists multiple perspectives rather than one true reality (Burr, 2015). Social constructionism understands the underpinning of experience as a production of social norms and the expectations society puts on individuals based on their characteristics, social status, race, and gender (Mallon, 2019).

Gender as a construct, refers to “the socially constructed roles, behaviours, activities and attributes that a given society considers appropriate for males, females, and other genders” (Morgan et al., 2016, pg. 1.), whereas sex refers to biological criteria, such as X and Y chromosomes (West & Zimmerman, 1987). Gender is a social phenomenon with which, meanings of gender are negotiated and vary by social context and histories (Morgan et al., 2016). Gender affects how people relate to one another at all levels, including within health systems. It also can determine power within relationships, including but not limited to vulnerability, decision making, health seeking behaviours, and access/utilization of health services (Morgan et al., 2016). Within this research, gender is understood as a socially constructed role. For the purposes of this research, the use of men/women will be used and refer to gender. Inclusion of other genders is beyond the scope of this study and an important consideration for future work. This study will focus on cis-gender experiences, specifically cis-gender men and their conformance or non-conformance to traditional gendered norms.

In this context, social constructionism considers predominant discourses of masculinity as a result of cultural norms and not as innately occurring in men. For example, Ribeiro et al. (2007) describes social constructionism as being salient and widely accepted within the literature on masculinity because it emphasizes the diversity of the men’s experiences and the different types of masculinities. Essentially, using a constructivist grounded theory approach to the research, with parallels to social constructionism, allows an acknowledgement of the variability in experience without imposing preconceived assumptions and allows space to conceptually explore.

Constructivist grounded theory as a method does not use a hypothesis or pre-existing theory (El Hussein et al., 2014). It allows for a distancing from the literature and allows meaning to be derived from the data rather than preconceived ideas or notions (El Hussein et al., 2014). This method allows this research to add to the current literature and address the gap in understanding the multiple experiences of men.

3.6 Research Design and Collection

This study employed a constructivist grounded theory approach to explore the experiences of older husband caregivers whose wives live with dementia and their experiences of being a caregiver. Constructivist grounded theory uses a series of structured (yet flexible) procedures to thoroughly obtain/create rich data about a social process (Charmaz, 2014). Constructivist grounded theory uses intensive interviews with participants to generate data, supported by memo writing and reflexivity of the researcher; revision of the interview guide; re-engaging participants (where needed) to clarify information; and systematic analysis procedure using constant comparison methods. This is an iterative process and occurs simultaneously and cyclically.

This study used semi-structured intensive interviews with participants to obtain rich data on their unique experiences. Data were collected in intensive individual interviews, ranging from 40 to 90 minutes, to promote conversation and further inquiry into experiences offered by participants. The interview "is the site of exploration, emergent understandings, legitimation of identity, and validation of experience" (Charmaz, 2014, pg. 91). Interviews were conducted online through a video conferencing platform or telephone calls, and audio recorded. Audio recordings were transcribed verbatim using a transcription software and checked by the author. Following constructivist grounded theory methods outlined by Kathy Charmaz (2014) the interview guide was reviewed and adapted following the interviews to allow themes to be explored as they emerged.

The interview guide offered a semi-structured format and was moderately revised through the data collection and analysis period to delve into themes and categories as they emerged. Prior to and through the data collection and analysis process, memos were written to provide conceptual depth and allow reflection on personal bias. Memos were recorded as both a space to practice reflexivity and as an analytic tool to capture the depth of the research and assist category development. The memos reflected ideas about the research direction, the researcher's perception of a situation and how it changed or confirmed previous thoughts, or elements of the interaction that occurred to provide further insight into the meaning and depth of a code or passage within the transcript. A methodological journal was also kept assisting with reflexivity.

3.7 Sample

The focus of this research was on the experiences of husband caregivers in the community caring for their spouse who has a diagnosis of dementia. Eligible participants met the following criteria: 1) identify as a man, 2) are aged 60+, 3) speak and understand English, and 4) have a wife with dementia who lives within the same household. Individuals whose spouse currently resides in a long-term care home or was deceased were excluded from participating.

This study used purposeful sampling, specifically convenience and snowball methods. Purposeful sampling allows the selection of participants who have the experience in question, such as caring for a wife living with dementia (Bradshaw et al., 2017). Convenience sampling refers to utilizing individuals or organizations that have connections with participants of interest (Bradshaw et al., 2017). Snowball sampling is accomplished through connecting past or current participant's networks using word of mouth and invitations (Naderifar et al., 2017). Recruitment was achieved through connecting with caregiver organizations, the Alzheimer Society, memory clinics, and social media. The Alzheimer Society of Ontario generously supported this research through engaging their network of Societies in Ontario. Interested parties emailed or called the researcher and were asked to confirm their eligibility. Those who fit the eligibility criteria were invited to an interview with the author at a convenient time for them. Those who did not fit the criteria were asked if they would like to receive the final findings from the study and their role and experiences were acknowledged as important considerations for future work. Participants in the study were also asked following their interview to share the recruitment materials with men they knew who fit the recruitment criteria and may want to participate in this study.

3.8 Data Analysis

Following the systematic process of constructivist grounded theory, constant comparative analysis was used to analyze the data. Constant comparison analysis uses comparing and contrasting of all data to form categories and iteratively addresses the themes within the data (Boeije, 2002). This approach to analysis allowed the researcher to engage deeply with the data to understand the experiences of husband caregivers between and within individual accounts, further pursuing commonalities, differences, and variability of experiences (Boeije, 2002).

Constant comparative methods in grounded theory makes comparisons at each analytic level (Charmaz, 2014). The data are compared with itself, with later interviews with the same interviewee, and with other interviews. Additionally, memos and codes are compared to grasp the meanings and links between them. Memos were utilized throughout data collection and analysis to provide reflexivity and offer an analytic tool in constructing abstract thought. Memos captured thoughts, reflections, analytic notes, comparisons, and ideas as they occurred. They helped to identify questions and directions to pursue. Memo writing offers a bridge between reflexivity and analysis. It encourages deconstruction of codes and data, comparison, and establishing potential links (Charmaz, 2014).

Analysis of transcripts, memos, and researcher reflections were iteratively assessed throughout the data collection period and compared at different stages. Analysis began with line-by-line coding of the transcripts, followed by focused coding. Line-by-line coding sticks close to the data and allows for naming of themes, of which analytic ideas may occur and a memo is written to accompany the codes (Charmaz, 2014). Focused coding uses the earlier codes to define the most significant themes and delineate analytic sense of the data. This process helped to synthesize and conceptualize the data. Following coding, memos were sorted to assist the analysis, shaped the research, and provided structure to the writing process.

3.9 Ensuring Rigour

The quality and rigour of a grounded theory study is determined through the researcher’s skill and organization, appropriateness of the method for the research question, and “procedural precision” (Chun Tie et al., 2019, pg. 7). As a novice researcher, expertise and skill was addressed by using the constructivist grounded theory framework to guide data generation and analysis. As well, support from the thesis committee ensured methodological congruence with the research question and supported the accuracy and coherence of the codes and following data. Dr Carrie McAiney provided support through assisting with reviewing initial code development, reviewing theme development, and provided feedback. The thesis committee provided oversight and assisted with code checking and provision of feedback and suggestions, as necessary. As constructivist grounded theory is a construction of research from the researcher and participant lens (Charmaz, 2014), the purpose of oversight and review of the codes and themes is to reduce bias within the analysis. Grounded theory methods as a process enhances rigour through the systematic approach to the analysis of the data and is a strength of grounded theory (El Hussein et al., 2014). Additionally, procedural precision was addressed through keeping a detailed audit trail of decision tracking, maintaining a management strategy for the data, and producing memos (Chen Tie et al., 2019). Please see Appendix N for the detailed analysis plan.

3.10 Position and Role of the Researcher

The use of constructivist grounded theory in this study was purposeful to align with my personal epistemological stance. My theoretical orientation is that of social constructionism, with the belief that our understanding of the world is developed and enacted through social relations including how we perceive and understand gender and caring. In pursuing this research, I was able to dismantle my own conceptions of men and their role in providing care. The experience of this study challenged my preconceived ideas of men who provide care. The interview process was deeply emotional, men shared parts of themselves with me that they likely hadn't shared with many. I was touched by the love and dedication that they had for their wives, for their great sense of loss, and their continuation to persevere in caring through grief and for their willingness to share their experiences with me. I was surprised to find that I had so much interest in my research from potential participants, as well as men who didn't quite fit my criteria but felt such urgency to share their experiences. I regret that I was not able to engage with them; however, their outreach exemplifies the necessity of research and the lack-there-of within this field on men's experiences. I am truly grateful to have had the opportunity to enter into this space and honour the reality of men who provide care for their wives.

My role in this research was multifaceted. I took on a research question that was posed in a brain-storming session in 2019 with the Murray Alzheimer Research and Education Program, asking how to engage men caregivers in the services available to caregivers of persons with dementia. Participants in this session noted that most of the people who came to events, support groups, and gatherings were women caregivers. Originally, I sought to understand what the barriers and facilitators were to accessing services for men caregivers; however, in reading the literature, the question on their experiences in being a caregiver as a whole was still underdeveloped. In order to capture the reason for lack of service use, the question about their experience also had to be considered.

As a woman, I found it interesting to consider how men conceptualize caregiving because it is considered a predominantly female role. As a researcher the impact of my gender may be supportive in gaining insight into the experiences of men as caregivers. Discourses of masculinity may prevent sharing experiences with emotional depth to a researcher of the same gender, but this may not occur with me as a woman, who may be seen as an “insider” to the experience and more understanding.

Chapter 4

Findings

4.1 Sample Description

Interviews were conducted across Ontario, Canada with 11 men who lived with their wives who had dementia. All participants lived in the community and were between the ages of 61 and 88 years. Age ranges were evenly distributed; 60-69 (n= 3), 70-80 (n= 4), 80+ (n=4). Ten participants identified as Caucasian, and one participant identified as Portuguese. Two men expressed that they moved to Canada from Holland, two men were from England, and five men identified as Canadian, one man was from Portugal, and one did not disclose their country of birth.

Participants' education varied, with one participant completing a high school equivalent, two completing skilled trades, two completing college diplomas, three completing a bachelor's degree, and three completing a master's degree. Most participants (n=9) lived in an urban centre, and two participants lived in rural areas. One participant shared that he and his wife had moved from a rural area due to safety considerations with her dementia. The number of years since their wives' diagnosis ranged from eighteen months to approximately ten years.

Table 1: Participant Demographic Response

Participant Age	**# of Participants**
60-69	3
70-79	4
80+	4
Urban/Rural	
Urban	9
Rural	2
Education Level	
High School (or equivalent)	1

Skilled Trades	2
College Diploma	2
Bachelor’s Degree	3
Master’s Degree	3
Self-Identified Race	
Caucasian	10
Other	1
Country of Origin/ Ethnicity	
Canada	5
England	2
Holland/Netherlands	2
Portugal	1
Unknown	1
Number of Years Since Diagnosis	
1-3 years	3
4-6	5
7-9	1
10+	2

4.2 Overview

The findings offer a range of experiences for men as caregivers reflected in the quotes provided. Participants' quotes are labelled by symbols A01 to A11 to protect their identity. This chapter shares the study's findings and the dynamic interplay of managing an evolving relationship with a wife with dementia, the impact this experience has on husbands, and their perception of support for men.

Three themes were developed in this study as part of the process of being a caregiver as a man; *Becoming a Caregiver, Navigating and Managing Changes in the Relationship*; and *Organizing, Planning, and Re-evaluating the Future*. Each theme was broken down into three corresponding subthemes (See *Table 2*) that followed the trajectory of the men's experience and their journey with their wives' dementia. Participants described their experiences of caring for their wives, of their individual experiences, the challenges and struggles they experienced as a result of being a caregiver, and how they went about navigating and managing their experiences.

The men experienced a dynamic shift in how they interacted with their reality because of the complex relationship changes that were experienced because of their wives' dementia. Men negotiated their relationship around behavioural and relational changes their wives were experiencing (such as personal care needs and their wives' altered perception of reality) and altered their way of doing and relating to elements of their life as a result. However, the way men experienced this life transition existed within a range of experiences and perceptions with caring for their wives with dementia.

Table 2: Overview of Themes and Subthemes

Becoming a Caregiver	• Learning to be a Caregiver • What it Means to be a Caregiver • Experiencing Changes in Self
Navigating and Managing Changes in Relationship	• Navigating Loss and Grief • Managing and Avoiding Conflict • Maintaining Intimacy
Organizing, Planning, and Re-evaluating the Future	• Planning and Making the Decision for Long-Term Care • Re-assessing Money's Value • Meaningful Gender-Specific Supports

4.3 Becoming a Caregiver

The first theme within this study related to the process of becoming and being a caregiver for their wives through the diagnostic journey onwards. This journey started with learning to be a caregiver and making sense of what caregiving means to older husbands. Often participants relied on past life experiences to make sense of and transition into their role. Learning to be a caregiver required husbands to undergo a process of self-evaluation and growth, often experiencing changes in their sense of self. The first theme, *Becoming a Caregiver,* comprised of three subthemes: 1) *Learning to be a Caregiver*, 2) *What it Means to be a Caregiver*, and 3) *Experiencing Changes in Self.*

Learning To Be a Caregiver

With their wives' diagnosis of dementia, men were thrust into a new role: being a caregiver. Men described the necessity of learning their role and taking on new skills. Participants' development of their role as a caregiver was greatly influenced by their unique life experiences, impacting the ease with which they adapted and what types of support they utilized.

For most men, being a caregiver was not something they had done before. The learning process was often considered to be out of necessity. A participant who was starting to provide more and more personal care for his wife described the process as one that created discomfort for himself as he made the adjustments needed for her safety and care needs.

> *"It's out of necessity. To say it was smooth I have to admit... Seeing her struggle to get into the tub a few times, made me nervous." – A07*

This participant relayed that learning to be his wife's caregiver was something he struggled with and described grappling with elements of fear as her dementia progressed which influenced his more active role. For some, learning to be a caregiver was a trial-and-error process. Participants discussed figuring out what worked and what didn't work for their wives when managing care tasks and aspects of their relationship.

> *"I've had to learn for a long time, and I learned by repeating things. And finally, it just dawns on you that certain ways is the proper way of handling situations so, so, yeah, it's a learning process, and I'm still learning." - A03*

Learning was an ongoing process that enabled men to be attuned to and aware of their wives' needs through changing circumstances. Most men sought support in learning how to provide care, build resiliency, and cope with this new role. Men utilized a range of supports, including education and training, support groups, personal support workers, and services, such as meal delivery and housekeeping. The amount of access of support mechanisms was variable between participants. Some men sought out many avenues of support and education in order to learn, whereas others only briefly engaged with services, such as those offered by the Alzheimer Society.

Additionally, unique life experiences influenced how men provided care to their wives, including their upbringing and learning from women in their lives or their connection to their own mothers; generational social or gender roles; experience with providing care previously; personality type and belief system; their previous work and professional skills; and utilization of support to aid in the development of their role. These life experiences impacted how men transitioned into the caring role and created variations in how they conceptualized themselves and their marital relationships. For some men, the process of becoming a caregiver for their wives was relatively easy. These men shared how they had been socialized to provide care from their families and were influenced by their mothers.

> *"My mother actually took care of her grandmother and mother, and her mother also got a stroke right away. And so, I had heard all these stories of how women deal with these kinds of situations, and it has acted as a model and an inspiration for me to follow the same path."- A05*

This participant, for example, reflects that his upbringing around women who provided care served as a model and inspiration for his caring role. His past experiences and the way his family dynamic emphasized the role of women and caring influenced how he conceptualized his ability to care for his wife.

Additionally, some men had expressed that within their own families and their marriage, less restrictive gender roles existed and had enabled an ease of transition into providing more care work.

> *"My father had been ill before. And my mother worked. My father died in 47. So, I used to do, help around the house and go shopping, and do some cooking even what even at that age. […] So, I've always been involved, knew how to do the laundry, knew how to cook, nothing fancy but I've always been involved*

> *that way. […] And as far as most of it, it hasn't been hard to do all of the things. It's just that I wasn't expected to be doing all of them every day." – A04*

In this participant's experience, he grew up supporting his family, which later followed into his marriage. He took on roles within his household that were traditionally considered more women's work. For him, the transition into providing more care work was about the totality of the work rather than learning new skills. His experience shows that transition into a caring role may be easier for men who had previously performed more feminized work.

The participants who had caring experience previously expressed that their transition into the role of a caregiver was natural to them. For example, one man describes how caring was a role that was honoured in his family.

> *"I've thought about that a little bit. And I think the best way to say is that I come from a long line of caregivers. There's a lot of people in my family, both on my mother's side and my father's side who were nurses or doctors and at one time, I thought I was going to be a nurse."-A10*

This participant reflects that he would have become a nurse at one time and felt that caring was natural to him. However, he later disclosed that he did not pursue being a nurse because few men were in nursing at the time. His experience both reflects how familial history impacts role structuring within caring for a wife with dementia and shows that gender roles and socialization impact and influence men's life experiences which may later translate into how they develop as a caregiver.

Other men did not describe a sense of ease with the transition into their role but relied on metaphors of obligation and morality or comparison to previous careers as a means to understand their role. These men described how their belief system directed their sense of responsibility to their wives and motivated them to provide care.

> *"She's one of my own, so and again I feel moral obligation, moralized to do as much as I can, give as much as I can, in order to minimize her suffering. To impersonate a kind of life I'd like to have if I was in her situation. Do to others*

> *what you'd like other to do to you. So, I believe I am doing that, I'm achieving that." – A06*

This participant draws on religiosity and moral duty to construct meaning into his role. He feels that he needs to provide her the best care possible and facilitates a positive sense of self through this moral obligation. This participant's reflection exemplifies how some men draw on their religious views, morality, and sense of duty to provide care for their wives.

Some men drew skills from their previous work and professional skills to aid in the transition to caring for their wives. A man who had prided himself on his career described how he conceptualizes his care role:

> *"My whole career was in administration at [college]. And so we did a lot of, you know, staffing, and contract administration. And so I read a book early on, from a lady that lived in Toronto whose mother was in Oshawa, I think. And she was an accountant. And she worked full time. And she said, I don't know how to provide care to my mother, but I know how to run a business or service from a business perspective. And that's what she did. I thought, that's a heck of a good idea. I don't, you know, I'm not trained in personal care. But I do know how to get services to provide and meet my needs. So basically, that's kind of the way I've approached it." – A02*

This participant utilized his professional background to help facilitate care in a way that he understood- through coordinating care. For him, his role became managing elements of his wife's needs. This exemplifies how men may restructure their professional roles to enable the transition into a role they previously did not do.

The examples above illustrate how men drew from their previous life experiences to understand and construct their roles as a caregiver for their wives. The construction of their role varied significantly between the men and showed a dynamic range of unique life experiences that influenced their perception of their role as a caregiver.

What It Means to Be a Caregiver

The second subtheme within *Becoming a Caregiver* was a conceptual understanding of *What It Means to Be a Caregiver*. Men perceived caregiving as an all-encompassing experience, describing it as relational, emotional, physical, and all-consuming. For example, a participant shared that caring is comparable to a balance between emotional and physical work.

> *"There's two things to each one. One is an emotional thing; the other is a physical thing. You can put it off to the, those starving children which is a care, but you're not giving them any emotional support. One is caregiving is equal to or less than 50% […] ultimate caregiving would have to have both of those components." – A09*

His example articulates that caring at its best requires both emotional and physical elements to it, emphasizing that care without one of the elements is incomplete.

Participants explained that caregiving, as a concept, was both emotional and physical work, ensuring that their wives' mental health is taken care of as well as her physical needs. However, the conceptualization and practical application of caregiving were not aligned for all participants: all men thought of caring as both physical and emotional work, but not all men provided personal care. One participant succinctly described how he perceived caregiving as a concept:

> *"I guess the question was what is the term caregiving mean to me? Taking care of the needs of another person. Taking care of all the needs. I'm not sure whether I qualify to call myself taking care of my wife. I don't take care of her personal needs. I don't think she would let me anyways." – A04*

His reflection exemplified the discrepancy between providing care and the conception of being a caregiver. He expresses that he believes caring is about caring for the whole person and their needs; however, he doesn't feel that he accomplishes this in his daily life with his wife. Rather he questions whether he would define himself as a caregiver. In this context, the definition of caregiving as "emotional and physical" can potentially limit the self-definition of being a "caregiver" if men do not provide support in personal care. Some participants described a sense of confusion about whether they would consider themselves a caregiver since they did not perform personal care. This conception may explain why fewer men self-identify as a caregiver.

Experiencing Changes in Self

Within *Becoming a Caregiver*, participants navigated and negotiated their sense of self. The process of caring for a wife with dementia facilitated opportunities for personal growth for many of the men. They described experiencing varying levels of personal growth and self-reflection or Experiencing Changes in Self. Their experiences impacted their view of themselves and compelled reflection on their own perception of their role and their marriage.

Most participants reflected that the process of becoming and being a caregiver for their wives enabled self-awareness and the development of patience. For example, one participant articulated how the journey through his wife's dementia opened the opportunity for him to be more aware of himself:

> *"I've become more aware of myself and more aware of my faults and weaknesses. I've tried to work on those, and I think to some, with some success, perhaps quite a bit of success. I've learned a lot of new skills, things like, [wife] always did the cooking and everything else. And now, I'm making meals. […]. But it's more, It's more spiritual. When you look out and you see something beautiful, you think how lucky you are. My wife is very loving, and we hug and kiss a lot. So that's important. That's still there."- A11*

For this participant, becoming and being a caregiver was just as much a spiritual journey for him. He now constructs his experience through a lens of gratefulness of "beautiful" things, comparing his wife's affection to moments of joy and an appreciation for the skills he learned through becoming a caregiver.

As part of accepting their wives' dementia, men also described how the circumstance positively impacted them by teaching them tolerance and describe becoming a "better person". The men often explained that they developed more awareness of their wives and of others.

> *"I think I'm a better person for taking care of her. I have certainly become more aware. She can't tell me if she's got an ache or pain or anything like that. So I've become more aware of… I never wanted to be a doctor (laughs), but I am I'm a lot wiser on some of that stuff."* – A07

This participant shared that he learned how to become more aware of his wife and her needs without having her express them verbally to him. He believes that he is a better and more self-aware person through learning this skill and adapting to his new role. Another participant described what advice he would give to another man who was caring for their wife with dementia, reflecting on the patience he learned as he developed as a caregiver.

> *"You know what I face to say, do to her what you'd like her to do to you. So, and I will tell him, you have to have lots, loads, loads of patience, you know, because the kind of behavior that they exhibit you know, it's demands tremendous, tremendous amounts of patience, but again you have to realize that its not her fault. You know, it's, these are the circumstances. […] I know that she doesn't ask for that, she didn't create that […] you have to be extremely patient, extremely careful with her, right."* -A06

Many of the men developed a positive appraisal of themselves through their caring role, learning patience, feeling like they've become a better person, developing a positive lens to their experience, and increasing self-awareness. However, the process was not linear and required new and continuous reconstruction of their sense of self. One participant also reflects this process acutely:

> *"As I think it made me, making me a better person. Yeah, although I question myself that I do a good job, continuously. So, I'm doing it. It's not easy. That's not easy to express myself in."* – A03

His reflection is muddled with questioning if he is doing a good job as a caregiver, even though his initial thought is that he has become a better person. The way he expresses both the positive elements of his experience with caring and how he questions his perception of himself exemplifies how growth is a process and may be experienced in different phases and negotiated over multiple self-reflections.

Growth was a deeply personal process and was not universally understood in the same way. The majority of participants were at some level of engagement with the process of personal growth that facilitated a positive appraisal of their self-concept. Some men were at a high level of self-awareness and had embraced the growth process. These men described how they conceptualized the experience of caring for their wives. The men described a lack of concern for others' perceptions of them, of appreciating the time they have left with their wives and accepting her where she is and her reality.

> *"I'm lucky enough that my situation is that I, I'm in retirement now so that I can focus on this and spend as much time as necessary. I look at each day is as a gift and take it from there. So, I'm not really concerned about what other people think or what what's going to happen, you know, a year from now. It's taking more of a day at a time. So, your perspective changes. So, there's less, less stress that way, I get a much better sleep." -A08*

This participant shows a deep sense of acceptance for his wife's dementia which facilitates an ease of caring for him. Other men were at early stages of understanding themselves and their wives' dementia, beginning to recognize elements of themselves that had changed over time and experience. A participant who had more conflict with their wife reflected that the positives for him were with how he related to others.

> *"The only positive thing is that my relationship with other people is probably much better, if that makes any sense. My relationship with other people with friends. I'm much better, I think, more caring than... and understanding situations than before. That's, that's the most positive thing, yeah." – A03*

Although his reflection does not depict a positive relationship with his wife, he felt that he still engaged with positive growth with how he understood others. However, not all men had a positive appraisal of their experiences and had not fully engaged in a growth mindset. In contrast, men who experienced more conflict with the growth process often described themselves in ways that were self-deprecating or experienced internal conflict. One man described that he worries about how his kids think about his caring.

> *"It's constantly on my mind how other people think about me. And how my kids think about me, am I doing the right thing for my sons, two sons. Do I keep a good relationship with them?"* - A03

He worries that his relationship with his sons may become frayed with how he cares for and provides support to his wife and how he cares for himself. Another man described how the process of being a caregiver has made him more nervous and has had struggles navigating challenges with his wife:

> *"I'm not as patient as I was. I tried to be. I realize that all the writing say somebody with dementia, don't yell at them. That's very hard not to do. Soon as I've done it, I've regret it. But it's very hard. Because she can be stubborn and what she decides she doesn't want to do, even though I don't ask her to do anything that isn't for her good. I think I've changed a little bit; I think I think I'm probably a more nervous person than I was."* -A04

This participant reflects that he has had a difficult time with his wife and navigating communication through challenges. He expresses that he knows he should communicate a certain way and struggles to accomplish this in his conflict with his wife. The acknowledgement of knowing what he should do is a step towards changing his own behaviours and positive personal growth; however, executing positive communication strategies described in the dementia education (or writing as described by the participant) may be more challenging. He may first experience a decline in his mental health as he initiates the steps for personal growth.

Elements of the growth process may be facilitated through being and becoming a caregiver for their wives over time. These reflections suggest that growth is an individual, non-linear process negotiated through time, experience, and self-reflection. Positive self-appraisal may be associated with acceptance of their wife's dementia and learning skills to promote patience and self-acceptance. Those who struggled with the growth process may need to continue to navigate negative perceptions of themselves and their caring as they experience changes in their self-concept.

4.4 Navigating and Managing Changes in their Relationship

The second theme developed in this study was *Navigating and Managing Changes in their Relationship.* As the process of being a caregiver for their wives continued, men needed to navigate changes that occurred as their wives' dementia progressed. Men needed to navigate loss and grief and find ways to cope with change within their relationship. The men managed their relationship by avoiding conflict with their wives and finding ways to continue to maintain intimacy. This theme is composed of three subthemes: 1) *Navigating Loss and Grief*, 2) *Managing and Avoiding Conflict*, and 3) *Maintaining Intimacy*.

Navigating Loss and Grief

Throughout the journey of dementia, men described a great sense of loss both within their relationship and their personal experience. This included a loss of an idealized future, a loss of independence, and a loss of partnership with their wives, or the relationship they had as it once was. The process of loss triggered feelings of guilt and grief for men that occurred at different times through their journey and as their situation evolved.

Loss of Idealized Future and Loss of Independence:

Many of the men experienced a loss of an idealized future. An idealized future refers to men's experiences and dreams about their future, including their retirement. Some men felt a loss of "the golden years", a loss of a planned second career, and an inability to travel or be "snowbirds". For some men this meant a loss of things that they enjoyed, such as hobbies, often giving up pieces of their identity to ensure safety and provide care for their wives.

> *"What I have given up is I was teaching photography and Lightroom and like Adobe courses and things like that, and that I've had to give up, because I don't have time for preparation. And I can't guarantee at any given time I would have*

> *been able to go out. And since COVID-19, I can't even guarantee I'd be able to sit and do a Zoom thing. So, I've given that up." – A01*

These men articulated that pieces of who they are were abandoned due to the circumstances of caring for their wives or that they no longer have the ability to enjoy activities that brought value to their lives.

The loss of an idealized future was associated with a loss of independence and time as their wives' needs and, subsequently, their caring role became more intensive. The intensity of care required created barriers to exploring what the men had thought they would like to do in their retirement. Many men expressed giving up hobbies and activities that they enjoyed and were part of who they were. One man described how he enjoyed walking in the "bush" but didn't do so now because his wife wouldn't be able to handle it with him. Other men gave up hobbies to avoid long periods of time away from their wives. It was common for men to express that they spent increased time with their wives and lost much of their independence as a consequence.

> *"Well, she needs 24/7, care. Like I, I used to curl about three times a week. And so did she. But now to get someone in? [...] Curling takes two hours, and then you got to get there and get home again. So minimum three hours you'd be out. And since [wife] was incontinent, that's a lot to ask of someone else and I wasn't going to pay to have a stranger come in and do it. [...], it's just as [wife] progressed to the point where, like I say, I just didn't want to leave her alone and I'm only gonna have so much time with her going in the future. So, I've kind of set my goals to get through this year. So, every time we hit the next month, that's kind of a success." – A07*

In some cases, like the participant quoted above, men accepted the loss of their past life and instead focused on what time they had left with their wives. This conception of their remaining time as a gift allowed men to move into the preservation of their relationship and cherish the remaining time with their wives.

In many cases, as their wives' needs and reliance on their care and support increased, men's sense of independence decreased. This loss of independence also facilitated a sense of loneliness. Every participant described feeling lonely at some point in their journey. Some men describe the intensity of being a caregiver and lack of understanding of their situation, the stigma associated with dementia, and the lack of their own social networks influenced their feelings of loneliness.

The struggles experienced through such losses also influenced men's reflections. Some men desired for their wives' illness to be over, wishing her an easy death. However, they quickly retracted and expressed that they didn't actually want their wives to be gone.

> *"There are some days it runs through my mind; let it happen quickly. But then that isn't what I really want. But in times of almost desperation, I'm thinking, let it happen soon. But I really don't want that."-A04*

Participants recognized that they would feel loss and loneliness following their wives' death. The conflicting emotions experienced by participants was associated with ambiguous loss and grief, wanting the hardship and suffering to be over for themselves and their wives, while also recognizing that the end of the journey, or death, means a loss of their life partner.

Loss of Partnership:

All men experienced some form of loss of partnership within their marital relationship. In caring for their wives, the men were forced to accept a new version of their relationship through grief or sometimes through denying grief. This often required a reconceptualization of their relationship, although this experience varied between participants. Some men showed a deep awareness of loss and had moved into reconceptualization of their partnership. Other men were in intermediate stages of the process and were struggling with the negotiation of loss. Some men had not engaged with the process of coming to terms with change and used denial to distance from the changes and conflict in their relationship.

Most men expressed that loss of partnership occurred concurrently with the progression of dementia. After the onset of relationship changes, men struggled with the loss of companionship that was the basis of their marriage. This occurred over time and experience with additional changes and challenges. One participant described struggling with loss of partnership, wanting a loving and affectionate relationship, and feeling jealous of people who seemed to have that aspect remain in their relationship.

> *"…Continuous thoughts of I didn't bargain for this I didn't want this in my later life […], I want some companionship […]. I want somebody to talk to. Of course, that's not, that doesn't happen anymore. And some people some in our [support group] are so passionate with their wives, they are, call them Sweeties, "I got to take care of my sweetie now. I gotta, sorry." Anything for their wives. I'm learning from that and that's not easy…" – A03*

The participant quoted above struggled with a deep loss of companionship and affection. His reflection highlighted that he was navigating this process and used other people's experiences in his support groups to learn how to be a partner with his wife again.

In later stages of dementia, men needed to navigate the loss of recognition of who they are and what their relationship is with their wives. In some instances, men underwent a process of reconceptualization of their partnership and marriage. One participant described that he is not sure who he is to his wife anymore.

> *"She hasn't recognized me as her husband now for a long time. Although she did tell the one PSW "Yeah, that's my husband", while I was out. But to me, she hasn't called me by my first name in at least a year and a half. And I, even though she says she loves me, and she'll give me a kiss and so on. And we still sleep in the same bed, […] I'm not sure. I think she's not sure what the relationship is. And I've asked her a couple of times as well. You know, like, Who am I to you? What's our relationship? You know, just to see what she has to say. And she's never been able to really to come up with an answer other than one time. It was sort of a friend, but no more than that." -A01*

He describes how the way his wife perceives him fluctuates and that he has had to become more-or-less comfortable with the instability of her conception of their relationship. When describing his struggle with this process with his counsellor, he is told to remember that the woman he married is still in there.

> *"I mean, as the counsellor one day was saying, remember, she's in there, she's in there, and yeah, she is in there. But day to day, it's not the person I married or lived with all those years."- A01*

His journey through loss required a reconceptualization of his role in their marriage as a way to cope. He highlighted the profound sense of loss in his reflection that she is no longer the person he married. He conceptualized her as a figure of his previous relationship but acknowledges that it is not the same, that he cannot expect the same companionship and relationship as before.

Men often described accepting that dementia is a "one way journey", and that the person they had married is not the same anymore. A participant acutely expressed how he went from not appreciating advice from the doctor to understanding and accepting the diagnosis.

> *"I didn't appreciate what he said to me at the time, but I do now. He said, once he diagnosed [wife] as having dementia, he said, you figure out what gives you joy in life and go and do that as long as you can. And I thought what kind of medical advice is that? I want a pill that's gonna fix it, right. But in the end, it was probably really good advice because there is no fix." -A02*

Part of the negotiation process was finding ways to re-establish connection with their wives and accepting the irreversible nature of the disease. Some men relied on remembering who she was in the past as motivation to continue on with caring. Some men also used strategies, such as reframing conflict to remember that she didn't choose to have dementia, that the disease is happening *to* her, not *because* of her. Other men compared their wives' behaviours to a child in order to accept the changes and bring empathy forward in their relationship. One man described appreciating the value of seeing his wife as a child and seeing the joys in that experience.

> *"The other thing I consider… have the impression, is that I'm looking into childhood of my wife. Right? I'm looking back in time. Sounds a bit weird, no? What I see […] is a lovely, naughty, independent child. That's what I see. I see some value in that so, two wives for the price of one."- A05*

He conceptualized her behaviour changes as akin to childhood play. Another participant shared that he views his wife now as similar to his granddaughter.

> *"And now she is function, I would say like a four-year-old child. And I have a four-year-old granddaughter, you know, both of them, they are in same, intellectual speaking, they are in same level, problem solving." -A06*

These are examples of how men have tried to reconceptualize their experience and their relationship and create meaning through relating to something they know well, children or childhood. Although not perfect metaphors, the comparison brought gentleness into their conception of their wives' experiences.

However, in some cases, men did not undergo reconceptualization and instead refused to acknowledge their role in meaning-making or their relationship's dynamic. Some men stoically assessed their actions as inconsequential and did not engage with self-reflection or reconceptualization of their relationship. For example, one man denied an emotional response to his distress and compared the difficulty with his wife as insignificant compared to the COVID-19 pandemic.

> *"The overall […] scenario, we're all going to die, sooner or later we all die and that's a fact. There's no use weeping about it, that doesn't solve anything, doesn't provide any relief. If you look around, we've got a pandemic with hundreds of dying all over the world. […] Any little thing that happens between my wife and I, I compare it to that, it's water off a ducks back. She has bad days, bad moods, there's nothing really, I can do except feel sorry for her. And feel sorry for how the world has been." – A09*

In these cases, men may experience difficulty with navigating relational changes if they deny changes in their circumstance, their wives' needs, or their own emotional difficulties.

Experiencing Grief:

The level of grief experienced by the participants of this study existed on a spectrum and was described as evolving over time, often emerging and re-emerging as change arose, such as memory losses, functional decline, or when crisis points were experienced. When changes occurred with their wives' dementia that required additional support, the level of grief fluctuated as the men experienced new challenges and then adapted to their new context. For example, a participant described how he felt sorry for himself, while backtracking his experience so to emphasize that he shouldn't complain or express difficulty.

> *"Most of the time, I feel sorry for myself and moan and groan and complain. Sorry, I'll do, I [have it] pretty good. If you, you probably think I have it pretty good too." -A03*

His reflection of his grief demonstrates how complex emotions may be expressed in conflicting ways. Further, grief existed with other emotions as well. Anger, frustration, sadness, hurt, despair, and guilt. Navigating difficult emotions became a part of the process of managing their experience with their wives' dementia. Men described varying levels of which they were able to process their negative emotions. Some relayed that they recognized their negative emotions and were actively trying to mitigate them.

> *"I guess I'm happy with myself that I am still managing with her at home. A lot of the times, things do run reasonably smoothly. I'm not so happy with myself because the Irishman in me still comes out in the way of a temper, even though I try to work on keeping it under control. So, some days it's very, very hard." – A04*

Many men, like the participant quoted above, recognized their negative emotions prior to finding ways to mitigate them. Additionally, some men described feelings of internal conflict at times during their experience. Internal conflict was related to the experience of negative emotions, experiencing relational conflict, and lack of acceptance of the disease. Many men were able to confront elements of the internal conflict and learn how to navigate their negative emotions. One participant described how he recognized that his negative emotions were coming out in a harmful way, and mitigated the impact of his emotions by removing himself away from his wife.

> *"[…] for some reason it got to me at that point and I just briefly, I mean, I had to walk away for a bit and just take a few deep breaths then come back and it was, it was okay again but for the most part now, it's a struggle I find to, to force myself to be detached enough not to let things like that bother me, but not become so detached that she isn't my wife anymore."* -A01

He was able to recognize his negative emotions and seek support in learning how to react and what to expect with dementia. This participant took on active forms of support by seeing a counsellor which helped facilitate this skill. Other men in the study had not yet successfully confronted their internal conflict and struggled with negative emotions while wanting to be a better person and caregiver. For example, a participant discussed how he was unsure how to conceptualize himself:

> *"I guess, sometimes I'm disappointed in myself because I can't seem to handle things the way I really feel I should. And other times I pat myself on the back. Because so I'm betwixt in between. Am I a Good Guy or am I a Bad Guy?"* – A04

In this case, negative emotions may be associated with navigating the loss and confusion that occurs as husbands learn about dementia as the disease progresses, especially at the onset of the disease where men have little knowledge of the disease, and again when additional challenges occur in providing care.

Managing and Avoiding Conflict

For participants in this study, part of navigating their evolving relationship with their wives was managing and avoiding conflict that arose due to the progression of dementia. Men experienced an increase in conflict that needed to be managed, often using both prosocial or maladaptive techniques to prevent or respond to conflict.

The men described an increased conflict between their wives and themselves associated with changes in behaviours and needs as a consequence of their wives progressing dementia. For example, one participant explained that when his wife becomes irritable and confused, and demands he leave the house, he must assess the situation and determine how to manage this conflict to de-escalate and protect himself and his wife.

> *"The one time she wanted me to leave, it was 6:30 at night after supper and we're just about to get ready for bed. So now it was, okay, this is how's this gonna go? So, it was more a concern for how am I going to manage this over the next few hours, or whatever time it takes to resolve it."*- A01

Learning how to de-escalate conflict was a prosocial skill that some of the participants developed and enabled a more confident and positive self-perception of themselves. Other men used validation techniques to avoid conflict and affirm their wives' realities or implemented environmental changes such as removing the knobs off the stove top to prevent their wives from turning it on. This action was described as a way to provide protection while also changing the environment to prevent conflict arising in having to deter her from using the stove. The action is paired with deflection or "white lies" to foster their wife's comfort with the environmental changes and prevent negative discourse over safety elements arising out of her dementia.

> *"So, and deflection, use deflection a lot, starts down something and then say "Oh, would you like to go for a walk[...] because there's Alzheimer's can lead to wandering, all our exterior doors now have little chimes on, so when I put those on, I said to [wife], that's in case somebody ever breaks in "Well, that's fine". And [she…] took the kettle that we had- one of those electric kettles and put it on the stove and turned on the heat and [burnt] the bottom out of it. So, I took off the knobs off the stove […]. And if she asks about where the knobs just say, oh, I had to take them off. And it passes, her memory for things like that's 15 seconds. It just disappears very quickly."* -A11

Preventing conflict from occurring in the first place enabled the men to keep a closer connection with their wives and promoted more positive reflection of their overall relationship.

In some cases, men used avoidant or distancing techniques to prevent conflict. Some men hid from their wives (in a closet, garage, or basement) to avoid eavesdropping or confrontation when they were talking with other people.

> *"Yeah, I'm sitting in the garage, and I know she can't hear me, but she might just eavesdrop. Which she has done in the past. […] I had a conversation with my son the other day and I noticed that she was leaning over upstairs. Over the banister, […] to listen in on my conversation to my son. So, I know she's very anxious about these things, I'm […] trying to avoid a confrontation, with her, so." – A03*

Additionally, some men explained that using the words Alzheimer's or dementia was, or may be, upsetting to their wives and therefore avoided using these terms. For example, one man avoided the use of the "Alzheimer's Society" around his wife to avoid conflict. Instead, he would tell her he is involved with the Local Health Integration Network (LHIN).

> *"She doesn't know I'm in contact with Alzheimer's, as far as she's concerned, is through LHIN. I haven't hooked Alzheimer's word to it. And she seemed satisfied with that. I can't pull that stunt too many times. […] Because with some of the things she's forgotten, she has trouble believing what I tell her. Somebody else tells her that's okay. But if I tell her, it isn't necessarily the truth. So, I try to skirt around things."- A04*

Another man explained that his wife had asked him to kill her if she ever developed dementia and in order to preserve her sense of peace, he avoided the use of the word "Alzheimer's" or "dementia" around her.

> *"Now for your information, my wife told me when we're, we're still dating, many years ago, that I should kill her if she will get Alzheimer's. So, I consistently have prevented use of the word Alzheimer's or any, any indication that of Alzheimer's for all this time, yes. I make mistake once, mentioning Alzheimer's*

> *in her presence. And she had a very scared look on her face and says, "I have Alzheimer's?" And after …. "Alzheimer's no", she said "okay". So, I don't I don't do that that way."*- A05

Navigating the relationship changes that occur due to dementia includes elements of avoiding conflict. Wives' perception of reality was different from that of their husbands, which, without a clear understanding of dementia or what their wives were experiencing, can increase conflict between the couple. To adapt to this process, men may use avoidant strategies and deflection to reduce the incidence of conflicting realities. Other men adopted prosocial strategies that enable their wives to experience their reality while maintaining safety.

Maintaining Intimacy

The third subtheme within how men navigated and managed the evolution of their relationship was through *Maintaining Intimacy*. Although there was grief in the experience of losing the relationship they once had, there were also beautiful glimpses into maintaining intimacy (albeit differently). Maintaining intimacy was a way for men to hold onto their marital relationship. How they showed affection and intimacy varied with each man and was unique to their marriage. Within this study, men showed a range of ways in which intimacy was expressed in their relationship, through the employment of familiar everyday strategies, holding onto moments of affection, or when experiencing extreme loss or conflict men refrained from intimacy and withdrew or focused on protecting themselves. Men often used a combination of these strategies while navigating the progression of dementia and their caring role.

Men maintained intimacy through how they engaged their wives in their daily life. They described doing things together as a way to provide care as well as continue to share their lives together within their relationship. Provision of care in this context extended to emotional and recreational care that enabled higher quality of life. Some men focused on engaging their wives in everyday tasks to enable her autonomy, making sure that she feels helpful and needed, exemplifying an awareness of her need for belonging and feeling useful regardless of her memory challenges.

> *“She's good at stirring things though. Pasta or any sauce that needs stirring. She'll sit there and stand there and stir it quite nicely and she's good at doing that. […] One of the struggles is still trying to redirect her without saying no. Because no she takes as […] I've done something wrong. But yeah, I still let her help where she can with that. The dishes after supper she normally wants to wash. I sometimes if we've been having greasier stuff or there's more greasier dishes, I'll try and convince her to dry so that I know I can get everything washed with soapy water. And I won't have to redo them after she's gone to bed. But either way, she helps with it. And I don't discourage her from helping. Again, because she seems to enjoy it”- A01*

Men engaged their wives in in everyday tasks to help them feel autonomous and valuable. Many participants put in effort to ensure their wives felt like she was doing the right thing and helped her keep a sense of herself by facilitating the sequences of actions. Often the men used this shared time together to maintain normalcy, which can be comforting to both individuals.

Participants also maintained intimacy through paying attention to what their wives enjoy and being part of that experience together. For example, one participant described the importance of music to his wife:

> *“There's been some music programs that have been available on and off and so able to put them on the computer and some of them are sing along and some of them are just listened to. And my wife’s got a music background, sang in choirs and so on. So, music is very important for her.” – A08*

The participant quote above exemplified how there is some continuity of elements of his wife’s life that are important to her and recognizes that through facilitating those elements, he can engage her in a meaningful way. Facilitating experiences that men know their wives will enjoy may enable positive feelings for their wives. Understanding what their wives enjoy allows them to have strategies to utilize when their wives experience distress or may need a sense of comfort. Engaging in these experiences together may attune their ability to draw on these strategies in times of need, while also bridging feelings of enjoyment for their wives with themselves.

Additionally, many men described ways in which their actions promoted feelings of closeness and affection with their wives as a way to care for their emotional needs and maintain intimacy. For example, one man described reading to his wife each night.

> *"And since the fall, I've been reading to her most nights till either 7:30 or eight o'clock. So, half an hour to an hour depending on the story and whether she's nodding off or whether my voice is getting hoarse. And she likes that."* -A01

Another man described rubbing his wife's back each morning when they wake up to start their day.

> *"Well, I wake up in the morning. Often, I give her back rub in the morning and back rub at night. We've been, we're coming up on 60 years at the end of June and started giving back rubs when we were first married. Now, I'm over 20,000 backrubs. So that's often the start."* - A11

The men also promoted intimacy by adding emotional and deeply personal elements into their care provision. One participant went into great detail about how he supports his wife, he took care to feed her carefully and serve food from her culture which she is more familiar with at her current stage of dementia.

> *"I make some food, or I make tea for her, because she can no longer, umm, she can not tell when the tea is too hot, so I'm taking great care of the temperature, and I'm using laboratory squeezable to basically squeeze the liquid into her mouth. […] I make Japanese dinner basically every day. So, around six o'clock we're sitting together at the table and having Japanese dinner."* – A05

This detailed orientation to her care showed his love and dedication to his wife that remains throughout the progression of the disease and his ability to adapt to her current reality. Men who described practices of being present to their wives' reality enabled a closer connection with their wives. Connecting with their wives in this way may maintain intimacy longer and allow a deeper sense of love to continue into later stages of dementia.

Another way men provided emotional connection was through paying careful attention to their wives. One man described how he attends to his wife's bids for attention and speaks of the value of being present in those moments.

> *"If there's curling on, she'll want to sit and watch curling, but within a minute or two of it starting she'll start talking. So, we do spend a fair bit of time. And as soon as she does that, I either turn the TV off or mute it, turn, and face her and let her talk. Because I find if I do that, she stays more engaged. And I have to be careful because if I show if it looks like I'm not showing interest, she'll sometimes get annoyed."- A01*

By turning off the TV and being fully present in his conversation with his wife, he shows her that he still values her presence and their relationship. By attuning to her bids for attention he may promote emotional safety in their relationship. Another participant described the process of being attentive to his wife to facilitate feelings of closeness and connection. He describes the benefits for himself of being attentive to his wife and how through paying careful attention to her, it opens opportunities for shared love and affection in "bright" moments.

> *"So, I bring her to bed, right? And I lead her by hand, and while I bring her to bed, I am looking in her eyes, and she's happy. I can see she's happy. Right, and I have more occurrences like that right, I mean the other thing Alzheimer's is, it's like a lighthouse, long, long periods of absolute darkness, and then sudden, sudden beams of brightness. But it's totally, comes randomly. You have to be aware, and when you are aware of that, these moments are great." -A05*

He describes his experience with his wife's Alzheimer's to be like a lighthouse, offering moments of brightness that can be missed if he does not pay attention. These experiences show that throughout the journey of dementia, many men hold onto their affection and love for their wives and look for ways to maintain their marriage in new ways. Utilizing active forms of affection may promote a feeling of closeness for longer with their wives.

In contrast, some men described a withdrawal of intimacy as a form of self-protection. One participant described that a reciprocal and intimate relationship with his wife was limited.

> *“So, it's really, it's really pretty limited to tell you the truth, right, at this point, or at this stage, which I think is probably […] it's pretty typical, I think.” – A02*

He shares that this removal of the more intimate self may be typical as dementia progresses. This may reflect more of how he perceives his wife at later stages of dementia or how he perceives intimacy. It may be more difficult to share intimate moments if intimacy is perceived as primarily a more sexual or physical act when their wives' dementia has progressed to later stages. Another participant described the choice of withdrawing from being her primary caregiver was facilitated by the choice to preserve positive memories of her.

> *“If there's wandering, or if things get physical, which can happen with Alzheimer people. I know men who have gone through that, then that's time. I don't want to destroy the memories that I have of her with having to put up with that and trying to work around physical confrontations or, or wandering. I just can't do that. So and then, when she gets in there, it'll be whatever time it takes until Alzheimer's finally claims her.” – A11*

He sees long-term care as a way to preserve his memory of her as she was and their marriage as it was before conflict. In these cases, withdrawal of caring may be a mechanism in which men maintain intimacy with their wives by protecting memories of their life and love previous to later stages of dementia and feelings of significant loss.

The ways in which men conceptualized and produced levels of intimacy varied and are subject to change over time, experience, individual perception of their wives, and conflict. Measures of self-preservation may disable more significant intimate connection with their wives but may preserve memories of their wives and act as a protection mechanism.

4.5 Organizing, Planning, and Re-evaluating the Future

The third theme in this study is *Organizing, Planning, and Re-evaluating the Future*. This theme encompasses three subthemes of how men experienced their caring role and the socialized requirements of being a man and husband through this journey. The first subtheme is *Planning and Making the Decision for Long-Term Care.* This subtheme reflects how through their wives' journey with dementia, the men were required to make difficult decisions around long-term care or their choice to provide care within their own home. The second subtheme, *Re-assessing Money's Value,* discusses how the value of money shifted due to their caring role and evolved as new meanings of wealth were developed. The third subtheme, *Meaningful Gender-Specific Support*, encompasses how masculinity and gender impact the wants, needs, and access of support for husband caregivers and participants' reflections on what they would have wanted for support and their current needs as a caregiver.

Planning and Making the Decision for Long-Term Care

The subtheme of *Planning and Making the Decision for Long-Term Care* encompassed how men were confronted as part of navigating loss and the evolution of a relationship with making difficult decisions in terms of their wives' care and planning for her needs and end of life. Every participant discussed the impact of decision making for their wives regarding long-term care. Long-term care was conceptualized as a moral decision involving discussion around the difficulty of making the decision, delaying the transition for as long as possible, the implications of making the decision, having distrust in the long-term care sector, and planning for crisis.

Men felt significant negative emotions in the process of making the decision for long-term care. The emotional impact of putting their wives on the list for long-term care was described as a feeling of abandonment. The men felt that they were failing by "abandoning" their wives by placing them in long-term care.

> *"I know when I signed her up for on the list for long term care. […] it's about a five year wait. So that's why I signed it up. […] I wouldn't have put her in if they'd have called immediately and said there was a spot. But that part, getting them on the list early. It feels like you're abandoning them." -A07*

The abandonment feeling may have been exasperated by a distrust in long-term care, especially as COVID-19 increased the negative perception of care.

> *"And also seeing what's happening with the long-term care over these COVID, COVID times and even now, you know, after everybody's been vaccinated, and*

> *all these long-term care places. It just, just makes me want to want to carry on even further, because I just don't want to want to put her in there."* – A08

However, the men also felt that they needed a contingency plan in case their capacity to care depleted and they could no longer provide the level of care their wives needed, or if they were to pass away before she did.

> *"The other decision I have to make has to do with for unfortunate events. […] it is fairly possible that I could get up half an hour from now and get hit by a bus and I'll die. What will happen to my wife at that point? Well, I do know what will happen to her, and she will end up in misery, in a situation I would never have wished for her. So, I need to take measures to prevent that from happening."* - A05

Many men expressed distress at making the decision for long-term care and described the feeling as "giving up" and needing strength to continue to care for as long as possible. For some, they felt that through learning their role and adapting to their new circumstances they could continue providing care for longer. Men spoke about how they experienced internal and moral conflict with the idea of placing their wives into long-term care. Those who felt they could make the decision rationalized their choices with having support from their family.

> *"The same struggle comes when I look at long-term care, will I be able to let her go to long term care? And will I be making the right decision? And we've talked about that, and both the courses and support groups as well. But I think now about how I feel about myself with that I feel that I can probably make that decision. Doesn't mean I won't be sad, or I won't question it when I make it. But I feel I can do that. Now. […] I don't think I could have made that decision a year ago. I think now I can. But I know I'll also have the support of my boys because I won't be making it by myself."* – A01

Some participants decided that long-term care was a choice that would enable better care, while others felt that it would decrease their wives' quality of life significantly or went against family values.

> *"And, in fact, at this point in time. [….] I have to make two important decisions. One, I let her go into long term care home because about two weeks ago on the telephone call that a place was available in long term care for her and I have decided not to do that. It's not a decision I take lightly. But, I do think that […] this is what I need to do, so if it was the level of care will go down so much. I don't like that, I don't want that." – A05*

The moral implications of the decision of long-term care were evident in the participants reflections of their decision making. Many describe family values, care quality, and the emotional toll of not knowing if it was the right choice in their reflections. This decision was individual and based on their own circumstances, how they adapted into their role, their wives care needs, and their own ability to provide care. Although the individual decisions were based on their unique circumstance, every participant experienced distress while contemplating their choices. Clearly, the decision was an extremely difficult emotional process which required men to assess their capacity as a caregiver, navigate feelings of loss, and come to terms with elements of their morality.

Re-assessing Money's Value

As part of *Organizing, Planning, and Re-evaluating the Future*, men in this study revealed how going through this journey with their wives had fundamentally challenged and changed their view of finances. Many of the men described a greater appreciation of the little things and a re-evaluation of the value of money. The value of money existed on a spectrum and was conceptualized in a way that affirmed men's self-conceptions. For some, the value of accumulating money had disappeared. They spoke of the worth of their experiences with their wives as much more meaningful to them, either expressing that they are glad they made choices to travel or use their money as a tool to give her a good life.

> *"And we chose consciously to have a mortgage in order to do some other things that we wanted to do. And it makes me so glad we did those things. Because we got to do a fair bit of traveling after we both retired, and because [wife] retired in 2009, and I retired in 2008. And so, we were able to do a lot of traveling and do a lot of things that if we'd waited till we were 65 simply wouldn't have happened. We'd have had money in the bank and nothing else. So, it's. it's made me glad for that."- A01*

This participant was grateful that he had spent his money in a way that allowed him to experience life with his wife before later stages of dementia. Another participant expressed that prior to his wife's dementia he had been inclined to save all of his wealth and has since re-examined this behaviour and what it means to him.

> *"The value of money has totally changed for me and what I mean by that, before [wife]'s Alzheimer's: save money, save money, save money. Work, work, work, work, save, save, save. And now its something like, What for? None of the money in the world will bring her brain back, right, and so the value of money has fundamentally changed for me, and its now a tool, method of keeping her happy or making things easier for her." -A05*

The participant quoted above now reflects that his personal values have shifted to provide the best possible care for his wife. Money is now a tool and method for providing care. In contrast, other men shared that money is of utmost importance and can enable them to provide good care for their wives.

> *"And another thing that I can say- Look, I am providing the kind of care that not so many people can afford to." – A06*

Although the sentiment of using money as a means to provide care was shared by multiple husbands, the values that were reinforced through their reflections differed, which may also reflect their caring styles. While some shared that accumulation of wealth became less valuable as their caring journey made them re-evaluate what was meaningful to them, other men shared that their caring journey reinforced the value of wealth as a means to provide care. Additionally, the men who shared money as of primary importance were more inclined to utilize and pay for personal-care services whereas the men who re-evaluated money's worth were more likely to provide personal care themselves. These men's reflections show that values and traditional masculine ideals are not necessarily experienced in the same way by every man caring for their wives.

Meaningful Gender-Specific Support

Within all aspects of this journey is a negotiation of what it means to be a man in a caring role, with masculinity presenting as a dynamic process. Constructs of masculinity point towards adopting new strategies for engaging men in services and supports that have meaning to them and adopting *Meaningful Gender-Specific Supports* in future program and support development. This can include purposeful engagement and specific supports for men centered on community and connection rather than emotions or aspects of caregiving. The men in the study discussed the importance of having tailored supports that understood the experience of men and valued peer connection.

Some men recognized that their behaviours could impede or facilitate support access and use. Participants expressed the value in seeking support, although they often were reluctant to do so. For example:

> *"Well, I mean, the counselor had to, you know, give me a metaphorical kick in the butt to get somebody in for respite. Because I was saying "I can do it". I'm doing it, we're doing it. I'm stressed. Yes, but I can do this." -A01*

Although he was dealing with higher levels of stress, he needed an additional push to access respite services. Many other men mirrored this in their reflections of how men in particular resist seeking support. Most of the participants described a shift in their mentality after accessing supports, regretting not doing so sooner, advocating for other men to access supports, and recognizing the value in the help they received. They also recognized that they themselves behaved the same way originally. One participant who now runs the support group for men for his community reflected on how he was reluctant to access supports:

> *"I find most like in my men's group, a lot of people either don't have the initiative to do something like that. And they just seem to be kind of reluctant to reach out and ask for help. And a lot of people say, oh, well, I don't really need any help. And I guess I was kind of the same until I got somebody in. And then I thought, wow, this is, you know, kind of got my life back, I can go out and play golf for a couple hours and come back home." – A02*

Participants reacted more positively when others took the initiative to include them directly through personal invitations, whether that be in support groups, research, or other services. One participant described how the men's support group he is a part of has difficulty recruiting men to join and his observation that men require a more nuanced and proactive approach to recruitment.

> *"Somehow you have to find them and have a conversation with them, which is not easy […] But it would have been nice. If, when I was identified as a male caregiver, I had gotten a call from another male caregiver to say, hey, we got this great group we meet once a month, […] we think you could benefit from what we do, why don't I pick you up for the next meeting and bring you to the meeting? And we're not very proactive about that kind of stuff. We tend to, you know, sit in the meeting room and leave the door open and hope somebody wanders in." -A02*

Men also appreciated the availability of gender-specific supports and having solidarity with men who were experiencing the same thing as them. One participant described how he found emotional support in a men-specific group for caregivers of people living with dementia.

> *"Okay, so my biggest, my biggest help that I've got, because I was emotional, I had really emotional problems with the whole situation. […] mentally I was in, not in a very good shape. And then I discovered […], [the] Alzheimer's [Society]*

> *[…] they got me on to a breakfast meeting and I went every third Wednesday of the month, and I've found that, wonderful help from them, just by talking and ranting, talking to other men. It was a men's breakfast. […] Yeah, and I religiously went every third Wednesday, and […] it's helped me tremendously."*
>
> *– A03*

He expressed how valuable the experience was for him and his mental health. However, these supports often were not centered on caregiving, rather they were founded on connection and community. Men also felt that in support groups they would rather engage with someone undergoing the same process and stage they were experiencing.

> *"Somebody else that's sort of at the at the same stage that I'm at. […] somebody else that I can, I can talk to you and share, share experiences, because I don't know of anybody that that is a man […] that's at […] that stage. That's around my age."– A08*

Additionally, when men did not have access to a gender-specific support group, they struggled to relate with support groups that mostly consisted of women and felt they would benefit from having connection with other men.

> *"I did find that there's not a lot of guys there. It just like, like you say, there's not a lot of guys there. It's mostly women. So, it's, it's difficult. I've gone to some support groups, where it's all women and, and, and, and they're having trouble with her husband, and it's hard for me to relate so. So, I haven't continued." – A08*

The men who did not have access to men-specific support groups described the value of having a peer that they could connect with.

> *"[…] we hadn't really been in touch for a long, long time. But now and we just talk about anything […]. And this is a time when having friends, you can rely on can I think can make a big difference." -A01*

This participant relies on a long-time friend as a companion and confidant. He finds value in being able to not only talk with another man, but also being able to talk about anything. Another participant utilizes his community's woodworking shop to connect with other men.

> *"I enjoy the woodshop I go to which is a hobby type of thing. It's a group that's been in existence for a long time. I've been going there since '96. […]. I certainly enjoy that. As much for the social thing. The fact that I, I get to see a few guys we don't spend all our time talking but it is a bit social. […] friends enough to talk about whatever you want to talk about." – A04*

His experience with the woodshop is a source of respite that responds to his need for socialization in a space for men. These experiences both reflect the value of having peers and a space to do or talk about other things than caregiving. Having peer connection may also act as a source of companionship. With the loss of the marital relationship as it once was, having peer support in a meaningful way may provide a sense of companionship that is no longer fulfilled by their wife in the same way.

Chapter 5

Discussion

This study sought to explore the experience of husbands whose wives have dementia, how they provide care and construct their sense of self. This research was necessary to contribute to the currently under-developed understanding of men's experiences in caring in the context of dementia and adds to the literature through showing the importance of relationships, and personal navigation and construction of self in understanding spousal caregivers' experiences. Although there have been studies that address relationships and couplehood through dementia (Merrick et al., 2011; Keady 1999; Molyneaux et al., 2011; Hellstrom et al., 2007), this study adds to the current understanding by exploring what men experience in providing care to a spouse with dementia and how men conceptualize caregiving and themselves. This study also highlights the complex and dynamic nature of being a husband caregiver for a spouse with dementia and identified variability in husband's experiences when providing care for their wives and the notion of being a caregiver as a man for a spouse living with dementia.

Eleven Ontarian men who had wives living with dementia were interviewed. Utilizing a constructivist grounded theory approach, this study developed three primary categories from the experiences of husbands caring for their wives who have dementia; *Being a Caregiver, Navigating and Managing Changes in their Relationship, and Organizing, Planning, and Re-evaluating the Future.* The findings suggest that husbands as caregivers experienced having to navigate the process of becoming a caregiver and manage an evolving relationship both relationally with their wives (in providing care) and in themselves.

In this chapter, both the conceptual and practical implications of this research are discussed. The conceptual implications include new expressions of how husbands provide and conceive care, how they construct their sense of self and their relationship, and how they navigated and managed their evolving relationship. This chapter ends with the practical implications of what husbands find supportive in their experiences of caring, and the strengths and limitations of the research.

5.1 How Men Provide and Conceive Care:

Although caregiving is not traditionally considered a role performed by men, this study explored the concept of being a caregiver as a man. Previous literature has highlighted that men may not consider themselves to be caregivers (Ribeiro et al., 2007). In this study men's definition of caregiving and conceptualization of providing care was nearly unanimous among participants; however, their approach of providing care was not. The men perceived caregiving as both emotional and physical, describing caring for their wives through personal care and activities of daily living (bathing, feeding, continence care, etc.) as well as her mental and emotional well-being. Husbands who did not provide elements of personal care struggled to conceptualize themselves as caregivers. If men conceptualized caregiving as both emotional and physical caring, but do not provide personal care, many men may not see themselves as a caregiver.

This thesis contributes to the current literature on caregiving by husbands in dementia by expanding the conception of how men perceive care. Rather than construct caregiving as "men's work", as previously described in the literature (Hong & Coogle, 2016; Greenwood & Smith, 2015; Calasanti & King, 2007; Riberio et al., 2007), this research contends that men offer a dynamic range of care provision that is developed through unique life experiences and evolve with new circumstances. Participants in this study described that their life experiences, previous work-roles, socialization, and sometimes less-restrictive gender roles within their marriage impacted the development of their caregiving role. This is reflected in Riberio et al.'s (2007) study where they discuss how men's caregiving is negotiated through their current life situation, as well as culturally and socially constructed norms of what it means to be masculine. Other research has described personal characteristics that contribute to the variability in outcomes for someone caring for a person with dementia, which include "individual […] variables that include socioeconomic, demographic, health, personality, and interpersonal factors that are the context in which caregiving is rendered and which influence every caregiving situation in unique ways" (Noyes et al., 2010, pg. 10). Such characteristics may also lend themselves to and explain the variability in how men provide and conceive care. Further research on the aspects of life experiences and cultural norms that impact men's care provision and how they perceive care may offer a deeper understanding of their unique perspectives and experiences in caring for someone with dementia.

5.2 Constructing Their Sense of Self and Relationship

One of the core components of the conceptual implications of men's experience in caring for their wives who have dementia was an active construction process. Navigating through change required the men to re-evaluate their situation to make sense of their circumstance and re-conceptualize their wives and themselves to adjust to their current reality. This impacted how men saw their relationship with their wives and altered their conception of couplehood. Participants depicted the experience of constructing their sense of self as an expression of personal growth and a re-evaluation of values, including the importance of money.

Findings from this thesis suggest that part of understanding husbands' experiences in caring for their wives with dementia was within how they experienced changes in their relationship. Participants managed their experience through adjusting their view of their wives and their relationship, engaging in active (re)construction of their sense of self and their marriage. All participants reflected that their marriage and their wife was not as it was before she was diagnosed with dementia and reflected on coming to terms with what that meant.

Some participants described that through becoming self-reflective they reframed their circumstance in a positive way to embrace the remaining time they had with their wives. Some men conceptualized their wives as a figure of their previous relationship while acknowledging that the disease is a "one way journey", and their relationship and companionship was different than before. Some men described conceptualizing their wives as "like-a-child" to promote positive and more understanding feelings towards her. Other men expressed a more negative appraisal, expressing that they viewed themselves as poor caregivers in the eyes of others or became more nervous as a result of caring.

Previous studies on the experience of couplehood through the journey of dementia reflect similar reconstructing processes as seen in this study. A study by Merrick et al. (2016) on how couples construct their experience in dementia relationally found that couples navigate the journey by continually constructing their relationship. Some literature describes an oscillating process of self-reconstruction that occurs in caring for a loved one with dementia, where caregivers reflect on what they had lost and what remains (Merrick et al., 2011; Keady 1999). This is similar in how men in this study underwent a process of reconstruction of their perception of their wives and how they related to her throughout the changes they experienced as a couple. Hellstrom et al. also identified that the process and phases that a couple engages with during their journey of dementia were "temporal", but "not linear and involved a delicate interactive and iterative relationship" (2007, pg. 391), which can be seen in some of the men's reflections in this study, especially in how they constructed and reconstructed their understanding of their relationship and self through the progression of dementia and the corresponding changes and challenges they managed.

Another study described how couples attempted to maintain their experience of their relationship as it was before when faced with challenges (Molyneaux et al., 2011). In contrast, most participants in this study described adjusting to changes rather than trying to maintain the relationship as it was. Rather, participants described a variety of adjusting that included learning new skills previously done by their wives, reconceptualizing their marital relationship, and their own sense of self. In this case, continuity in relationships may not mean as much or be necessary when role changes occur that alter the previous structure and gender dynamics of the relationship.

Additionally**,** personal growth was a significant experience for many husbands in this study and existed at different levels**.** Some men had experienced substantial growth and were able to articulate a deep awareness of this process. Most of the men were engaging with the growth process at varying levels; however, other men were more conflicted with their experience. Some men were at a more advanced level of self-awareness and reflection than others and expressed less emotional turmoil than those who did not disclose practicing elements of self-awareness. Many of the men became involved with meaning-making of their situation and circumstance. These men developed by becoming more of a caring individual and gaining "perspective". In this context, the men gained perspective and awareness of themselves, of their wives and social roles. Personal growth from caregiving is suggested to be a common experience with between 55% to 90% of caregivers experiencing positive growth outcomes following difficult experiences (Ott et al., 2007; Butcher et al., 2001; Farran, Keane-Hagerty, Swalloway, Kupferer & Wilken, 1991; Hogan and Schmidt, 2002). Participants in this study described feeling more caring and understanding because of their experiences with caring and offered sentiments of connecting with their children or wives because of the difficulties they experienced with their caregiving journey. Hong and Schmidt (2002) also describe that through personal growth individuals can experience an increase in feeling more caring and connected to others. They may also experience an evaluation of what is really meaningful in their life, and reassign their priorities (Hogan & Schmidt, 2002), which is reflected in this study as well.

The concept of reassigning priorities as part of personal growth is further reflected in how husbands in this study described a shift in personal values, specifically in terms of finances. Finances are a traditionally masculine domain as part of the ideal of serving a “provider role”. The perspective shift for the value money may have challenged men to redefine their role within their household. The traditional discourse of men being the “breadwinner” may be both enforced and challenged in the caring experience. The focus shifts from accumulating wealth to using it as a tool to provide better care and the intent of money shifts from being perceived as mainly to fill the provider role to include the caring role. This exemplifies the bridging of role structures necessitated by the process of becoming a care provider and learning a feminized role. Men experienced growth to include aspects of a feminized role into their identity in a way that affirms and adapts their previous self-concept. More research is needed to examine how masculine identity is affected and impacted by caregiving as well as how the growth process is experienced and varies between men.

5.3 Navigating and Managing an Evolving Relationship

Husbands in this study expressed that their experience caring for their wives involved a significant navigation and managing of emotional and physical elements of their relationship. Participants described navigating loss and grief, managing and avoiding conflict, and working to maintain intimacy in their relationship.

Participants in this study experienced substantial losses that included loss of an idealized future, loss of their own independence, and a loss of marital partnership. These losses are reflected in other studies including a qualitative descriptive study conducted in 2018 with husband caregivers of spouses with dementia, who also found primary themes of loss, describing loss of self, loss of golden years, loss of friendships and hobbies (Simpson et al., 2018). Loss as a central theme in caring literature is common (Simpson et al., 2018; Peacock et al., 2018); however, the negotiation process of loss and grief over the caring journey for men specifically has been understudied.

Participants in this study described a considerable navigation of loss and grief. Husbands described losing pieces of themselves as a consequence of the intensity of caring and losing independence which facilitated a sense of loneliness. Participants described an influx in grief as new challenges arose or their wives' dementia progressed. In this context grief is most associated with loss of partnership and the person their wives were before dementia. In the dementia context, current literature classifies the losses experienced in caring for a loved one with dementia as ambiguous, which is common for those caring for someone with a chronic illness (Noyes et al., 2010; Meuser et al., 2004). The Alzheimer Society of Canada defines ambiguous loss in dementia as a type of loss that occurs "when a person with dementia is physically here but may not be mentally or emotionally present in the same way as before" (Alzheimer Society of Canada, 2019, pg. 2). Relationally, this is mirrored in this study with the participants expressing their grieving process through the journey of dementia and using active re-construction of their relationship to enable coping through grief. Reconceptualization assisted these men in accepting the changes within their relationship as well as navigate the losses they were experiencing.

Participants navigated their experience through feelings of grief by processing negative emotions and trying to mitigate them. Some men expressed that they recognized their negative emotions and used strategies to deal with them in a way that was less harmful to their wives, while others expressed that they had not fully confronted their internal conflict and were unsure how to conceptualize themselves as a good or bad person. Within the navigation of loss and grief, if caregivers have difficulty interpreting their emotions alongside the complex nature of this loss, grief may not be recognized appropriately (Noyes et al., 2010). Rather, grief could be internalized to cope or projected in unhealthy ways. This may be compounded in the experience of husband caregivers and their individual compliance with dominant discourses of masculinity and explain the differences in the grieving process seen in this study, specifically with those who had not successfully navigated their grief or challenging emotions or resisted altering their conception of their relationship with their wives.

Additionally, men who struggle with reconceptualization of their partnership or marriage may benefit from therapeutic approaches that address and normalize their grief and use cognitive behavioural therapy to navigate the relational changes they are experiencing. Noyes et al. (2010) identify that therapists can help caregivers through their grieving process by normalizing the experience of grief and offering support through education, and encouraging practices that foster positive emotional connection. More research should be done on how masculinity affects the grieving process for husband caregivers.

Another central element in navigating and managing their relationship was the avoidance of conflict. Some men displayed positive techniques or more active processes to avoid conflict with their wives, such as validation or environmental changes. These processes were more proactive and in line with their wives' experiences which facilitated more ease when challenges arose. Other times husbands adopted avoidant behaviours to avoid conflict, such as hiding from their wives. However, the motivation of the use of avoidant techniques may facilitate and contribute to the overall outcomes of the technique. Although two participants shared how internalized stigma of dementia created distress for their wives and thus, they avoid using the terminology to avoid conflict, the men had differing approaches. One man used the mentality of preserving her peace as a motivator to avoid the language, whereas the other man's approach was motivated by attempts to avoid confrontation.

Although certain communication and self-regulation techniques can assist in avoiding conflict, participants in this study also experienced distressing interpersonal conflict that was difficult for them to process and navigate. Herron et al. (2019) wrote about avoiding conflict in their study on communicating the "right way" in dementia care. They identified this theme as how caregivers tried to manage their own emotions and the emotions of the person with dementia. They describe an emotional dissonance that occurred when persons had emotional scripts or expectations of providing good care to someone when they were experiencing instances where they needed to prioritize their own needs (Herron, et al., 2019). This is congruent with this study and relates to the experience of internal conflict and ambivalence that some participants described in their care roles. Herron et al. (2019) suggest that taking a sensitive approach to the way in which caregivers cope with their challenging experiences, and to be careful not to minimize the complex emotional process and challenges that caregivers go through. They address how expectations on caregivers to avoid conflict in the dominant narrative in dementia care (including dementia education courses) can be problematic and pressure caregivers in to staying in harmful or threatening experiences. This is particularly salient when working with older husband caregivers as past literature has taken a homogenized conception of their experience (Calasanti & King, 2007; Simpson et al., 2018) and dominant discourses of masculinity may perpetuate harmful stereotypes of men being able to "handle" harmful situations stoically (Connell, 2005). This study highlights that men have a deep emotional range with varying needs, and should be attended to with sensitivity.

Another way in which men navigated their relationship was through maintaining intimacy with their wives. This study discusses intimacy as any means of affection that maintained aspects of the couples' marital relationship. Other research has outlined types of intimacy between couples that include: emotional, social, physical, sexual, spiritual and intellectual (Garand et al., 2007). Moss and Schwebel also categorized romantic intimacy as 1. Commitment, 2. Affect intimacy, 3. Cognitive intimacy, 4. Physical intimacy, and 5. Mutuality (Moss and Schwebel, 1993; Harris et al., 2009). These categories conceptualize intimacy as more than sexual and expands intimacy into shared experiences, corresponding with this study and suggests that many forms of intimacy exist in complex relationships.

The men in this study engaged with intimacy by employing everyday strategies, holding onto moments of affection, or withdrawing from intimacy as a form of protecting memories and love. The men maintained intimacy within their relationship through using everyday strategies to continue sharing their lives together. Some men put in significant effort in planning activities together or purposefully engaged their wives in everyday tasks, such as cooking, cleaning, or sharing activities that they enjoyed together. Facilitating shared experiences that the men knew their wives enjoyed enabled positive feelings for each other and offered strategies to utilize when their wives experienced distress. Encouraging men to engage their wives in positive forms of task sharing may enable maintenance of partnership for longer periods of time. The men also utilized rituals of affection as a way to maintain emotional connection and intimacy throughout their journeys. Moments of affection embedded into their care provision provided ways for men to connect with their wives beyond providing for their wives' basic physical needs. However, some men withdrew from intimacy as a self-protection mechanism.

Intimacy within relationships evolve and when one component of intimacy is challenged with the changing circumstance of dementia, partners have an opportunity to shift their conception of intimacy in order to maintain its existence, rather than pulling away from their partner. Reconceptualization of their wives offered a pathway into maintenance of intimacy by challenging what it means to be intimate and how they perceive themselves and their wives' relationship. A study by Hayes, Boylstein and Zimmerman (2009) investigated the changes in self-concept in relation to intimacy in the journey of caring for and being a spouse with dementia. Their concept of changes in intimacy and self were described as "the identities of both impaired and caregiving spouse are likely to transform overtime and marital relations are reconstructed within the changed social context that emerges as a result of each person's shifting social identities" (Hayes et al., 2009). Although their study was predominantly focused on sexual intimacy, it can be extended into other aspects of intimacy and would be mirrored in this study in the way that men engaged with changing their intimate selves in their marital relationship through their adaption of everyday strategies and holding on to moments of affection. It was not a universal transformation for men to reconfigure intimacy with their wives, rather those who expressed a change in their conception of intimacy with their wives did so by actively framing intimacy through small interactions every day and learning to be present in the moment.

Interestingly, from the perspective of a man who lived with dementia, Richard Taylor (2007) in his personal essays described intimacy as being less sexual and full of levels: "Once I found that sex was not enough to create and maintain an intimate relationship, I began exploring additional components to create and maintain intimate relationships. There are levels within levels of intimacy" (Taylor, 2007). His reflection mirrors some of the experiences of husband caregivers, especially those who engaged in more emotionally focused responses to their wives and altered their perception of intimacy to include moments of affection. The perspective of a man with dementia aligned with the husband caregiver and raises questions about how intimacy is maintained by the couple more than the individual in early stages of dementia and evolves over time in later stages. Exploration into the evolving nature of intimacy throughout the caregiving journey from a man's perspective may be considered in future studies.

Sexuality within their relationship and from the perspective of men may be an important consideration for future research. This study did not specifically ask about sexual intimacy and it was not information readily given which may reflect the taboo nature of speaking about sexuality and a cultural hesitancy to share such experiences and difficulties. Additionally, the dynamic of the interviewee (older man) and interviewer (younger woman) may have influenced the lack of disclosure as well. Sensitivity to the gender and generational dynamics of interviewing older husband caregivers on sexuality should be considered in future work.

5.4 What Men Find Supportive as a Caregiver

Literature currently recognizes the lack of participation by men in support groups for dementia (Brown et al., 2007; Fee et al., 2020) but has not fully addressed the reasons why. This study offers the beginning of an understanding of the format and content that men feel is supportive to them in group settings and how they would appreciate connection. Participants expressed their needs for support and preference for context specific to men. Participants envisioned the experience of supports for men as meaningful opportunities to socialize that are not centered on the disease or experience itself. Rather, they voiced that socialization and community connection can be used to express feelings and talk about anything that enabled respite and support. This contrasts with the traditional support group setting that centralizes on the caregiving experience (Fee et al., 2020; Calastani & King, 2007; Greenwood & Smith, 2015).

Previous literature has discussed that men are more reluctant to seek supports (Simpson et al., 2019; Greenwood & Smith, 2015), which is mirrored in the participants' reflection of their own behaviours and the behaviours of their peers. Participants described how they eventually accessed support and desired a purposeful approach from organizations or individuals to initiate contact. When men did access supports, whether that was respite services, support groups or housekeeping, they expressed relief and more control over their situation. Some research has indicated that participation in support groups for men is limited by lack of recruitment efforts or an unwillingness of men to discuss their feelings (Tise, 2015; Simpson et al, 2019; McFarland & Sanders, 2000). The men in this study also reflect the sentiment that recruitment efforts currently do not fit the needs of men as caregivers. However, the unwillingness to discuss emotions in this study came from feeling different from women caregivers in support groups and a lack of connection with the feminine experience.

Findings of this study suggest that purposeful engagement initiated by organizations or individuals takes the onus off the caregiver to initiate help seeking and is more meaningful to the men than offering blanket-services. A personal and direct invitation was welcomed and seen as a sign of camaraderie rather than an extension of charity. This may relate to socialized norms of masculinity that require men to refuse support and stoically deal with their emotions alone (Connell, 2005). However, offers of camaraderie may be non-threatening to the masculine identity and may provide a useful tool in engaging men in services.

Currently, there are only 9 specific support groups for men in Ontario (see Appendix O) offered for men as caregivers of someone who lives with dementia. The limited availability of this specific format influences men to seek opportunities in informal settings where their dementia specific questions or needs may not be addressed, or they may not seek out any supports if they find that their needs are not met in formal groups. Similarly, Simpson et al. (2019) found that men valued having a specific group for men to create a community setting that offered them a space to share their feelings with others of their own gender. More research should be done to understand specific access needs, recruitment considerations, and content that enables the best possible support for men as caregivers.

5.5 Strengths and Limitations

This study adds to the limited scholarship of husbands as caregivers within the dementia care context. This research further identifies important components of conceptual and practical elements of men’s experiences in caring: how husbands conceive and provide care; how they navigate their relationships through reconstructing their sense of self and their perception of their wives; and important considerations for supporting husbands who provide care in ways that are accessible and attentive to the needs of men. Given that most literature available on the experience of caring for persons living with dementia, especially a spouse, relies heavily on woman-dominated samples (Houde, 2002; Lauderdale & Gallagher-Thompson, 2003), this research offers a new understanding of an underexamined perspective.

This study offered an approach to identifying variation between experiences for men as caregivers and addresses concerns over the current literature's simplification of the men's experiences in caring for someone with dementia. The constructivist approach permitted deviation from the original conception of how men may experience caregiving and allowed for new insight into previously under-examined components of being a caregiver as a man. Men deserve to be addressed as complex individuals with diverse experiences.

Using constructivist grounded theory as a guiding method may increase the validity of the research; however, is limited in terms of generalizability. The structure and process of the method is rigorous and offers a systematic analysis of the data, ensuring rigor and trustworthiness (El Hussien et al., 2014). Additionally, the constant comparison process identifies the similarities and differences within the data and increases validity (Boeije, 2002). The constructivist method may provide a thorough investigation into a specific context; however, it views knowledge as socially constructed and thus may not be translated over into other contexts (Charmaz, 2014). The sample of this study was mainly middle-class white men who were exclusively in heterosexual relationships. This means that the experience of these men may not reflect the experiences of other men in other provinces, countries, care contexts, non-heteronormative relationships, sexualities, ethnicities, or sons as caregivers. More research should be done within these contexts to explore further variation and unique needs based on an intersectional approach.

Additionally, due to the recruitment accessibility and out-reach constraints of the COVID-19 pandemic, most participants were reached through the Alzheimer Society or other support organizations. This study may not accurately represent the men who are more likely to be socially isolated or struggling with their roles. The sample of this study may also reflect those who had accessed support networks and may not represent men who do not or have not engaged with support organizations and service providers. Although the COVID-19 pandemic may have impacted recruitment efforts, the pandemic may have also facilitated a level of access as well. Participants may have expressed interest in participating in this research as a result of having additional time and a desire for socialization that could be facilitated through participating in research. Additionally, the interviews were conducted exclusively over the phone or online platforms. This distance may have also created a distance from the researcher that impacted the level of disclosure and freedom of expression. Having physical distance may have allowed the men to engage more by offering the removal of emotional intensity that can come from in-person interviews.

In an effort to contain experiences and be able to cross-examine perspectives, men whose wives resided in long-term care or had passed away were excluded from this study. Many men had reached out to participate even though they did not fit the inclusion criteria. The significant response from these men signifies a need for more research to be conducted to assess these populations' unique experiences, stress, and concerns.

This study also did not result in a developed theory. Due to the logistical and time constraints of a master’s research project, the author and committee members agreed to refrain from attempting multiple in-depth rounds of data collection, nor attempt theoretical saturation for the production of theory. However, due to the lack of literature currently available on the experiences of men as caregivers within dementia care, an analysis of experience is a valuable contribution to the literature and can inform further inquiry and future theory development. A multi-year study that engaged men from other provinces, sexualities, and those who did not engage with service organizations would have resulted in a greater understanding of potential variances in experiences and provided greater saturation of the data.

A concern with grounded theory studies is the risk of imposing bias on the data when reviewing literature prior to data collection (Glaser & Strauss, 1967). Classic grounded theory calls for a delay in reviewing literature before embarking in research to avoid producing preconceived ideas that can be imposed on the data (Glaser & Strauss, 1967). However, Robert Thornberg (2012, p.249) argues that having prior knowledge in the field or phenomenon does not take away from the analysis, rather it allows necessary sensitivity to the data that enables researchers to make informed inquiry. To mitigate the risk of imposing preconceived ideas on the data and within the interview guide, the research took a constructivist approach to grounded theory, acknowledging that research is a construction with both the participant and the researcher (Charmaz, 2014). Additionally, memos and methodological journaling facilitated reflexivity, as well as coding and the analysis of the study were reviewed by the thesis committee which assisted in limiting the potential of imposing bias.

Additionally, the scope of the study was not able to address all identified gaps in the literature mentioned in Chapter 1. The scope of this study focused exclusively on the experience of husbands who care for their wives with dementia to allow depth of inquiry into their experiences. In fact, the content of the data analysis deviated from the original conception of the research and emphasized the impact and importance of relationships within the experience of men in providing support to their spouse with dementia.

Chapter 6

Conclusion

As the population ages and social dynamics shift, more men will become caregivers, specifically more older men will become caregivers for their wives living with dementia. There is a limited representation of the experiences of husbands who provide care in the current literature, often portraying men as unidimensional and incompletely recognizing the variation and diversity in men's experiences. When studies do include men in their research, the proportion of women to men respondents is inequal and may misrepresent their perspective. This research provided a purposeful inquiry into men's experiences in providing care and examined their perceptions through a constructivist lens, allowing the acknowledgement of the depth and breadth of the experience of husbands caring for their wives. Consequentially, both practical and conceptual implications came out of this research.

Men in this study revealed that their conception of being a caregiver is an all-encompassing process, one that is both physical and emotional. However, not all men provided what they would consider to be physical care. Those who did not provide this kind of care were hesitant to consider themselves as caregivers.

The findings of this study suggest that men (re)construct their sense of self and their relationship as a way to navigate and manage the changes they and their wives experienced. Men re-constructed their sense of self and their marriage and adjusted to their roles through learning new skills, experiencing personal growth, and re-evaluating values. The men shared the experience of being a caregiver involved navigating loss and grief, managing and avoiding conflict, and working to maintain intimacy within their relationship.

Additionally, men highlighted the importance of supports that were sensitive to their needs. Participants found gender-specific group settings that allowed socialization and connection more supportive to their needs than emotion-focused support groups. The men felt that they could be supported by having a personal and direct invitation to supports.

Overall, this research offers a varied exploration of husbands' experiences in caring for their wives with dementia. More research is needed that address intersectional components of experience to further identify and understand specific experiences, including the aspects of life experiences that impact men’s care provision, how masculinity affects the caring experience, how intimacy is affected in the caregiving journey, access needs of men as caregivers, experiences of grief and coping, and content that enables the best possible support for husbands as caregivers.

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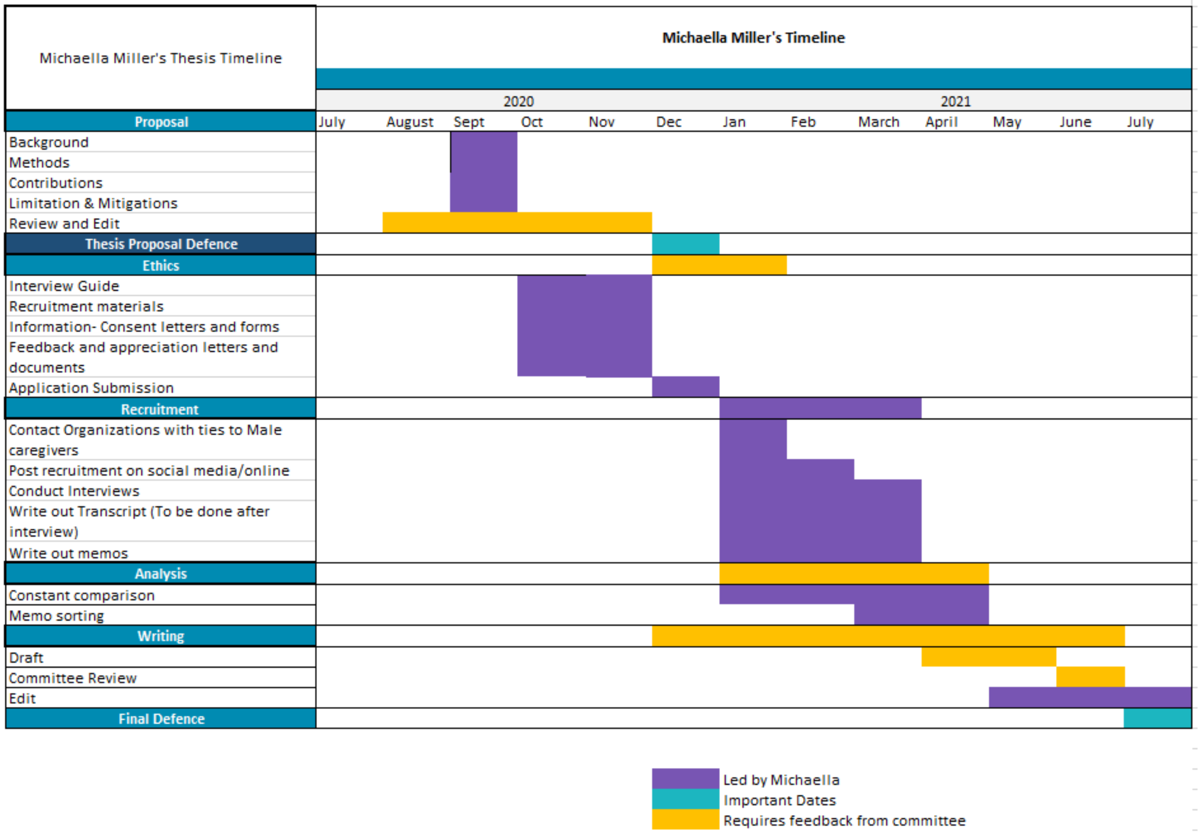
Appendix A: Original Workplan Timeline



Michaella Miller's Thesis Timeline	Michaella Miller's Timeline												
	2020						2021						
Proposal	July	August	Sept	Oct	Nov	Dec	Jan	Feb	March	April	May	June	July
Background			🟪										
Methods			🟪										
Contributions			🟪										
Limitation & Mitigations			🟪										
Review and Edit		🟨	🟨	🟨	🟨								
Thesis Proposal Defence						🟦							
Ethics						🟨	🟨						
Interview Guide				🟪	🟪								
Recruitment materials				🟪	🟪								
Information- Consent letters and forms				🟪	🟪								
Feedback and appreciation letters and documents				🟪	🟪								
Application Submission						🟪							
Recruitment							🟪	🟪	🟪				
Contact Organizations with ties to Male caregivers							🟪						
Post recruitment on social media/online							🟪	🟪					
Conduct Interviews							🟪	🟪	🟪				
Write out Transcript (To be done after interview)							🟪	🟪	🟪				
Write out memos							🟪	🟪	🟪				
Analysis							🟨	🟨	🟨	🟨			
Constant comparison							🟪	🟪	🟪	🟪			
Memo sorting									🟪	🟪			
Writing						🟨	🟨	🟨	🟨	🟨	🟨	🟨	
Draft										🟨	🟨		
Committee Review												🟨	
Edit											🟪	🟪	🟪
Final Defence													🟦

🟪 Led by Michaella
🟦 Important Dates
🟨 Requires feedback from committee

Appendix B: Original Interview Guide and Script

Hello, it is great to meet you on zoom. I wanted to thank you for agreeing to participate in this study. To give you a bit of background, I am working on my Master's degree at the University of Waterloo and am looking into the experience of men whose wife who has dementia. What we know about the experience of a spouse with dementia is mostly gathered from the female perspective, and so I am trying to get a better understanding on how men experience this circumstance and journey. I just want to let you know that I will be recording this conversation so that I can accurately depict your experience. Is it okay to record? Some of these questions may feel hard to answer, I know talking about this can be emotional- so please let me know if you need a break or would like to skip a question or stop altogether.

Thank you,

To start,

1. Can you tell me about when you started to notice your wife had symptoms of dementia?
    a. How did you feel during this time? How are you doing now?
    b. How long ago was she diagnosed with dementia?
2. Can you tell be a bit about your experience since her diagnosis?
    a. How has her diagnosis changed your home life? Your social life?
    b. As a man, how did this change how you think of yourself?
    c. How have you had to adapt?
3. Could you describe a typical day for you and your wife?
    a. How do you help her?
    b. What are some of the challenges you face?
    c. What are some things you've found have been easy to adapt to?
4. How do you take care of yourself?
    a. Do you have hobbies?
    b. Do you use any support services (such as support groups, or programs?)
    c. If yes, what do you think about them?
        i. What influenced you to look for them?
        ii. Why did you choose them?
        iii. How did you find out about them?
        iv. How have they been helpful?
        v. How could they be better suited to your needs?
    d. If no, can you explain more?
        i. Have you looked for services before?

        ii. Why did you decide not to use them?
        iii. Would you use supports if they were different? In what way?
5. What do you find supportive?
6. What do you think would be supportive to you in your current circumstance?
7. How do you think your experience differs from women? Differs from other men?
8. What does masculinity mean to you?
    a. How would you say that affects how you support your wife?
9. If you were to give advice to another man caring for his wife, what would you tell him?
10. Is there anything else you'd like to share, or feel is important for me to know?

Thank you again for sharing your experience with me. I will be conducting a few more interviews and wanted to ask if you'd like to connect in a few weeks to clarify anything I may have questions about?

Wonderful, I look forward to reconnecting in a few weeks. Have a great day!

Appendix C: Revised Interview Guide and Script 1

Interview Guide to follow after Verbal Consent script.

To start,

1. Can you tell me about when you when your wife was first diagnosed with dementia? (Or when there were problems with your wife's memory or cognitive abilities if the wife hasn't been diagnosed.)?
    a. How long ago was this?
    b. What was this time like for you and your wife? How are you doing now?
2. What, if anything, did you know about dementia before your wife developed it?
3. Could you describe a typical day for you and your wife? How has this changed over time?
    a. What are some ways you provide your wife support? What is this like for you?
    b. If you recall, could you tell me about how you learned to be in the role of a caregiver for her?
4. Caring for a person with dementia can be quite difficult for spouses. But it can also have positive impacts. How has caring for your wife impacted you?
5. What positive changes have occurred in your life since she developed dementia?
6. What negative changes, if any, have occurred in your life since she developed dementia?
7. Has it affected the way you think about yourself?
8. Tell me how you go about taking care of yourself. What do you do?
    a. Do you take part in any support services (e.g., support group, counseling, respite care, wife attends a day program)?
9. Who, if anyone, was involved in supporting her and you? When was that? How were they involved?
10. What does the term *caregiving* mean to you?
11. You've told me about your experience as a husband caring for his wife with dementia. How do you think your experience would be different if you were wife caring for her husband?
12. If you were to give advice to another man caring for his wife with dementia, what would you tell him?
13. Is there anything else you'd like to share, or feel is important for me to know?

Demographic Questions:

1. Can you tell me the year you were born?

2. What is the highest level of education you have achieved?
3. What is your ethnicity?
4. Do you live in an urban or rural area?

Thank you again for sharing your experience with me. I may be conducting a few more interviews and wanted to ask if I can contact you to clarify anything I may have questions about?

Yes: Wonderful, I look forward to reconnecting. Have a great day!

No: Not a problem, thank you again for talking with me today. Have a great day!

Appendix D: Revised Interview Guide and Script 2

Interview Guide to follow after Verbal Consent script.

To start,

Demographic Questions:

1. Can you tell me the year you were born?
2. What is the highest level of education you have achieved?
3. What is your ethnicity?
4. Do you live in an urban or rural area?

Interview Questions:

1. Can you tell me about when you when your wife was first diagnosed with dementia? (Or when there were problems with your wife’s memory or cognitive abilities if the wife hasn’t been diagnosed.)?
    a. How long ago was this?
    b. What was this time like for you and your wife? How are you doing now?
2. What, if anything, did you know about dementia before your wife developed it?
3. Could you describe a typical day for you and your wife? How has this changed over time?
    a. What are some ways you provide your wife support? What is this like for you?
    b. If you recall, could you tell me about how you learned to be in the role of a caregiver for her?
4. Caring for a person with dementia can be quite difficult for spouses. But it can also have positive impacts. How has caring for your wife impacted you?
5. What positive changes have occurred in your life since she developed dementia?
6. What negative changes, if any, have occurred in your life since she developed dementia?
7. Has it affected the way you think about yourself?
8. Tell me how you go about taking care of yourself. What do you do?
    a. Do you take part in any support services (e.g., support group, counseling, respite care, wife attends a day program)?
9. Who, if anyone, was involved in supporting her and you? When was that? How were they involved?
10. What does the term *caregiving* mean to you?

11. You’ve told me about your experience as a husband caring for his wife with dementia. How do you think your experience would be different if your roles were reversed?
12. If you were to give advice to another man caring for his wife with dementia, what would you tell him?
13. Is there anything else you’d like to share, or feel is important for me to know?

Thank you again for sharing your experience with me. I may be conducting a few more interviews and wanted to ask if I can contact you to clarify anything I may have questions about?

Yes: Wonderful, I look forward to reconnecting. Have a great day!

No: Not a problem, thank you again for talking with me today. Have a great day!

Appendix E: Letter of Information and Consent Form

University of Waterloo
[Date]

Dear Participant:

This letter is an invitation to participate in a research study titled: *Exploring the male perspective: The experiences of male spouses of wives who have dementia*. The purpose of this study is to examine and explore the experiences of older men whose spouse has dementia. This study aims to build an understanding of men's experiences in supporting their wives have dementia and how it has influenced them.

This study will be undertaken by Michaella Miller, a Master's student in the School of Public Health and Health Systems under the supervision of Dr Carrie McAiney and with approval of the University of Waterloo's Research Ethics board.

Participation in this study is voluntary. It will involve taking part in an open-ended interview that will take approximately 40-60 minutes to complete. The interview will take place in an online format, such as the Zoom platform or Skype, or through the telephone. When information is transmitted over the internet, privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party. University of Waterloo researchers will not collect internet protocol (IP) addresses or other information that could link your participation to your computer or electronic device without first informing you.

During the interview you may decline to answer any of the interview questions and/or share your personal information with the researcher. You may withdraw from this study at any time by advising the researcher. If you wish to withdraw, we will erase the interview transcript and all the research notes that were take during the interview process. Your participation will be considered confidential. Any identifying information will be removed from the data that is collected and stored separately. Audio-recordings will be transcribed and will be destroyed within two years of being recorded. Paper copies of study materials and data collected will be shredded once they have been transcribed electronically, within two years of being collected. All electronic copies of study materials and data collected from you will be kept for a minimum of 7 years on a secure, password protected data storage system in the Faculty of Applied Health Sciences at the University of Waterloo. Your name will not be included in any presentations or publications resulting from this study; however, with your permission anonymous quotations from your interviews may be used.

Participation in this study may not provide any personal benefit to you. We hope the information collected will inform and contribute to the current understanding of how men experience supporting their wife with dementia and how it themselves. We must acknowledge that this research may not be translated into practice for a number of years and cannot guarantee any changes in the current dementia care or caregiver services. This research has been deemed as a minimal risk to yourself. Speaking to your experience may be emotionally difficult and illicit an emotional response. If you feel you would like support during or following the interview, the researcher can direct you to appropriate services.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42861). If you have questions or would like additional information about participation, please contact Michaella Miller at 519-580-6769 or email at m29mille@uwaterloo.ca .

I look forward to speaking with you and thank you in advance for your assistance in this research.

Yours Sincerely,

Michaella Miller

Consent Form

By providing your consent, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

Title of study: Exploring the male perspective: The experiences of male husbands whose wives have dementia

I have read the information presented in the information letter about a study conducted by student researcher, Michaella Miller, and Dr Carrie McAiney from the School of Public Health and Health Systems at the University of Waterloo. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions and any additional details. I was informed that participation in the study is voluntary and that I can withdraw this consent by informing the researcher. This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42861). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or oreceo@uwaterloo.ca. For all other questions contact Michaella Miller at 519-580-6769 or by email, m29mille@uwaterloo.ca.

Please Select:

☐ I agree to my interview being audio recorded to ensure accurate transcription and analysis.

☐ I agree to the use of anonymous quotations in any thesis or publication that comes from this research.

I agree of my own free will to participate in the study.

Participant’s name:______________________________ Date: _______________
Participant’s signature: ___________________________ Date: _______________
Researcher’s/Witness’ signature ___________________ Date:________________

Appendix F: Information Sheet and Consent Form

Title of Study: Exploring the male perspective: The experiences of male spouses of wives who have dementia.

Investigators, Department, Institution:
Michaella Miller, School of Public Health and Health Systems, University of Waterloo Carrie McAiney, School of Public Health and Health Systems, University of Waterloo

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You are being invited to participate in a research study because you are a spouse of a person living with dementia.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study. Once you understand the study, you will be asked if you agree to participate in the study. Please take your time to make your decision. Feel free to discuss it with others.

What is the purpose of the study?

The purpose of this study is to examine and explore the experiences of older men whose spouse has dementia. This study aims to build an understanding of men's experiences in supporting their wives who have dementia and how it has influenced them.

Your responsibilities as a participant

What will you be asked of you if you agree to participate in this study?

Participation in this study is voluntary. If you agree to participate, you will be asked to:

- Participate in an interview about your experiences with having a wife with dementia and how it has impacted you. Interviews will be conducted using an on-line platform or the telephone, depending on your preference. Interviews will be approximately 45 minutes in length.
- You will be asked to provide information on your demographics (e.g. your age, ethnicity etc.). These questions will help describe the sample of the study.
- You may be asked to participate in a follow-up interview at a later date to clarify any new ideas or themes that may arise. A researcher may contact you following your initial interview to invite you to participate in a second interview. At this contact you may accept or decline the invitation.

With your permission, the interviews will be audio-recorded so that we are able to capture all of the information you share with us.

I. Your rights as a participant

Is participation in the study voluntary?

Participation in this research is entirely voluntary. You can decide to end your participation in the research at any time, without penalty. If you decide to end your participation, simply tell a member of the research team that you no longer want to participate. You do not need to provide a reason. If you decide to end your participation in the study, your data can be destroyed but this cannot be guaranteed if data analysis has already begun. Data analysis will start approximately one week after you have participated. The researchers will aim to permanently delete your data, including audio files and transcribed electronic files within 2 weeks of withdrawing.

What are the potential benefits of your involvement?

We cannot promise any personal benefits to you from your participation in this study. We hope the information collected will inform and contribute to the current understanding of how men experience supporting their wife with dementia and how it affects themselves. We cannot guarantee any changes in the current dementia care or caregiver services.

What are the possible risks and discomforts associated with this project?

There is the potential for risks or discomfort associated with participation since the questions may ask you to recall a time that was stressful or distressing. If you experience any feelings of discomfort, please let the researcher know. You may also skip any questions you do not want to answer. As well, you may end your participation in the study at any time by advising the researcher of this decision.

If you require any support as the result of this study, the researchers may provide you with information about available resources.

Confidentiality and management of data

Any identifying information will be removed from the data collection sheets and audio-recordings that are collected. Paper copies of study materials and data collected will be shredded once they have been transcribed electronically, within two years of being collected.

All electronic copies of audio-recordings and transcriptions will be kept for a minimum of 7 years on a secure, encrypted server in the Faculty of Applied Health Sciences at the University of Waterloo. Your name will not be included in any presentations or publications resulting from this study; however, with your permission, anonymous quotations from your interview may be used.

If you participate online, when information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you.

If you wish to withdraw consent to participate at any time, contact Michaella Miller at m29mille@uwaterloo.ca or by phone (519-580-6769). Only researchers associated with this study will have access to study records. All records will be destroyed according to University of Waterloo policy.

I. Questions, comments or concerns

What are the potential costs of participation?

There are no costs to participate.

How will I find out about the findings from this study?

If you are interested in receiving a summary of the study findings, we will ask for your email or mailing address and will send a copy of the summary when the results are available in late 2021.

Whom do I contact if I have questions or concerns?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42861). If you have questions for the Committee contact the University of Waterloo Office of Research Ethics at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

If you have questions about the study, please feel free to contact either Michaella Miller at m29mille@uwaterloo.ca or Carrie McAiney at carrie.mcainey@uwaterloo.ca

Consent Statement: Verbal/Implied Consent

Title of Study: Exploring the male perspective: The experiences of male spouses of wives who have dementia

Investigators, Department, Institution:
Michaella Miller, School of Public Health and Health Systems, University of Waterloo
Carrie McAiney, School of Public Health and Health Systems, University of Waterloo

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By continuing with the interview, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

Participant

I have read, and the researcher has explained verbally, the information presented in the information letter about a study being conducted by Michaella Miller and Carrie McAiney at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study without penalty at any time by advising the researchers of this decision.

I consent to the following:

- To participate in an interview
- To having the interview audio-recorded to ensure accurate transcription

I consent to the use of anonymous quotations in any presentation or publication that comes from this research.

Yes
No

During this research, participants may be asked to participate in a follow-up interview to clarify new ideas and themes. May we contact you for a follow-up interview?

- Please contact me

- I do not wish to be contacted for a second follow-up interview.

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

- Yes, please e-mail/mail me a summary of the results.
- I do not wish to receive a summary of results.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42861) If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca

Appendix G: Oral Consent Script

Exploring the male perspective: The experiences of male spouses of wives who have dementia.

Oral Consent Script

Introduction:

Hello, it is great to meet you. I wanted to thank you for your interest in my research and agreeing to participate in this study. To give you a bit of background, I am working on my Master's degree at the University of Waterloo and am looking into the experience of men whose wives have dementia. What we know about the experience of caring for a spouse with dementia is mostly from the female perspective, and so I am trying to get a better understanding of the experience of husbands who are caring for their wives.

[*If the LOI was provided in advance*]

Have you had time to read the Letter of Information I sent you?

[*If the LOI was provided in advance and the participant responds that they have read the LOI*]

Great, then I would like to take a moment to review some main points from the Letter of Information before we continue. [*Proceed to review the highlights of the LOI, be sure to include risks and what will happen with their data, and confirm the important points about voluntary participation and withdrawal listed below.*]

[*If it is not possible to give an LOI to the participant, or if the LOI was not sent in advance, or the participant responds that they did not read the LOI in advance, then proceed to go through the full LOI in detail with the participant and confirm the important points about voluntary participation and withdrawal listed below*.]

Confirm the following to the participant:

- Your participation in this study is voluntary.
- If there are any questions you prefer not to answer, just let me know. As well, we can take a break at any time.
- You can decide to stop at any time, even part-way through the interview for whatever reason.

- If you decide to stop during the interview and withdraw from participating, I will ask you how you would like me to handle the data collected up to that point, destroying it or using the data collected up to that point.
- You can ask to remove your data from the study up until approximately **one week after the interview.**
- This study has been reviewed and cleared by the University of Waterloo's Research Ethics Board.

Do you have any questions or want me to go over any study details again?

Consent questions:

Do you agree to participate in this study?

If yes,

- Would you like a copy of the study results? If yes, where should we send them (email, mailing address)?
- Do you agree to have the interview audio-recorded to ensure accurate transcription?
- Do you agree to the use of anonymous quotations in any presentation or publication that comes from this research?
- Do you agree to be contacted for a follow-up interview? How do you prefer to be contacted?

If no, “Thank you for your time.”

Appendix H: Organizational Recruitment

Date
Dear ___ :

This letter is a request for [name of organization]’s assistance with a project I am conducting as part of my Master's degree in the School of Public Health and Health Systems at the University of Waterloo, Ontario, under the supervision of Dr. Carrie McAiney. The title of my research project is “*Exploring the male perspective: The experiences of male spouses of wives who have dementia*”.

The purpose of this study is to examine and explore the experiences of older men who care for their spouse who has dementia. This study aims to build an understanding of the experiences of older men who have a wife living with dementia, how they provide support, and how it has influenced them. Knowledge and information generated from this study may help organizations, service providers, and other researchers in better understanding the unique experiences of male caregivers.

It is my hope to connect with participants who are engaged in the programs of the [name of organization] to invite them to participate in this research project. During the course of this study, I will be conducting interviews with husbands to gather their perceptions and experiences of supporting their wife with dementia.

To respect the privacy and rights of the [name of organization] and its participants, I will not be contacting the participants directly. What I intend to do is provide the [name of organization] with a information poster to be distributed by the [name of organization] at their discretion. Contact information for me and my advisor will be contained on the posters or invitation letters. If a husband is interested in participating, they will be invited to contact me, Michaella Miller, to discuss participation in this study in further detail.

Participation of any husband is completely voluntary. Each participant will make their own independent decision as to whether or not they would like to be involved. All participants will be informed and reminded of their rights to participate or withdraw before any interview, or at any time in the study. Participants will receive an information letter including detailed information about this study, as well as informed consent forms.

To support the findings of this study, quotations and excerpts from the stories will be used labelled with pseudonyms to protect the identity of the participants. Names of participants will not appear in the thesis or reports resulting from this study. Participants will not be identifiable.

Paper copies of study materials and data collected will be shredded once they have been transcribed electronically, within two years of being collected. All electronic copies of study materials and data collected will be kept for a minimum of 7 years on a secure, password protected data storage system in the Faculty of Applied Health Sciences at the University of Waterloo. Finally, only myself and my advisor, Dr Carrie McAiney in the School of Public Health and Health Systems at the University of Waterloo will have access to these materials.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE # 42861). However, the final decision about participation belongs to the [name of organization], and the participants.

If you have any questions regarding this study or would like additional information to assist you in reaching a decision about participation, please contact me at 519-580-6769 or by email m29mille@uwaterloo.ca . You may also contact my supervisor, Dr Carrie McAiney at 519-888-4567, ext. 45642, or by email carrie.mcainey@uwaterloo.ca
I hope that the results of my study will be beneficial to the [name of organization], to your families, and to the communities of families including people living with dementia across Canada, as well as the broader research community. I very much look forward to speaking with you and thank you in advance for your assistance with this project.
Yours sincerely,

Michaella Miller
Master's Candidate
School of Public Health and Health Systems
University of Waterloo

Dr Carrie McAiney
Associate Professor
School of Public Health and Health Systems
University of Waterloo

Appendix I: Appreciation Letter

University of Waterloo

Date

Dear,

I would like to thank you for your participation in this study: Exploring the male perspective: The experiences of male spouses of wives who have dementia. As a reminder, the purpose of this study is to examine and explore the experiences of older men whose spouse has dementia, how they provide support, and how it has influenced them.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42861). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For all other questions contact Michaella Miller at 519-580-6769 or by email at m29mille@uwaterloo.ca

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or would like a summary of the results, please provide your email address, and when the study is completed, anticipated by late 2021, I will send you the information. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email or telephone as noted below.

Michaella Miller
School of Public Health and Health Systems
University of Waterloo
519-580-6769
m29mille@uwaterloo.ca

Appendix J: Recruitment Poster

School of Public Health and Health Systems

University of Waterloo

PARTICIPANTS NEEDED FOR RESEARCH PROJECT ON:

Exploring the male perspective: The experiences of male spouses of wives who have dementia.

We are looking for male volunteers ages 60+ whose spouse is living with dementia and in the community (in a home, condo, apartment or retirement setting together) to participate in the research project on the male experience of this journey.

As a participant in this study, you will be asked to share your experience in an interview that will take approximately 40-60 minutes through the telephone or online. The questions will be open-ended and will focus on your experiences with your wife's dementia, how you provide support, and how it has influenced you.

For more information about this study, or to volunteer for this study, please contact:

Michaella Miller
Student Investigator at
519-580-6769
Email: m29mille@uwaterloo.ca
or
Carrie McAiney
School of Public Health and Health Systems at
(519) 888-4567 Ext. 45642 or
Email: carrie.mcainey@uwaterloo.ca

This study has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42861)

Appendix K: Recruitment Email

If being sent by organization:

Hello [Participant Name], the email below is being sent on behalf of the researchers conducting a study on male spouse caregivers. If you are interested in participating, please see the details below.

****

Dear [Participant Name],

My name is Michaella Miller and I am a Master's student working under the supervision of Dr. Carrie McAiney, in the School of Public Health and Health Systems at the University of Waterloo. This email is an invitation to participate in a research study about **Exploring the male perspective: The experiences of male spouses of wives who have dementia**. The purpose of this study is to examine and explore the experiences of older men whose spouse is living with dementia, how they provide support, and how it has influenced them. We are specifically looking to engage men aged 60+ who currently live with their wives in the community or retirement settings (i.e. in a house, condo, apartment or retirement home where they live together).

Participation in this study is voluntary. It will involve taking part in an open-ended interview that entails you sharing your experiences with your wife's dementia and how it has affected you. The interview will take approximately 40-60 minutes to complete and will be arranged either over phone, or online platform. Attached is a Letter of Information and Consent where you can learn more about the study's purpose and procedures. I would like to assure you that the study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Committee.

If you are interested in participating in this study please contact Michaella Miller at m29mille@uwaterloo.ca . Once I receive your confirmation email, I will provide you with more information about the study and, if you are still willing to participate, will set up an interview time.

For more information regarding this study feel free to contact me at m29mille@uwaterloo.ca or the course instructor, Dr. Carrie McAiney at (519) 888-4567 ext. 45642 or carrie.mcainey@uwaterloo.ca

Sincerely,

Michaella Miller

Appendix L: Consent Log

Exploring the male perspective: The experiences of male spouses of wives who have dementia.

Michaella Miller

RESEARCHER'S LOG FOR

RECORDING VERBAL CONSENT

Study Consent	Consent for quotes	Consent for follow up	Participant's Unique ID number (i.e. 08-A01)	Participant's name	Date:

Appendix M: Participant Contact Log

Exploring the male perspective: The experiences of male spouses of wives who have dementia.

Michaella Miller

RESEARCHER'S LOG FOR

RECORDING Participant Contact Information

Participant's Unique ID number (i.e. 08-A01)	Participant's name	Email	Mailing Address	Phone

Appendix N: Analysis Plan

1. Complete individual interview.
2. Record notes after interview in methodological journal.
3. Create memos throughout as thoughts emerge (in reviewing and transcribing interviews and with coding).
4. Transcribe interview verbatim. Review interview transcript for accuracy and emersion in the data.
5. Line by line code using gerunds ("ing" words).
6. Compare codes within the interview.
7. Focus code. Delineate codes from the codes to help define themes and categories.
8. Repeat (1-7) process with second interview.
9. Compare codes between interviews to explore emerging themes.
10. Revise interview guide to follow emerging themes.
11. Repeat as interviews occur.
12. Reinterview participants as themes emerge to collect new data.
13. Compare interview transcripts with the other interview with same participant. Identify commonalities or differences.

Writing Stage:

1. Sort memos into themes and categorical groups.
2. Critique memo themes into logical categories and write initial draft.
3. Review memos and codes.
4. Write introduction and conclusion.
5. Review and revise.

Adapted from *Constructing Grounded Theory* 2nd ed. By Kathy Charmaz. (Charmaz, 2014)

Appendix O: Men’s Caregiver Support Groups in Ontario

Table 3: Men’s Caregiver Support Groups in Ontario

Alzheimer Society Durham	**Men’s Breakfast:** A peer-led group, which provides peer-to-peer support for male care partners in a casual, comfortable setting. For more information, contact Support Services and Groups at intake@alzheimerdurham.com or phone 905-576-2567 ext. 5233.
Alzheimer Society Halton *Offered occasionally	**Men’s Caregiving Support Group** – Halton (Mar 25 to Apr 15) March 25th to April 15th (Thursdays 10:00 to 11:30AM). This group will meet in-person at our Burlington office. To register, please call 289-837-2310 x 309 **Program Description:** A four-week support group for male caregivers of a person living with dementia. Connect with others and learn about strategies and community resources
	Men’s Discussion Group – Virtual (Oct 9-Dec 4) October 9th to December 4th (Fridays at 10AM to 11:30AM) This virtual group will meet online. To register or learn more, please call Corey at 519-428-7771 ext 507. Program Description This online discussion group will meet every two weeks (over the course of 9 weeks). It is designed for male caregivers to discuss the different challenges they may face through their caregiving journey.
AS Dufferin County:	**Male Support Group**
AS Hastings-Prince Edward:	**Men's Caregiver Support Group** with Darlene Jackson 3rd Friday of month 9:30-11:30am. ZOOM / CALL-IN (in person on hold)
AS Kingstin, Frontenac, Lennox & Addington Counties	**Men’s Group** Kingsdale Chateau Retirement Home 520 Kingsdale Avenue A group especially for men caring for a partner in any stage of dementia 10:00 am to 11:30 am Third Thursday of each month
AS Lanark Leeds Grenville	**I’ve Got The Tools… I’m Ready To Care Men’s Caregiver Support Group** 3rd Tuesday of each month 10am – 11:30am Alzheimer Society Office 100 Strowger Blvd, Suite 107 Brockville *Not in their support group brochure
AS Niagara:	**Men's Social & Support Group** Join us **the 2nd Tuesday of each month from 10:00 am - 11:30 am** for a fun social gathering using the Zoom platform! This online group is for male care partners of individuals living with dementia. Each group will be facilitated by one of our counselling staff.

AS Toronto:	**Men’s Cooking Group**