‘My hope is that he doesn’t forget that he’s loved.’: Understanding Relationship Quality Between Spousal Caregivers and their Partners with Dementia

by

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Abstract

The purpose of this study was to examine how caregiving for a partner with dementia affects relationship quality. A qualitative design was used, and 6 spousal caregivers who were providing care to a partner in their homes participated in interviews. The research was informed by the theoretical approach of critical gerontology with the aim to reflect the dominant social discourse on aging and the dementia experience. The data analysis involved the use of thematic analysis. Key themes emerged, including difficulty coping with the onset of dementia, changes in the relationship, and lack of informal and formal support. Changes in the relationship were related to shifts in how couples spent quality time together and communication difficulties arising from the symptoms of dementia. Caregivers experienced increased responsibilities due to role changes within the relationship. Caregivers and their partners with dementia had varying experiences related to accessing support, including help from friends, family, healthcare providers, and community resources.

This study contributes to existing literature on the impact of caring for a partner with dementia on relationship quality. First-hand experiences shared by participants offer valuable insights into this important topic, providing a deeper understanding of how the disease affects everyday life and relationships. Future research should consider including the perceptions of persons with dementia to provide an understanding of relationship quality from both perspectives.

Keywords: dementia, spouse, caregiver, spousal caregiver, relationship quality, intimacy

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Chapter 1 - Background

In 2022, the Alzheimer Society of Canada unveiled the first of three reports from the Landmark Study, a significant research endeavor that projects future dementia rates in Canada. The second report, released in 2024, provides estimates for dementia rates across different demographic groups, while the third report, set for release in 2025, will delve deeper into the economic effects of dementia (Alzheimer Society of Canada, 2024c). The inaugural report, titled *Navigating the Path Forward in Dementia Care: The Landmark Study Report 1*, reveals that over 600,000 people are living with dementia across Canada, with projections to reach 1 million by 2030 (Alzheimer Society of Canada, 2022). While dementia is not a normal part of aging, being an older adult is considered a risk factor for developing these diseases (Public Health Agency of Canada [PHAC], 2019).

According to PHAC's (2019) report, *A Dementia Strategy for Canada: Together We Aspire*, "Improving the quality of life of those living with dementia and caregivers is the motivation for the national dementia strategy" (p.31). PHAC's (2019) report outlined strategies such as advancing research to prevent and cure dementia and includes addressing issues related to accessing care, support, and resources for informal caregivers or unpaid family, spouses, or friends and persons with dementia (PWD). The impacts of caregiving roles can vary significantly, particularly in the context of dementia. There is a compelling body of evidence indicating that informal caregivers often experience negative effects on their psychological, physical, and emotional well-being. This study, however, specifically examined the impact of caregiving on spousal relationships.

With the aging generation of baby boomers, it is expected that there will be substantial pressures on an already strained healthcare system. The Canadian government has expressed its commitment to initiatives that support older adults to stay at home longer. Nevertheless, there are still significant gaps in funding and support for informal caregivers and PWD in the community (Canadian Institute of Health Information [CIHI], 2018). Research has shown that substantial costs and resources are needed to support individuals to remain at home (Alzheimer Society Canada, 2022). In 2016, 69% of PWD under the age of 80 and 58% above age 80 continued to be cared for in the community by family or friends (Alzheimer Society Canada, 2022). It is estimated that informal caregivers spend an average of 26 hours per week caring for PWD (Alzheimer Society of Canada, 2022). The responsibilities associated with caring for an individual at home can hinder caregivers from maintaining paid employment (PHAC, 2019). Some individuals also face additional obligations, such as childcare, that can increase caregiver stress.

Research has indicated that caregivers and PWD would benefit from additional programs and services in the community (CIHI, 2018). Increased hours dedicated to providing care, for example, can prevent caregivers the opportunity to spend meaningful and quality time with the PWD. With growing needs for support, caregivers are unable to reserve time for their self-care and well-being (PHAC, 2019). Although there is research to support that caregiving can provide positive, rewarding experiences, caregivers face increased risks for burnout and depression (Alzheimer Society Canada, 2022). According to data from the CIHI (2018), 45% of care partners reported feelings of stress related to their caregiving responsibilities. Furthermore, 21% acknowledged feelings of no longer being able to continue providing care due to unmanageable stress.

In the context of dementia, caregivers are encumbered with the responsibilities of personal care as well as the behavioural and psychological symptoms of dementia. These challenges can make it difficult for caregivers to leave their homes to complete necessary tasks such as grocery shopping or attending appointments (Evans & Lee, 2014). Moreover, stigma related to dementia can cause family and friends to withdraw from the PWD and their caregivers, further affecting important social and community connections. When caregivers feel isolated, lack support, and become overwhelmed with the responsibilities of caring, feelings of frustration can have considerable impacts on their emotional and physical health putting caregivers at additional risk of developing depression and burnout (Holdsworth & McCabe, 2018).

While over half of caregivers in the community are children of PWD, 32% of caregivers are spouses or common-law partners (CIHI, 2018). The focus of this research project was on spousal caregivers providing support to a partner with dementia in the community. Research has shown that the quality of a relationship between partners can impact the overall health of caregivers and PWD (Holdsworth & McCabe, 2018). Given the level of support often required, roles in intimate relationships can change over time, becoming more like a job rather than a mutual partnership. As a result, spousal caregivers have reported considerable changes in their intimate relationships and expressed experiencing a loss of companionship (Holdsworth & McCabe, 2018). When the quality of the relationship is affected, the caregiver may be more likely to place their partner in institutional care. Decisions regarding the need for long-term care (LTC) can cause distress for both caregivers and PWD (PHAC, 2019). Increased needs for LTC beds cause further strain on the healthcare system which is struggling to address the growing population of older adults with higher care needs and a lack of qualified specialists and interdisciplinary support in dementia care (PHAC, 2019). Understanding how caregiving challenges influence relationship quality may mitigate premature institutionalization.

According to a national survey conducted by March of Dimes in 2021, over 81% of older adults in Canada expressed a desire to age in their own homes (Fenton et al., 2024). This highlights the need to provide appropriate support and services for informal caregivers and PWD to remain at home longer while recognizing the challenges associated with assisting older adults in aging in place, such as access to community resources (Fenton et al., 2024). Limited research exists in Canada on how providing care for a partner with dementia affects relationship quality. Additionally, it is important to enhance understanding of how to maintain intimate bonds between partners to improve overall quality of life.

Purpose of Study

In referencing Engel & Schutt (2017), the first question I asked myself was whether the research I am considering has social importance and scientific relevance and is a feasible endeavor to undertake. Dominant discourse in health and social care continues to reflect a reductive and ageist understanding of aging, dementia, and caregiving. Perceptions of the public, including healthcare workers, policymakers, and other government officials will continue to influence the care and services older adults are provided in the community. As a collective, we need to speak up about harmful aging stereotypes that can directly affect care and services, and pertaining to the question at hand, shifting the focus from the disease trajectory to the expressed and individualized needs of caregivers and their partners by finding appropriate ways to promote quality of life.

My next step was to narrow my topic into a reasonable, researchable question. I began by questioning the meaning of relationship quality; defined below in the key terms section of this document. I then asked how caregiving affects an individual’s ability to feel intimate with their partner. Are these topics discussed with healthcare professionals? What supports are available to address these important issues?

The purpose of this study was to examine how caregiving for a partner with dementia affects relationship quality. While caring for a partner with dementia may strengthen the relationship between couples, the progression of the disease could also have harmful effects on relationship quality. This project then aimed to better understand how relationship quality changes in the context of the provision of care, the progression of dementia, or both. My research question was finalized as, 'How does caregiving for a partner with dementia affect intimate relationships in older adults?' This study contributes to existing research that intends to improve the quality of life for caregivers and their partners with dementia.

Key Terms

Below is a list of key terms relevant to this research. These key terms will help provide further understanding of the main concepts discussed throughout this document. The key terms include dementia, informal caregiver, and relationship quality.

Dementia

Dementia is an umbrella term used to describe a set of symptoms that affect the functioning of the brain. These symptoms include a decline in cognitive abilities, which impacts memory, fine motor skills, comprehension, speech, and self-awareness (PHAC, 2019). Dementia has significant effects on an individual's ability to make decisions and slowly causes the loss of independence. All forms of dementia are progressive, with symptoms worsening over time.

While there are medications to help manage the symptoms, there are currently no cures (PHAC, 2019).

During the progression of dementia, individuals can lose their ability to maintain essential activities of daily living (ADLs) and instrumental activities of daily living (IADLs), requiring increased support from their formal or informal caregivers (PHAC, 2019). ADLs include personal hygiene such as bathing, oral care, continence care, feeding, dressing, and mobility (Giebel et al., 2015). IADLs include managing finances and medications and completing household tasks, including meal preparation, laundry, and grocery shopping (Giebel et al., 2015). Although Alzheimer’s disease is the most common form of dementia, other prevalent types include Lewy Body, Frontotemporal, and mixed dementias (Alzheimer Society of Canada, 2022). The progression of dementia can be measured using levels of severity by standardized stages including mild, moderate, and severe. To determine what stage an individual fits within, clinicians consider a patient’s level of cognitive impairment. Cognitive impairment can be measured using assessment tools such as the Mini-Mental State Examination (MMSE).

Informal Caregiver

Informal caregivers are individuals who provide personal care to a family member or friend, most commonly in the community (PHAC, 2019). The term ‘informal’ is used because these caregivers do not receive payment for supporting the PWD (Alzheimer Society of Canada, 2022). Informal caregivers have also been referred to as care partners (Alzheimer Society of Canada, 2022). Family and friends who act as care partners often assist individuals with physical and cognitive disabilities including individuals with dementia. Caregiving activities can range from general supervision to assistance with all ADLs and IADLs. In Canada, there are more female care partners than males primarily consisting of children and spouses of PWD (PHAC, 2019).

In the initial stages of this research project, I referred to spousal care partners as “informal caregivers”. However, I now understand that this term may not fully acknowledge the important role that family members and friends play in caring for their loved ones. Therefore, for the remainder of this research paper, I will use the more specific term 'spousal caregivers'. This research focused on spousal caregivers who provide care and support to their partners with dementia while living at home in the community. These partners were not required to be legally married but must have been living together for at least a year before the dementia diagnosis.

Relationship Quality

Relationship quality is developed and enhanced when individuals spend meaningful time building emotional connections with romantic partners, family members, friends, or colleagues. For partners, relationship quality includes considerations for both physical and emotional intimacy. It involves building a foundation of trust and co-constructed communication patterns and social norms (Colquhoun et al., 2019). Relationship quality can be subjective and difficult to define given individuals have diverse needs based on beliefs, values, cultural backgrounds, upbringings, education, race, age, and sexuality. It is important to consider that every relationship is unique.

Older adults who develop positive emotional bonds over their life course are found to have stronger relationship quality (Clare et al., 2012; Colquhoun et al., 2019; Rippon et al., 2020). Research indicates relationship quality supports psychological well-being, while relationship dissatisfaction can result in negative mental health outcomes for partners (Rippon et al., 2020). According to Clare et al. (2012), relationship quality for older adults can be influenced by the onset of health issues such as those associated with dementia when healthy partners take on caregiving roles.

Personal Interest & Social Location

The idea for this research project developed from my volunteer work as a caregiver support group facilitator for the Alzheimer Society of Nova Scotia. Although the group consists of different types of caregivers, there are often participants supporting a partner with dementia. Having worked with support groups for several years, I started to notice themes in participant narratives largely centering around caregiver burden, lack of support accessible in the community, and apprehension to move their partners to LTC facilities. What was rarely discussed or acknowledged by members was the experience of loss, particularly the loss of companionship, intimacy, and relationship quality among partners. I started to question why these topics were never addressed and whether caregivers would feel comfortable discussing personal and intimate details of their relationships. Were members of the group too overwhelmed with the stress and burden of care to reflect on the losses experienced in their relationship? Was it possible that providing care could bring partners closer together?

As a social worker in the field of geriatrics, I have observed that dementia care ascribes to a medical model of practice. Rather than treating individuals holistically, concentration is instead on the disease process. While there has been a small shift in language regarding person-centered approaches to care, this way of thinking continues to dominate the way clinicians practice. I have also found that healthcare workers are uncomfortable discussing sexuality and intimacy with older adults. In my role at a LTC facility, for example, I have seen the need to provide education on the rights of older adults to seek physical and emotional intimacy. I acknowledge that I am not an older adult, nor have I cared for a partner with dementia. Through the personal narratives shared during support group, however, I have gained small insights into their experiences which I hoped to further explore in a more expansive, formal research study.

As a social work student, it was crucial to reflect on my social location and how it influences my interpretation and understanding of the research. My social location comprises of various intersecting categories that shape how I perceive the world around me. This includes identifying as a cisgender, heterosexual, Caucasian, young, and educated woman. Before pursuing social work education or practice, my understanding of social norms and identity was primarily shaped by my family values, western and white cultural upbringing, middle-class status, and interactions with individuals from similar backgrounds. My perception of personal identity was further influenced by dominant social ideologies related to classism, sexism, racism, and ageism. It was not until my social work education that I was confronted with the privilege and power I hold over others. Through critical self-reflection, I was then able to deconstruct my identity and build a deeper understanding of how my social location may affect those I aim to support.

As I worked on my thesis, I took time to consider how my social location might influence my understanding and interpretation of the research. I came to realize that various aspects of an older adult's identity may impact how they experience aging, caregiving, and the dementia journey. For example, an older adult may face multiple forms of oppression due to their age, abilities, race, sexuality, gender, or socioeconomic status. It is therefore important to be aware of the diverse experiences and challenges caregivers and PWD experience. Without critical self-reflection regarding my social location, I could unintentionally contribute to harmful stereotypes and stigma that further marginalize older adults. These were important considerations throughout my research and to carry forward in my professional practice as a social worker supporting older adults.

Chapter 2 - Literature Review

From the review of the literature, it was evident that previous research was available on understanding how relationships are impacted when individuals provide care to their partners with dementia. One key finding was that providing care to partners has a complex effect on the ways couples experience emotional and physical intimacy in their relationships. I also discovered that there are both positive and negative changes related to caregiving. While some individuals found providing care a rewarding experience that improved emotional intimacy, others reported negative outcomes to their overall relationship quality (Bruinsma et al., 2020; de Vugt et al., 2003; Evans & Lee, 2014; Fee at al., 2021; Harris et al., 2011; Youell et al., 2016).

During the exploration of existing research, themes became apparent across the studies. These themes will be explored in more detail and include the following: different forms of loss, gender considerations, effects on physical and emotional intimacy, understanding supports, and strategies to maintain couplehood. I will also include research regarding new partnerships developed in later-life and comment on the lack of diversity among participants in these studies.

Loss

Grief and loss are critical topics in the study of aging, particularly in an ageist society. Older adults experience a convergence of losses throughout their life course. This can include physical losses such as decreased mobility and emotional losses like loss of purpose after retirement or loss of friends and family who have passed. On the dementia journey, both caregivers and PWD in spousal relationships share experiences of loss, such as the loss of cognition due to the disease process and the loss of established roles in the relationship as the

PWD's care needs increase (Evans & Lee, 2014). Loss experienced by couples can have an impact on their quality of life as well as on their relationship quality (Colquhoun et al., 2019).

When discussing grief and loss concerning dementia, disenfranchised grief and ambiguous loss should be recognized. Disenfranchised grief refers to grief that is not socially accepted or acknowledged by others (Testoni et al., 2023). Caring for a loved one in the context of dementia exemplifies disenfranchised grief because individuals unfamiliar with these diseases may not grasp that loss occurs throughout the disease process, not just at the end of life (Testoni et al., 2023). Ambiguous loss occurs when grief and loss are experienced without the physical death of an individual (Testoni et al., 2023). In cases of dementia, ambiguous loss is related to the changes in the PWD during the progression of the disease (Nathanson & Rogers, 2021). Even though the person may still be physically present, their friends and family may feel a sense of loss due to changes in the individual's cognition and personality (Nathanson & Rogers, 2021). Caregivers may find it difficult to anticipate these changes while constantly having to readapt to new losses in the PWD (Nathanson & Rogers, 2021).

It is important to appreciate how disenfranchised grief and ambiguous loss impact caregivers supporting partners with dementia. Individuals need to be provided the opportunity to process grief while having their feelings validated to further prevent increased risk of stress and burnout (Testoni et al., 2023). With these concepts in mind, the following section of the literature review will discuss various types of losses that were apparent in the research.

Loss of Personhood/Identity

The concept of personhood in dementia care is connected to the philosophy of person-centered care. This approach provides a deeper understanding of the unique experiences of PWD

(Baikie, 2002). The Alzheimer Society of Canada (2024a) defines the person-centered philosophy as recognizing that all PWD have individual identities shaped by their personal values and experiences despite the progression of the disease. This approach emphasizes that each person has the right to dignity and respect throughout their care journey (Alzheimer Society of Canada, 2024a). Research has found, however, that the symptoms of dementia changed how couples understood their relationship and viewed the identity of their partner. In a study by Johnston & Terp (2015), spouses acknowledged that they still loved their partners but no longer felt as though they were the same person they married. Similarly, in studies conducted by Lewis (1998) and Walters et al. (2010), caregivers indicated that their partners felt like different people due to personality changes related to dementia. Youell et al. (2016) reported that caregivers identified as being legally married but described themselves as "functionally" single. Some individuals also saw their marriage shift from an equal partnership to something more like a parent-child relationship (Evans & Lee, 2014). This resulted in caregivers experiencing feelings of loneliness despite their partner still being physically present (Evans & Lee, 2014). Nevertheless, caregivers continued to feel marital obligations despite the challenges in their relationship and changes observed regarding the loss of their partner's identity (Evans & Lee, 2014).

Across the literature, changes in roles and responsibilities within the relationship challenged how couples viewed their self-image and partnership. For caregivers, this loss of self-identity was related to assuming new roles in caring for the PWD (Colquhoun et al., 2019). Some caregivers felt that changing roles in the relationship was a source of distress resulting in feelings of anxiety and depression (Colquhoun et al., 2019; Robinson et al., 2005). Role changes not only impacted how caregivers saw their shifting identity but also how these changes altered the identity of the PWD (Robinson et al., 2005). Individuals spoke to the difficulty of finding ways to meet their own needs while still providing adequate care to their partner (O'Shaughnessy et al., 2010). O'Shaughnessy et al. (2010) found that caregivers who were unable to find this balance were left with feelings of self-criticism and guilt.

In the study conducted by Bauer et al. (2001), caregiving was found to have a positive influence on self-esteem with respondents describing that the responsibility of caring added meaning to their lives. For those individuals, caregiving was a way to express feelings of love and gratitude while providing opportunities to maintain emotional intimacy (Bauer et al., 2001). Merrick et al. (2016) found both caregivers, and PWD recognized the loss of previous identity but worked as a couple to focus on a new reality and adapt to changes by embracing a different sense of self.

Loss of Couplehood

Participants of several studies discussed how their sense of couplehood had changed over the progression of dementia. It was apparent from the literature that with the advancement of symptoms, couples felt a loss of companionship. This included decreased quality time spent together resulting in negative outcomes on overall relationship quality (Bruinsma et al., 2020; Evans & Lee, 2014; Harris et al., 2011; Youell et al., 2016). Couples reflected on feelings related to the loss of common interests and shared activities they once spent time enjoying together (Davies et al., 2010; Molyneaux et al., 2012; O'Shaughnessy et al., 2010). Some individuals referenced how these activities, which had once defined their identity as a couple, challenged internal and external perceptions of their marriage (Molyneaux et al., 2012). In one study, those interviewed discussed how the lack of companionship resulted in feelings of loneliness (Benbow et al., 2019). Frustrations related to the behavioural changes of the PWD also altered couplehood. Caregivers described how repetitive questioning or wandering caused them to further isolate themselves from interactions with their partners (Wright, 1991).[1]

Caregivers and their partners with dementia tried to find ways to cope with the losses in their relationship and its influence on their couplehood. While some attempted to maintain activities to their best ability, others acknowledged the process of change and what those losses meant for the relationship (Merrick et al., 2016; Robinson et al., 2005). In their study, Hellstrom et al. (2007) discussed the importance of looking beyond the person-centered philosophy to consider the concept of couplehood. From this perspective, caregiver dyads should be considered not only as individuals but as a couple, focusing interventions on the relationship as a whole (Hellstrom et al., 2007).

Loss of Communication

Communication is part of our daily life and routines including how we express our needs, wants, concerns, and emotions. Communication between couples can include both verbal and non-verbal cues and allows for space to share opinions and validate feelings (Youell et al., 2016). According to Braun et al. (2009), "Research on marital relationships has identified communication skills as main predictors of marital satisfaction and relationship quality" (p.427). Healthy communication is then critical to strengthen the quality of relationships for all couples including those on the dementia journey (Braun et al., 2009).

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[1] Although this study was conducted in 1991 and may seem outdated, there was a lack of literature on how providing care to a spouse with dementia impacts relationship quality. This source was used because of the lack of available literature.

As all types of dementia are progressive, communication skills are often lost over time. This decline is related to cognitive function which can cause difficulty with word-finding, memory loss, and confusion (Youell et al., 2016). Deterioration in speech and language impacts not only how the PWD communicates but also how couples come to understand and share meaningful conversations (Evans & Lee, 2014; Youell et al., 2016). The ability to communicate provides emotional support through words of affection, reassurance, and comfort and influences how couples make decisions together such as how to spend quality time (Baikie, 2002; Youell et al., 2016). When communication is disrupted, couples must find new ways to share this information.

Fee et al. (2021) noted that a lack of communication between partners resulted in decreased emotional intimacy, which in turn contributed to feelings of loneliness. Caregivers commented that the behavioural symptoms of dementia were easier to cope with than the loss of conversation (de Vugt et al., 2003). This included difficulties maintaining communication with a partner who presented as apathetic and passively disinterested in conversation. Further research on understanding how couples can communicate effectively when coping with dementia is needed. Harris (2009) and Hellstrom et al. (2007) for example, questioned if the development of new communication skills between couples could help promote intimacy in relationships where one partner has dementia.

Loss of Social Networks

Our social networks consist of relationships we develop with friends, family, neighbours, and community organizations. Research indicates that a dementia diagnosis can influence the amount of social support individuals receive or are willing to access (Hellstrom et al., 2007).

Although it is critical to recognize interventions with the couple, maintaining meaningful connections with larger social networks can help to promote the quality of life of caregivers and their partners (Benbow et al., 2019). Increased social support may also reduce the risk of caregiver burnout (Daniels et al., 2007).

Connections to social networks varied among caregivers and PWD across the literature. Although some caregivers felt supported by family and friends, others reported further isolation with the progression of dementia (Benbow et al., 2019; Colquhoun et al., 2019; Robinson et al., 2005). In a study by Benbow et al. (2019), caregivers described avoiding acceptance of social support due to feelings of guilt and hesitancy to burden friends and family.

According to Youell et al. (2016) providing care for a partner leaves limited time to focus on other important shared social activities and interactions outside the caregiving relationship. Evans & Lee (2014) reported some caregivers drifted from social contacts because it became increasingly difficult to take their partners out in the community. Several women in the study conducted by Hayes et al. (2009) noted feelings of embarrassment related to how others would perceive their husbands' behaviour in public spaces. Couples also reported isolating themselves to prevent others from becoming aware of their partner's diagnosis (Robinson et al., 2005). In addition, caregivers were found to diminish the prevalence of symptoms when speaking with friends and family (Robinson et al., 2005). Robinson et al. (2005) discussed how negative perceptions of dementia can result in social withdrawal for caregivers and PWD, reducing the likelihood of accessing needed support. Caregivers who could not leave the home due to the increased complexity of care and supervision needs reported feeling a loss of freedom (Walters et al., 2010). According to Evans & Lee (2014) and Robinson et al. (2005), avoiding contact with friends and family prevented caregivers from maintaining important social connections, contributing to feelings of isolation and hopelessness.

It was evident from the literature that it is important to understand why some caregivers are hesitant to accept social support. Further research and discussions with caregivers and PWD can help to normalize feelings related to burnout including guilt or shame. By reducing social stigma about dementia, caregivers may feel more comfortable accepting help from family, friends, and community resources enhancing the quality of their time together.

Loss of Future Plans

Uncertainties regarding the progression of dementia altered couples' plans for the future invoking feelings of fear and loss related to the unknown. In studies by Harris et al. (2011) and O'Shaughnessy et al. (2010), participants discussed their feelings regarding the inability to control the future. Common among responses was a feeling of powerlessness and frustration with the unpredictability of the duration of the disease. Caregivers questioned how the progression of the disease would further change their role in the relationship and whether increased responsibilities would mean a loss of independence for their partner (O'Shaughnessy et al., 2010). In a study by Colquhoun et al. (2019), caregivers had mixed reactions when discussing plans for the future. While some adjusted to their new reality by acknowledging the disease process, others attempted to normalize the symptoms of dementia as part of aging. Couples in the study by Robinson et al. (2005) were aware of ongoing changes that would create challenges along their dementia journey. Participants discussed adjusting to difficulties over time and working together as a couple to make sense of their situation and the effects of dementia on their relationship.

Gender Considerations

Awareness of gender as a fluid concept has only recently been acknowledged. However, when considering the current generation of older adults, gender is often observed in traditional understandings of gender roles as defined by societal norms. This is an important consideration when aiming to understand how gender roles and perceptions of traditional family units may affect the older generation and their beliefs and expectations regarding marital relationships.

It was noted throughout the literature that roles within relationships shift over time with the progression of dementia. The research indicated that gender influences how roles change in these relationships (Evans & Lee, 2014). Although the concepts of sex and gender are often used interchangeably, they have different meanings (Government of Canada, 2023). According to Statistics Canada (2021), gender is defined as an individual's personal or social identity, encompassing male, female, or non-binary identification. Gender is a concept that has been socially constructed and relates to how individuals express their identity, influenced by behaviours, beliefs, and ideals about how individuals of biological sex should act, dress, and interact with others (Government of Canada, 2023). An individual’s sex, however, is based on biological understandings. From this perspective, sex is related to the human reproductive system in addition to other physical characteristics including, chromosomes and hormone levels (Government of Canada, 2023; Statistics Canada, 2021).[2]

Johnston & Terp (2015) discussed gender role reversals in caregiving relationships with a population that grew up with pressures from a patriarchal society. This included stereotypical

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[2] Although I found it important to provide clarification regarding the definitions of sex and gender, discussions regarding gender identification are beyond the scope of this research project. The focus of this topic was instead on the impact of gender role reversals in the context of caregiving relationships.

examples of husbands taking over cooking duties while wives started managing financial responsibilities (Johnston & Terp, 2015). Evans & Lee (2014) and Robinson et al. (2005) commented on how role changes in relationships were difficult for both spouses as previous roles defined their place in the marriage.

In the review of literature by Braun et al. (2009), men were found to adapt better to caregiving roles, reporting lower levels of stress, depression, and anxiety. Men were also more likely to have social relationships outside the spousal dyad as compared to female caregivers (Braun et al., 2009). Similar findings were discussed by Simonelli et al. (2008) and Bolystein & Hayes (2012) who reported that male caregivers were more likely to access support outside the relationship to aid with the care of their partner. Men were then found to pursue more support than women to cope with caregiving stress (Bolystein & Hayes, 2012; Simonelli et al., 2008).

In a review of literature conducted by Baikie (2002), women who were caring for spouses with dementia reported higher unmet needs in their relationships. Female caregivers were found to experience more stress and fewer moments of gratification from caregiving compared to male spousal caregivers (Baikie, 2002). Similarly, in the study conducted by Simonelli et al. (2008), women felt more accountable for assuming the role of caregiver and were further burdened by the emotional and physical stress associated with those responsibilities. Some female caregivers reported feeling more distant from their male spouses which resulted in less physical affection in the relationship (Bolystein & Hayes, 2012). In the study by Bolystein & Hayes (2012), caregiving wives provided more hours of care as compared to male caregivers and felt higher levels of stress and anxiety. Some women reported they felt that caregiving responsibilities consumed every aspect of their lives (Bolystein & Hayes, 2012). Research indicated that some women were more concerned with how others outside the relationship would perceive their partners (Hayes et al., 2009). In an earlier study conducted by Wright (1991), female caregivers reported feeling uneasy accessing outside respite support as the field was primarily dominated by female workers who they were unwilling to leave alone with their partners.

The research then led me to further questions about generational gender expectations and whether women feel more societal pressures to provide care to their partners. As previously discussed, there are more female caregivers for PWD in Canada than males (PHAC, 2019). Considering traditional gender expectations that often place women in caregiving roles, it is important to examine how this knowledge can be used to support other couples. It is essential to gain an understanding of how socio-political influences concerning gender norms impact the coping mechanisms of both men and women in caregiving roles.

Several studies have highlighted that gender may impact caregiving relationships where one spouse has dementia (Baikie, 2002; Bolystein & Hayes 2009; Clare et al., 2012). However, as Braun et al. (2009) reported, few studies on providing care to partners with dementia focus on gender considerations. Additional research would, therefore, be beneficial to understand how gender differences influence caregiving relationships to better provide appropriate support and interventions.

Impacts on Physical & Emotional Intimacy

Across the literature, intimacy was discussed in terms of physical and emotional connections. The research revealed that dementia does impact the intimacy caregivers and their partners share. This included both positive and negative outcomes, which are discussed in more detail in this section.

To understand intimacy in later life it is first important to challenge harmful stereotypes about sexuality and the aging process. Despite the common portrayal of older adults as asexual, aging does not mean sexuality is no longer desired or existent (Heywood et al., 2019). These misconceptions only serve to perpetuate harmful ideas that older adults do not have sexual needs (Childs, 2019). Ageist viewpoints can discourage healthcare professionals from recognizing the needs of older adults. Further research and awareness on this topic can help normalize discussions about supporting older adults in nurturing their emotional and intimate connections.

Like defining relationship quality, understandings of intimacy can differ based on unique beliefs and values regarding sexual orientation, gender, religion, ethnicity, cultural background, age, education, or upbringing. Intimacy can be experienced in many types of relationships, including with friends, family, and partners. Holdsworth & McCabe (2018) describe intimacy as positive feelings of affection, emotional connection, and a sense of physical closeness to a romantic partner. Although these feelings are meant to be reciprocal, there may be imbalances in how intensely one individual feels towards another (Holdsworth & McCabe, 2018). Intimacy includes a process of shared experiences where partners are free to disclose personal information. Youell et al. (2016) describe sexual attraction and connection as a sub-type of intimacy including sharing physical or sexual touch.

In their qualitative review of literature on the topic, Evans & Lee (2014) found there was an impact on intimacy between partners on the dementia journey. They reported that as the disease progressed, intimacy also changed. Changes in intimacy were related to several factors, including adapting to new roles within the relationship and cognitive decline in the PWD (Evans & Lee, 2014). Individuals also found that changes in their intimate relationship were related to behavioural concerns with their partner. Some people, for example, compared their partner’s behaviour to that of a child (Evans & Lee, 2014; Hayes et al., 2009). This was related to concerns regarding consent and physical intimacy. Caregivers, as such, expressed concerns about their partner's changing identity and questioned whether sexual touch was still appropriate given their spouse seemed like a different person. Others conveyed no longer wanting to pursue a sexual relationship as the cognitive decline in their partner had become too significant (de Vugt et al., 2003; Evans & Lee, 2014). Davies et al. (2010) and Fee et al. (2021) reported that caregivers attributed a lack of physical intimacy to decreases in desire and the functional decline observed in their partner resulting in issues such as incontinence.

In the study conducted by Youell et al. (2016), all participants reported engaging in some physical intimacy prior to the dementia diagnosis however, with the progression of the disease, perceptions of intimacy changed. Although some couples continued to express physical intimacy towards each other despite the challenges, others no longer participated in sexual relationships (Youell et al., 2016). Baikie (2002) found similar results, particularly with female caregivers who reported no longer participating in sexual relationships with their spouses. In the study by Harris et al. (2011), caregivers had mixed views about physical intimacy in their relationships. While some felt closer to their partner through the shared experience of dementia, others felt the disease had affected their ability to feel physically close (Harris et al., 2011).

Eloniemi-Sulkava et al. (2002) reported that there was a statistically significant decline in how PWD expressed their needs related to sexual intimacy as compared to before the diagnosis. Gender differences in this study were also relevant. For example, some female caregivers reported that their spouses displayed negative sexual behavioural changes. In their study, 24% of male participants diagnosed with a form of dementia had shown a desire to have frequent sexual contact with their partner (Eloniemi-Sulkava et al., 2002). The study conducted by Ballard et al.

(1997) showed that male caregivers were more likely than females to want to continue sexual intimacy with their partners. Some individuals, both male and female, reported continuing physical intimacy, such as intimate touch and massage (Harris et al., 2011). In a study conducted by Hayes et al. (2009), women attributed the lack of sexual intimacy with their partners to the exhaustion experienced from providing care. Many of the tasks required to help their partner took a physical toll on their bodies.

Studies have shown that dementia is not always a factor contributing to a decrease in physical intimacy between partners. Eloniemi-Sulkava et al. (2002) noted that dementia had little influence on whether couples continued to engage in sexual activity as compared to the normal aging population. Similar viewpoints were discussed in Wright's (1991) publication when participants interviewed felt no change in their physical relationship. Individuals credited a lack of sexual desire to physical limitations and other health-related issues including diabetes. Others made comments that a reduction in sexual desire was due to their age (Benbow et al., 2019; Eloniemi-Sulkava et al., 2002; Hayes et al., 2009; Wright, 1991).

Although some caregivers and their partners noted a decrease in physical intimacy throughout the disease process, others described an increase in emotional intimacy (Evans & Lee, 2014). De Vugt et al. (2003) and Harris (2009), found that caregivers felt stronger emotional connections with their spouses despite a decrease in sexual intimacy. Research showed that physical touch was an important part of preserving emotional intimacy such as hugging or holding hands. This type of touch allowed couples to find comfortable ways to still display affection towards one another (Benbow et al., 2019; Evans & Lee, 2014; Youell et al., 2016). Likewise, Wright (1991) reported that caregivers were more concerned with maintaining emotional connections rather than sexual relationships. Harris et al. (2011) however, found that with increased stress related to caregiving roles and responsibilities, some participants felt a decrease in both physical and emotional intimacy with their partner. Fee et al. (2021) reported varying experiences among male caregivers regarding the effect of dementia on their intimate connections. Some participants were found to value emotional intimacy over sexual contact. Others felt that stronger emotional connections resulted in more rewarding caregiver experiences. Some male participants described a decline in emotional intimacy, contributing to feelings of loss and decreased relationship quality (Fee et al., 2021).

As a result of ageist stereotypes about intimacy in later life, couples may not be provided the opportunity to discuss sexuality and intimacy with social or professional support (Benbow et al., 2019). In the studies by Benbow et al. (2019), Fee et al. (2021), and Youell et al. (2016), caregivers were hesitant to share their experiences related to sexual intimacy, reporting uncertainty about whether it was appropriate to discuss these topics. It is clear from the literature that it is important to understand how dementia influences the physical and emotional intimacy couples share to help contribute to proper interventions and support (Harris et al., 2011). Additional studies on this topic could aid in understanding whether stronger emotional connections help to prevent caregiver burnout.

Considerations for New Later-life Partnerships

Throughout the literature, there was limited consideration of new partnerships developed later in life. Older adults can enter new relationships with romantic partners in later life due to separation, divorce, or losing a partner. Previous research on marital status in later life has primarily focused on losses related to the death of a partner (Brown et al., 2012). However, as the number of older adults within the baby boomer generation continues to increase, new later-life partnerships in the form of cohabitation and remarriage are becoming more prevalent (Brown et al., 2012). This suggests that the formation of new partnerships in later life may become increasingly common with the growing population of older adults.

Couples in new later-life partnerships on the dementia journey may require different forms of support to meet their unique needs. Sherman et al. (2013), for example, reported that blended family dynamics may cause additional stress and burden for caregivers. Although caregivers discussed both positive and negative relationships with stepfamily members, these individuals were found to depend on broader social networks for support outside the family unit including friends and community resources (Sherman et al., 2013). Remarried couples felt they were less likely to receive support from stepchildren as compared to couples who shared biological children. This was linked to perceptions that biological children feel a stronger obligation to provide support to their parents (Sherman et al., 2013).

Lewis (1998) found that support from family and friends depended on whether the new relationship was accepted by the couple's social network. Benbow et al. (2019) suggested that healthcare workers be aware of the possibility that conflict may exist within the social networks of later-life partners. They further encouraged clinicians to introduce discussions regarding family dynamics to ensure that caregivers and the PWD feel supported (Benbow et al., 2019).

Understanding Supports

It is essential to find appropriate support for spousal caregivers and their partners on the dementia journey. Social and professional support systems may aid couples in maintaining relationship quality. Many of the studies I reviewed supported this argument; however, they provided little evidence that caregivers and PWD had accessed support. Instead, the research highlighted recommendations of support services that could be helpful for couples and called for additional study on this topic.

Healthcare professionals must recognize that every partnership is different. All couples have a unique story of shared experiences, challenges, and strengths that should be considered when planning for support services (Daniels et al., 2007; Wadham et al., 2016). According to O’Shaughnessy et al. (2010), recognizing and validating the individuality of caregiver experiences builds trusting relationships that can encourage more access to healthcare services. It is equally important to include both the caregiver and PWD in discussions regarding social and professional support (Daniels et al., 2007; Hellstrom et al., 2007). By taking time to build a better understanding of the lived experiences of couples, we can emphasize that there are people behind the disease with individual needs (Daniels et al., 2007).

Most of the studies reviewed recruited participants who had been in long-term relationships with their partners. When considering appropriate support services, it is therefore critical to understand what relationship quality was like before the diagnosis of dementia (Knop et al., 1998; O’Shaughnessy et al., 2010). This includes assessing how couples previously coped with stressful life experiences and overcame hardships in their relationships. Such considerations can help couples and clinicians plan accordingly for the future (Knop et al., 1998). Harris et al. (2011) and O’Shaughnessy et al. (2010), for example, found that the relationship quality before the diagnosis of dementia did affect how caregivers experienced their changing roles in the relationship. Further to this, Knop et al. (1998) suggested that caregivers who identified positive past relationship quality may find more value in the caregiving experience and are less likely to develop depression. Additional exploration of prior relationship quality may then help establish what enables some couples to maintain positive relationships. This could highlight potential risk factors and help identify couples who may need extra support in their relationship (Wadham et al., 2016).

Access to education and resources regarding the diagnosis of dementia was seen as valuable information for caregivers and their partners. Bolystein & Hayes (2012) argued that there is a need for specific types of education that are geared towards maintaining healthy relationships. Clare et al. (2012) discussed the importance of developing education related to the impact of dementia on relationship quality to allow professional support systems to provide relevant information. Psychoeducation was suggested as an approach to help couples prepare and explore how dementia may change their relationship (Johnston & Terp, 2015). Robinson et al. (2005) recommended that the education level of caregivers and the PWD be considered when working with couples. Their research showed that individuals with post-secondary education had a better understanding of what to expect from dementia and were more likely to seek support from community resources. Other research proposed that a lack of education regarding dementia may result in reduced quality of life for caregivers (Bruinsma et al., 2020). Robinson et al. (2005) concluded that the education and socio-economic status of caregivers and PWD were thought to have some impact on how couples may cope with dementia.

Davies et al. (2010) suggested that support for partners should start with early intervention and goal planning concerning how to strengthen relationships. Recommendations for early interventions included speaking with couples about realistic expectations during the progression of the disease (Bauer et al., 2001; Davies et al., 2010). Research also indicated that individuals consider accessing support groups which can provide emotional relief and opportunities to learn from peers going through similar experiences (Clare et al., 2012;

O’Shaughnessy et al., 2010). Additional recommendations included providing information about other community resources such as respite and adult day programs (Knop et al., 1998).

Couples therapy was found to allow partners to explore ways to connect, communicate, and show affection toward each other (Benbow et al., 2019; Clare et al., 2012). Couples counseling can provide partners with tools for conflict resolution as they adapt to changes in the relationship (Johnston & Terp, 2015). Earlier discussions in this paper regarding the loss of communication showed the importance of considering how to maintain communication within relationships. Benbow et al. (2019) added to this by suggesting that when providing counseling to couples, clinicians should help individuals maintain communication skills to further foster connection. Talking with couples about what aspects of dementia may alter their relationship could also allow partners to build a positive outlook for their relationship (Brunisma et al., 2020).

Robinson et al. (2005) highlighted that a lack of early intervention, including appropriate emotional and practical support for couples, may lead to feelings of isolation and hopelessness. Bauer et al. (2001) and Knop et al. (1998) suggested that early support for couples could help to reduce depression and caregiver burnout. Couples need to find positive coping strategies that work for their relationship. This includes embracing the unpredictable moments of daily life and working towards acceptance of the disease process (Harris, 2009). Although considerations for both the caregiver and PWD are critical to providing necessary support, some of the research focused specifically on the needs of spousal caregivers. In the study by O’Shaughnessy et al. (2010), caregivers expressed their need to feel heard and have their experiences validated. Many felt a lack of power regarding the changes and increased challenges in their relationships.

Clinicians should be mindful not to avoid discussions regarding sexual intimacy (Harris et al., 2011). Harris et al. (2011) argued that aging stereotypes regarding sexuality allow clinicians to make assumptions that older adults are not sexually active. Instead, professionals should learn to be comfortable asking sensitive questions and reflect critically about their personal biases. Simonelli et al. (2008) proposed that introducing questions regarding physical intimacy in early conversations may allow couples to feel more comfortable discussing these topics in the future. Some individuals reported feeling hesitant to bring forward concerns regarding their intimate relationship as it was not related to the care or treatment of the PWD (Harris, 2009). As physicians are often involved in early diagnosis and intervention, they must be aware of these important concerns and explore ways to support patients (Harris, 2009).

Hellstrom et al. (2007) and Wadham et al. (2016) highlighted that most interventions for dementia care are targeted at caregivers to prevent burnout. Although focusing on the needs of caregivers is important, research shows that supporting both individuals as a couple is vital. This was supported by Lewis (1998) who suggested that interventions to aid couples with relationship quality and emotional well-being should include both perspectives. Another consideration is to help couples understand how power dynamics in the relationship can change as one partner takes on the caregiving role (Wadham et al., 2016). Granted, there are benefits to recognizing the person-centered approach; support for couples should also be understood from a relationship-centered perspective (Molyneaux et al., 2012; Wadham et al., 2016).

The research clearly shows the value of creating more support and interventions for couples on the dementia journey. Such interventions could decrease significant stress for caregivers and PWD (Davies et al., 2010). Additional research, including input from caregivers and PWD, is then needed to understand further the ways to support partners to age in place and maintain healthy relationships.

Strategies Utilized to Maintain Couplehood & Relationship Quality

Although it was clear from the literature that providing care to a partner with dementia has negative outcomes on the well-being of caregivers and their partners, there were also positive strategies noted throughout the research for partners to maintain their sense of couplehood and relationship quality. Braun et al. (2009) and Evans & Lee (2014) reported that individuals felt supporting their partner was a positive experience that provided feelings of self-fulfillment in the relationship.

One strategy to maintain a positive relationship included efforts to show affection towards one another (Hellstrom et al., 2007). Couples also attempted to maintain an optimistic attitude by appreciating the simple pleasures of everyday life and remaining present with their partners (Hellstrom et al., 2007; Robinson et al., 2005). This encompassed spending quality time through meaningful activities that could still be enjoyed together such as going on walks, socializing with friends and family, and accessing recreational community resources (Hellstrom et al., 2007; Merrick et al., 2016). Colquhoun et al. (2019) reported that having a positive attitude was associated with feelings of gratitude which may improve well-being and aid in strengthening relationships. Couples in their study reported using strategies such as reminiscing about positive memories and avoiding negative comparisons to other couples. Merrick et al. (2016) discussed the importance of gratitude. They suggested that it is important to encourage the PWD to express their feelings of gratitude towards their partner for assistance with care.

Acknowledging losses and limitations while focusing on the strengths within the relationship is critical for caregivers and PWD. This includes appreciating what areas of everyday life the PWD can still manage independently (Hellstrom et al., 2007; Merrick et al., 2016; Robinson et al., 2005). Learning about dementia together was found to connect couples, allowing them to develop realistic views and plans for the future (Harris et al., 2011). Robinson et al. (2005) found that individuals who were educated and accepting of the dementia diagnosis adapted easier to changes with their spouse.

Reflections on Diversity

From the literature reviewed, it was apparent that there was a lack of diversity among participants in many studies. This included individuals from various educational backgrounds, ethnicities, sexual orientations, and genders. For example, among 28 caregivers, Hayes et al. (2009) identified 2 Black and 3 Indigenous participants. Wright (1991) interviewed 30 couples and noted 2 Black individuals, while Harris (2009) recorded 4 Black participants out of 32 couples. Additionally, Bauer et al. (2001) included 1 Black and 1 Asian participant out of 115 female caregivers. Studies conducted by Davies et al. (2010), Lewis (1998), and Knop et al. (1998), commented that most of their participants were Caucasian but did not provide specific information regarding other racial minorities. The study by Sherman et al. (2013) was the only publication to acknowledge the lack of racial diversity in their sample of participants. They stated that efforts were made to recruit racial minorities by contacting different organizations serving these populations; however, no individuals volunteered (Sherman et al., 2013).

In this literature review I examined 34 studies, mostly conducted in the United Kingdom and the United States. Two studies were completed in Sweden and the Netherlands, in addition to single studies from Finland and Italy. No studies from Canada were included in this literature review as there seems to be limited research on this topic in the country.

Nearly all studies included couples legally married or considered common-law while 2 studies mentioned new later-life marriages. Demographic information primarily consisted of the age of participants and marital length. Most participants were over the age of 65. Few studies made mention of education level but of those that did, many participants reported to have some post-secondary education. Types of dementia ranged throughout the studies while several focused specifically on participants who were diagnosed with Alzheimer's disease. PWD were mainly in the mid to moderate stages of the disease progression. Caregivers and their partners were recruited from various locations, including dementia support groups, geriatric assessment clinics, memory cafes, and hospital settings. There were more female caregivers than males noted in the literature. Two studies focused specifically on the perspectives of female caregivers (Hellstrom et al., 2007; Walters et al., 2010), and 1 study on male caregiver experiences (Fee et al., 2021). Although most studies highlighted the caregiver's perspective, some included the viewpoint of the PWD. There was evidence to suggest that more studies should incorporate the PWD to provide a better understanding of relationship quality from the perspective of both partners.

Further focus needs to be provided to promote inclusion and recruit participants from diverse backgrounds in this field of research. According to the second published report by the Alzheimer Society of Canada (2024c), *The Many Faces of Dementia in Canada, Part 2*, ethnic and cultural demographics for older adults across Canada have changed due to immigration patterns over the last few decades. Canada is becoming an increasingly diverse country consisting of various languages, cultural backgrounds, and ethnicities. The Alzheimer Society of Canada (2024c) provided statistics on the growth of these populations, which include several ethnic groups, such as those of Asian origin, African, Latin/Central, and South American descent. According to their study, there is a lack of research in Canada regarding the impact of dementia on these populations (Alzheimer Society of Canada, 2024c).

The lack of adequate research on the effect of dementia on diverse populations in Canada raises the question of how well we understand how power relations may be experienced by service users who have likely faced stigma, discrimination, and injustice from services meant to provide support. Additional considerations must be made for the importance of intersectionality and how different forms of identity contribute to our varying levels of privilege. It is crucial to reflect on how cultural differences may influence the understanding of gender roles and responsibilities, as well as how couples cope with changes in the relationship, symptoms of dementia, grief, and loss of access to social and professional support.

The report by the Alzheimer Society of Canada (2024c) touched on important gender concerns. For example, they recognized the challenges associated with traditional gender roles experienced by women of the older generation. This included considerations for the impact of systematic inequalities and discrimination women have experienced throughout their life course (Alzheimer Society of Canada, 2024c). Although it is known that more women have been diagnosed with dementia than men, it is equally important to understand how dementia impacts female caregivers to provide appropriate support (PHAC, 2019).

None of the studies reviewed included members of the two-spirit, lesbian, gay, bisexual, transgender, queer, and intersex (2SLGBTQI+) community. It appears that there is limited knowledge regarding how dementia affects the relationships between caregivers and PWD from the 2SLGBTQI+ community and how to provide support to these individuals. Kilicaslan & Petrakis (2019) argue, “Health care is entrenched with cisnormative, heteronormative and heterosexist perspectives and viewpoints” (p.612). In the medical field, heteronormative ways of thinking dominate decisions regarding what is considered for research selection and, in the past, have pathologized differences between marginalized groups including queer individuals and those of racial minorities (Kilicaslan & Petrakis, 2019).

In 2019, Egale Canada, an advocacy organization that helps to promote research, education, and equality for 2SLGBTQI+ individuals, partnered with the National Institute on Ageing. Together, they worked to support better research regarding the experiences of 2SLGBTQI+ individuals on the dementia journey (Flanagan & Pang, 2022). In their study, 2SLGBTQI+ people reported barriers to accessing healthcare services, including fear of discrimination from healthcare workers. Healthcare workers were found to lack education regarding the 2SLGBTQI+ community, including acknowledgment of the individual's relationship and partner (Flanagan & Pang, 2022).

From the research, it was evident that accessing formal and informal support is essential for the well-being of caregivers and the PWD. It is then critical to recognize how social networks may look different for diverse populations such as those in the 2SLGBTQI+ community, including considerations for chosen rather than biological families. Flanagan & Pang (2022) also recognized gaps in education provided to healthcare workers and suggested that additional study is needed to understand better how to increase professional competency to support 2SLGBTQI+ individuals. Because considerations for the 2SLGBTQI+ community have been left out of the narrative, 2SLGBTQI+ individuals continue to struggle with not only receiving supportive care but accessing safe spaces free from the stigmatization of healthcare workers (Kilicaslan & Petrakis, 2019). This calls for the importance of creating affirming spaces for 2SLGBTQI+ individuals in healthcare and finding ways to increase inclusion in research concerning perspectives on dementia and supporting relationship quality.

I would like to clarify that gaps related to the underrepresentation of diverse individuals in studies involving spousal caregivers and their partners with dementia was beyond the scope of this study. Nevertheless, my literature review revealed a notable omission of this subject and a deficiency in the involvement of caregivers and PWD from diverse backgrounds in past research. It became clear that the field of dementia lacks an understanding of the varied experiences of caregivers and PWD. Future research should prioritize the inclusion of caregivers along the lines of race, culture, religion, ability/disability, and within the 2SLGBTQI+ community. These are complex and intersecting aspects of identity that influence how individuals may cope with the challenges of dementia. This includes consideration for the potential stigma, discrimination, and marginalization faced by caregivers and PWD from diverse backgrounds, which can affect their access to healthcare, support services, resources, and education tailored to their unique experiences. Although this study did not explore the diversity of the caregiving experience, it is crucial to strengthen our understanding of how diverse experiences influence those navigating the dementia journey as dementia cases continue to rise.

Conclusion

In this chapter, I explored themes from the literature regarding caring for a partner with dementia and its effect on relationship quality. These themes included various forms of loss, the impact of gender on roles and responsibilities in the relationship, changes in physical and emotional intimacy, understanding essential support systems for caregivers and PWD, as well as strategies for maintaining strong partnerships or couplehood. I also briefly discussed research concerning new relationships formed in later life and concluded by addressing the lack of diversity among participants in these studies. This exploration allowed me to prepare for the interview process and provided context for the findings of this study, which will be discussed in a later chapter.

Chapter 3 - Theoretical Approach

The theoretical approach of critical gerontology informed this research project. In the 1980s, gerontologists studied the impact of the economic recession on older adults (Doheny & Jones, 2021). During this time, researchers realized there was a lack of theoretical application in the field of social gerontology (Doheny & Jones, 2021). Researchers instead discovered that the study of gerontology had been relying on stereotypical views and assumptions about the experiences of older adults (Doheny & Jones, 2021). The approach came to acknowledge that the aging experience is socially constructed by prevailing societal beliefs about what constitutes normal aging (Baars et al., 2006).

Critical gerontology plays a crucial role in identifying and addressing the challenges that older adults face, such as those derived from inequality related to socioeconomic status, gender, ethnicity, sexual orientation, and disabilities (Baars et al., 2006). It offers a lens through which to understand how older adults experience various forms of oppression based on age (Torres & Donnelly, 2022). Moreover, it points out that older adults who are discriminated against due to ageism may find their participation in society limited (Torres & Donnelly, 2022). This can lead to social exclusion based on stereotypes about older adults' physical and cognitive abilities (Torres & Donnelly, 2022).

Critical gerontology raises awareness of the challenges faced by older adults and promotes research, policies, and practices that can enhance their quality of life (Torres & Donnelly, 2022). According to Torres & Donnelly (2022), important concepts within critical gerontology include agency, autonomy, diversity, social justice, inclusion, and equality. This approach seeks to challenge ageism and provide alternative narratives about aging experiences to empower older adults (Duffy, 2017). In the field of social work practice and research, the principles of critical gerontology can be utilized to counteract negative discourse and language associated with aging experiences (Duffy, 2017).

Critical gerontology contributes to understanding the important needs of older adults, including intimacy and sexuality. Despite common social beliefs that sexual needs decrease as people age, older adults have the right to express their sexuality (Torres & Donnelly, 2022). Dismissing the needs of older adults related to intimacy and sexuality is a form of social exclusion (Torres & Donnelly, 2022).

The use of critical gerontology as a framework for this study helps create awareness that dementia is not a normal part of aging and that there is no single approach to managing dementia care. In healthcare settings, older adults may face paternalistic forms of care because of dementia. However, older adults should be empowered to make decisions related to dementia care, rather than being limited by stereotypes that portray them as frail, weak, or lacking interest in expressing their sexuality. As the population of older adults grows and dementia cases increase, it will be crucial to establish appropriate resources and access to support. Further research, including input from caregivers and PWD, will be necessary to better understand how to support partners in maintaining healthy relationships while aging in place. The use of critical gerontology theory helps to improve our understanding of the structural and intersecting nature of these issues.

A reduction in the social stigma related to dementia may allow caregivers and PWD to feel more comfortable seeking assistance from informal and formal support systems. This would enable couples the ability to spend more meaningful time together to improve their overall quality of life and well-being. As a social worker and researcher, I believe it is important to understand the diverse needs of older adults to create safe spaces to discuss intimate topics.

Bringing attention to this subject ensures that my research remains inclusive for older adults and helps to accept and normalize their needs regarding sexuality and intimacy.

I have used a critical approach in my research to avoid perpetuating the prevailing social discourse on aging and the dementia experience. The qualitative nature of this study allowed me to approach the research from a constructivist stance by recognizing that knowledge is actively constructed by the participants through their own experiences. In addition, I employed critical gerontology to guide my language usage throughout the research project, aiming to steer clear of reinforcing harmful aging stereotypes and to be inclusive of the diversity within the aging experience. Consequently, my research endeavors to challenge dominant discourse and bring attention to the issues older adults face. I recognize that because of my age, I cannot fully comprehend the experiences of older adults, even if others perceive me as an authoritative figure due to my role as a researcher. I acknowledge that my privilege creates power imbalances in my work, and I am committed to being an ally to marginalized groups by supporting their unique identities and stories.

Chapter 4 – Methodology

Introduction

This basic interpretive qualitative study consisted of interviews with spouses caring for partners with dementia. Questions explored caregiver perceptions and experiences regarding providing care and relationship quality before and after the diagnosis of dementia. The purpose of the qualitative design was to provide a deeper understanding of how intimacy between partners is affected by caregiving relationships. I aimed to have findings from this study contribute to existing literature concerning how to support caregivers and their partners with dementia.

Sampling & Recruitment

In this section, I will define the population, provide the inclusion and exclusion criteria, outline the recruitment strategy, and present the sampling plans utilized for this research study. The PHAC (2020) defines older adults as seniors aged 65 and above. This classification is based on eligibility for various programs, including old-age security pensions (PHAC, 2020). To ensure greater inclusivity, this study utilized the term older adult to encompass individuals aged 55 and above.

Inclusion criteria for this study included relational partnerships that fit within the definition of marriage or common law as set out by the Canadian government. The definition of marriage means having a legal spouse; living common law applies to individuals in a conjugal relationship who are not legally married but have been living together and combining finances for at least 12 months (Government of Canada, 2022). The purpose of including common law relationships was to ensure the study was inclusive of different types of partnerships.

Inclusion criteria encompassed individuals providing care to a partner with any type of dementia. By not concentrating on a specific diagnosis, like Alzheimer's disease, I hoped to recruit more eligible caregivers to participate in my research. In addition, spouses had to be in a relationship with their partner for at least a year before a diagnosis of dementia and living in the same home at the time of participation. The partner of the participant was to have a diagnosis that fit within the mild to moderate stages of dementia.

Although previous studies discussed the importance of including the PWD in research, this research focused on spousal caregivers in the relationship. Individuals with dementia were excluded from participation in the interviews because of the relatively short time frame of the data collection and challenges related to capacity and informed consent. Although substitute decision makers can make informed decisions about the PWD's ability to participate in research, potential issues could have disrupted the data collection process. For example, in some circumstances, an individual's partner is not their substitute decision-maker but rather another family member such as a child. Although a couple may be living together and a partner providing care, another family member acting as a substitute decision-maker for the PWD may not agree to have the individual participate in the research. Furthermore, there was a risk that the PWD could agree to be interviewed and later withdraw from the study due to behavioural issues or circumstances such as mood changes. I feel it is important to note that individuals with mild to moderate dementia may still have the ability to make their own decisions regarding research participation. The decision to exclude individuals with dementia from the interview process was also made to create a more open and comfortable environment for spousal caregivers to speak freely and honestly, without the pressure of a partner present.

Selection criteria considered the diversity of the participants, including those of racial minorities and individuals from the 2SLGBTQI+ community that, as has been noted above, have historically been left out of dementia research. This included attempts to select equal representation of male and female caregivers or other gender diverse individuals given the importance of understanding how gender influences caregivers' abilities to cope with care providing.

With this sampling strategy in mind, recruitment tactics included contacting the Alzheimer Society of Canada, geriatric assessment teams throughout the Atlantic provinces, and seniors' mental health services. To take into consideration the lack of diversity in previous studies, I reached out to agencies including immigration centers, the Elder Berries (Q-Elders network), and the diversity representative at the Alzheimer Society. The recruitment poster utilized for this project is included in the appendices of this thesis. The goal was to speak with spousal caregivers to analyze the impact of caregiving on their emotional and intimate relationships. I hoped to achieve a sample size of 10 spousal caregivers willing to partake in qualitative interviews.

Data Collection

Data collection for this study involved various steps. The first step was to provide participants with information regarding the risks and benefits of the study. Informed consent was provided in writing or recorded verbally before the qualitative interviews. The informed consent form can be found in the appendices of this document. Informed consent was an ongoing process throughout the interviews and subjects were made aware that their participation could be withdrawn until the deadline of June 30th, 2023. Participants were required to consent to conversations being recorded. The third step was then to determine the location of the interviews.

Data was collected using an audio recording device in person and over the phone. Some recordings took place through Zoom for Healthcare for participants who preferred an online option.

Questions were asked following a semi-structured interview format. Participants were asked to commit to a single interview no longer than 1 hour and 30 minutes. During the interview, I asked questions about their relationship with their partner, who had been diagnosed with dementia. Questions were also related to their partner’s progression of dementia and experiences providing care during that period. In addition, I asked spouses to provide their perceptions of a good relationship and to describe their relationship quality since providing care to their partner. The questions used for the interviews are included in the appendices of this document.

The literature review was used to help inform the questions for the interview; however, a semi-structured approach was to allow for flexibility in question order. A list of probing questions was prepared before the interview process. Having participants agree to be audio recorded with electronic devices allowed me to take jotted notes of thoughts regarding participant tone of voice, nonverbal behaviours or actions, and the environment where the interviews took place. As this research explored sensitive topics, the goal was to ensure spouses felt comfortable discussing intimacy in their relationships. The aim was to have the interview feel more like a conversation rather than a data collection process. This involved being self-aware of my reactions, body language, thoughts, and opinions to ensure I was maintaining a non-judgemental stance on the research.

How documents were stored and protected was an important consideration in the data collection process. Participants were provided with information about how data was to be stored and destroyed upon completion of the qualitative interviews. All data collected for this research project was stored on my hard drive, which was password-protected. The informed consent form for those participating in in-person interviews was kept separate as a printed document and stored in a locked cabinet. For spouses who conducted interviews virtually or over the telephone, I requested that the signed informed consent forms be emailed to my university account, or in some circumstances, verbal consent was provided and recorded. Data will be kept for a minimum of five years, as required by Memorial University's policy, *Integrity in Scholarly Research* (2021). Data will then be destroyed by deleting files and shredding/disposing of signed consent forms.

Ethical Considerations

This research project received ethics approval by the Interdisciplinary Committee on Ethics in Human Research (ICEHR). The ICEHR approval and renewal letters are included in the appendices of this document. Given the sensitivity of this research topic, many potential ethical issues were considered before pursuing this study. I used guidance from the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2* (Government of Canada, 2020). The first consideration was maintaining privacy and confidentiality. It was not possible for participants to remain anonymous because information was collected directly by the researcher in person, over the phone, and virtually. Atlantic Canada, although geographically large, can feel small. Even in my support group, which consists of members from across Nova Scotia, individuals have made connections to other participants based on relatives, family friends, or work colleagues. It was, therefore, important to ensure there were no specific identifiers in the information gathered during the data collection process.

As I gave participants the option to conduct interviews virtually, there were issues to consider regarding maintaining privacy and confidentiality. For example, interviews that were conducted in personal homes left potential for other family members present and off-screen to overhear sensitive and private information. A resolution for these circumstances was to ask participants to use headphones or a private space in their home if available. Considerations for a secure platform were made; Zoom for Healthcare was selected to ensure additional protection for maintaining online security. There were limits to confidentiality to consider when working with this vulnerable population. As part of the informed consent process, limits to confidentiality were explained to participants, including the researcher's responsibility to report concerns related to applicable legislation in the case of suspected abuse or concerns that participants may cause harm to themselves or another person.

The second ethical consideration was avoiding harm to participants. Discussing personal information such as emotional and physical intimacy, relationship quality and losses associated with dementia may have resulted in emotional upset to the participants. As part of the informed consent process, including information on the risks and benefits of participating in the study was imperative. Caregivers were provided the choice of where interviews were conducted so the process was both accessible and in an environment that was comfortable for them. It was essential to provide appropriate resources to participants to avoid the potential for psychological harm. I achieved this by taking time to debrief with participants after the interviews and providing necessary resources. A list of resources was included in the consent form, which all participants received before the interview took place. Resources included the contact information for the 24-hour mental health line and services available at the Alzheimer Society of Canada in the participant's geographic area.

The third ethical consideration was avoiding personal bias and achieving valid research results. Provided that my volunteer work was conducted with individuals like those included in this study, I had to remain conscientious about becoming personally invested in the research outcome. This included approaching the research question objectively and setting aside any predetermined opinions or observations gathered from working with spousal caregivers in the past. Utilizing a journal allowed me to keep appropriate boundaries and explore my assumptions and biases by separating my thoughts and research notes. In my journal, I noted the participants' tone of voice, as well as any visible nonverbal behaviors and actions. I recorded my personal opinions and perspectives using the journal to express my feelings. As a social worker, avoiding taking on a supportive role during the interview process can be difficult. Remaining objective in research can also be challenging and arguable, not always possible. Instead of interrupting the interview process, however, I wrote reflections in the journal related to my perspective as a social worker and as an outlet for these mixed emotions.

The final ethical consideration was ensuring that my research was inclusive, fair, and equal. Although individuals with dementia were not included in this study, I provided a clear rationale for why these individuals were excluded from participation. As previously discussed, strategies for recruiting diverse participants were undertaken. In addition, by providing a virtual option for conducting interviews, individuals who lived rurally could participate in the research without travel concerns. Likewise, those with potential internet issues or the desire for face-to-face contact had the option to meet in person.

Establishing Rigor

In my study, I employed several methods to ensure my research was trustworthy, comprehensive, accurate, and transparent. In qualitative research establishing rigor is an important consideration. One approach is based on the work of Lincoln & Guba (1985) and consists of four criteria referred to as credibility, confirmability, dependability, and transferability (Connelly, 2016). To establish credibility, for example, I maintained a journal for reflexive self-analysis, allowing me to reflect on my experiences throughout the research project (Stahl & King, 2020). My journal further contributed to maintaining confirmability by offering an audit trail throughout my research (Adler, 2022). Additionally, it enabled me to identify and reflect on my assumptions and biases during data collection through a process referred to as bracketing (Stahl & King, 2020). Bracketing therefore involved separating my thoughts and interpretations from the data (Stahl & King, 2020). Journal entries enhanced the dependability of the project, complemented by ongoing consultations and feedback from my supervisor. Furthermore, discussions with my supervisor bolstered the project's credibility, offering perspectives beyond my own reflections and analysis. (Adler, 2022). For transferability, readers can refer to the demographic table in my study to assess how applicable the information may be to their own research interests. This additional contextual information enhances how the study can be used by others pursuing similar research topics (Connelly, 2016).

Data Analysis

Data analysis for this project consisted of thematic analysis. As this was my first major research endeavour, I felt it appropriate to use thematic analysis as my introduction to the field of qualitative methods. According to Kiger & Varpio (2020), “thematic analysis is a good first analytic method for novice qualitative researchers to master" (p.847). Likewise, Braun & Clarke (2006) confirmed that qualitative analysis is an appropriate first method to use by researchers who are learning and developing skills for conducting research. For this research project, I referenced the thematic method as outlined by Braun & Clarke (2006), which consists of a 6-phase analysis. These steps include becoming familiar with the data, creating codes, searching for themes, reviewing themes, defining and naming themes, and creating a report (Braun & Clarke, 2006).

As part of this process, interviews were transcribed verbatim. Transcripts were then checked against audio recordings to ensure information was accurate. This process allowed me to accomplish the first step of becoming familiar with the data set. I was then able to apply a coding framework which was conducted line-by-line throughout the transcript. The process of coding was completed manually without the use of a computer program. The coding process started by printing all transcripts. I then worked through each transcript text and identified noteworthy aspects and possible patterns within the data (Braun & Clarke, 2006). Through this process, I was able to develop codes. Each code was then assigned an abbreviation. For example, a participant discussing challenges in communication with their partners due to the progression of dementia became the code, 'changes in communication' with the abbreviation, 'CIC'. A graph was created to organize codes and provide a quick guide for abbreviations. On the transcripts, next to each segment of data, I would write the appropriate coding abbreviation that best fit with the data. This was repeated throughout the entirety of the transcript to ensure all segments of data were coded. I then gathered all the codes and organized them into an additional graph to help develop meaningful groups, a suggestion outlined in Braun & Clarke (2006).

Knowledge gained from the literature review and theoretical underpinnings helped provide relevance to the transcript text. For instance, I compared and contrasted the experiences of caregivers in my study with previous studies discussed in my literature review. This allowed me to identify similarities in their experiences but also gain new insights from their unique perspectives. Using my understanding of critical gerontology theory, I reflected on the participant transcripts to help interpret their experiences. This involved connecting individual struggles to larger systemic issues, such as the challenges caregivers face accessing appropriate resources and support, which can be linked to broader social issues impacting older adults. Finally, to search for relevant themes, I used Braun & Clarke's (2006) method of thematic maps, which allowed me to review and define themes to discuss in the findings of this report.

Chapter 5- Findings

The goal of this thesis was to explore how providing care to a partner with dementia affects relationship quality. To achieve this, data was collected from participants to gain insights into their perspectives. The analysis of data revealed several key themes, which will be the focus of this chapter. Additionally, this chapter will provide an overview of participant demographics.

Participant Demographics

The final sample size for this study consisted of 6 individuals. Although I did not reach my goal of 10 participants, the individuals who were interviewed provided thick descriptions used for the data analysis. Of the participants, 4 individuals identified as female and 2 as male. One of the men was in a same-sex relationship. The length of relationships varied from 3 to 57 years spent together. Two relationships were classified as new later-life partnerships; one was due to a spouse's death, the other to divorce. Types of dementia included 3 unspecified diagnoses, 2 cases of Alzheimer's disease, and frontal-temporal dementia. The stages of dementia ranged from early to moderate, and participant ages varied from 57 to 82. Three individuals were still employed, while the remainder were retired. Using pseudonyms, the demographic characteristics of the participants are summarized in Table 1.

Table 1: Demographic Information

Spousal Caregiver	**Type of Dementia**	**Length of Relationship**	**Age**	**Gender**
Raymond	Alzheimer’s disease	30 years	Participant (69) Partner (71)	Participant (Male) Partner (Male)
Rose	Unspecified	47 years	Participant (82) Partner (82)	Participant (Female) Partner (Male)
June	Alzheimer’s disease	3 years	Participant (57) Partner (61)	Participant (Female) Partner (Male)
Betty	Unspecified	7 years	Participant (80) Partner (83)	Participant (Female) Partner (Male)
Bernard	Frontotemporal Dementia	46 years	Participant (65) Partner (64)	Participant (Male) Partner (Female)
Annie	Unspecified	53 years	Participant (77) Partner (80)	Participant (Female Partner (Male)

Themes

Based on the collected data, evidence suggests that dementia altered caregiver perceptions of relationship quality. Caregivers discussed how providing care impacted their well-being. The first theme that emerged from participant narratives was that caregivers were struggling to cope with their partners’ progression of dementia and their caregiving situation. The second theme was that caregivers felt their relationships had changed regarding how they spent quality time, communicated with their partners, and navigated changing roles in the relationship. The final theme resulting from participant interviews was a lack of social and professional support for dementia care.

Difficulty Coping With the Caregiving Situation

Almost all participants acknowledged that they were not coping well with their current situation. Several caregivers felt that they were not looking after themselves adequately because they were focusing on their partner's needs first. Feelings related to this were complex and included frustration and anxiety. Some individuals described the responsibilities of caring for their partners as overwhelming. Bernard explained:

> And of course my biggest problem is I'm not looking after myself in regards to like eating healthy or whatever because like I get home in the evenings from work…and the only reason I'm working because that's my social life, I should have been retired but…I clean up, probably wash a load of clothes and get supper ready and then feed (her), get that cleaned up. One evening I was out preparing supper and I heard her talking, I said Jesus, who's she talking to. I come around the corner and there she is talking to the wall, she carried on a conversation with I have no idea who, but anyway. I actually had to get up and leave the condo and just go outside for a break because it's very hard on the head seeing it. And that's the thing, people asking me how (she's) doing and I say, (she's) doing a lot better than I am because she doesn't know what's going on around her…and you know, it's not only the person that has this that these effect, it's the person that's looking after them as well.

Betty added to this by stating, "It's like everything is going into that care. And you're not filling your cup up with anything for yourself. And so, I'm working on getting more support for me. I'm really feeling the need".

Some feelings of frustration were related to how partners with dementia could no longer remember recent conversations or details about everyday life. Raymond explained:

> We love each other dearly and we'd do anything for each other and in the past, I've needed care and he's been there for me. So, I don't resent doing it but it's very frustrating especially when he doesn't remember things. Like I can go into detail and tell him we are going to do this, this, and this, and two minutes later he'll say, "Where are we going?" or he'll get in the car dressed to go out and like, "Why are we here?" yeah so, it's frustrating.

Three participants were also working full-time while trying to manage care for their partners. Working made it difficult to search for additional resources to help provide support to the PWD and allow the caregiver respite. Individuals discussed the desire to have support in place to help them cope with feeling overwhelmed. June provided further insight on this:

> And right now, I'm just, you know, trying to go to work, keep my job, pay my bills, have a relationship with (him). And I may, you know, go broke doing it or go crazy doing it, but I just have to keep moving forward. And it would be really nice to have some reprieve, but you have to go looking for it and hunting. I just don't have that kind of time. And I don't have the kind of job that I could ever, you know, some people can sit at their jobs and look for stuff online. Well, my job actually is… also I support somebody with special needs throughout the day. But my whole day is about caring for somebody else. And I just need somebody to care about me.

One individual was also working from home and having difficulty balancing the ability to care for their partner and complete their work. This resulted in an increase of hours when attempting to catch up in the mornings and evenings with work. Raymond explained:

> I’m seriously considering my options because I can’t cope. Yeah, because I can only do emails in the morning before he gets up and I work sometimes in the evening once I’ve got him settled. Sometimes he puts his headphones on watching TV.

Concerns regarding supervision altered another caregiver’s ability to leave the home to focus on their own self-care needs. Annie disclosed:

> And I've been very fortunate, up to, before 2023, I can say that I was still able to function quite comfortably with our situation. Like I could leave him a little bit on his own. And he didn't take part in any activities himself. But, you know, I could still do a few things on my own outside of the house. But now, I'm very restricted. I think I'm restricted to the house and taking care of him.

One participant spoke of wanting to pursue self-care activities, but that guilt prevented them from leaving their partner home alone. Betty stated:

> Well, we were all going out to places together. But you know, we sort of did. He had his circle of friends. And he was very active in the NDP. And so, he was on committees with the NDP. So, we did our separate things. But it's sort of been a fight. Internal like not any external, internal fight. Because I can feel guilty so quickly. I'm going out just to do something for a goal, then leave. You know what, I get my hair done that will go on for a couple hours. I can bring him to (town) and get something for a couple of hours, but to go and join an exercise class to the gym, this is to work on me. Because I get so aware of what he's not able to do anymore.
>
> Interviewer: You’re feeling guilty that he’s at home while you’re doing those things?
> Betty: Yeah.

Although all caregivers described difficulty coping with the increased responsibility of caring for their spouse, one participant discussed the importance of prioritizing time for herself. June explained:

> I do know that it's important for me to have my things. So, I also go out three nights a week to play pickleball. For the most part, he's okay during the day, but I do have a meeting in the (city) on Friday and Saturday this week and this is the first time I don't really feel comfortable leaving him alone that long. So, I'm paying to have somebody come and stay at the house and just to make sure that he has a supper, and he has his breakfast and that everything is fine.

The Relationship Changed

The second theme that became apparent during the data analysis process was that all caregivers acknowledged that their relationship had changed since their partner's diagnosis of dementia. Within this theme, subthemes emerged, including how spouses attempted to maintain quality time with their partners and the impact of dementia on communication and shifting roles within the relationship. There were mixed feelings amongst caregivers regarding how the impact of dementia changed their relationships. Raymond elaborated:

> We have been together for 30 years. We have always had a wonderful relationship. We've always been really open and discussed everything. No secrets whatsoever. It's been completely monogamous, and we've had a great relationship. But it's definitely been challenged of recent.

Betty provided insight into how the loss of quality time, such as traveling together, was starting to impact her perception of the relationship. She explained:

> I retired just after I met him. We did a lot of traveling for the first four years. Things started happening four years ago. Things have changed that. I will say more recently, it has started to affect how I feel about the relationship.

Two female participants became emotional when describing the changes in their partners and relationships due to the progression of dementia. Both women discussed how these changes affected their marriages and perceptions of their partners. The women made additional comments regarding the responsibility they felt to honor their marriage vows despite the challenges. Rose stated:

> It's kind of inevitable that your lives are changing. But I feel that I have, um, I'm going to get upset. With my husband, I feel like we're not married. He's still there to a degree but, he's not the person I married. I took a vow when I got married, for better or for worse, and sickness and in health and so, I fell in love with that, and in that, he's still that person.

Annie added:

> He was never one to show his emotions very overtly. So, I can't say that I've lost that because it was never much of that to begin with. But I just, I feel now like I'm dealing with about a three or four-year-old. And that's disturbing at times. But he's still kind. He's still funny. He's still smart. Still loving. His soul. He just may forget things. My hope is that he doesn't forget that he's loved. That to me would be the saddest thing. But anyway, I know that's what I signed up for when I said, for better or worse, in sickness and in health.

Annie also expanded on how her physical relationship with her partner had changed:

> We have very little physical contact now. But like I said earlier, we didn't show a lot of emotion to one another, or affection, I guess, is what it is. We didn't show a lot of

> affection. But I guess we always knew it was there. But I mean, that's gone completely now. If he doesn't show any affection. But if I show affection to him, it's almost like, I would show one of my grandchildren, it’s not the same as being on an even plane in the marriage. If you know what I mean. I don't know how to explain it any better. I just don't feel it's the same kind of relationship at all, that we used to have.

June reflected on her feelings regarding the impact of dementia on her relationship. She expressed a sense of loss related to the time she had hoped to spend with her partner:

> When he had the assessment, essentially, they give you the end of life book, you know, the, as I call it, the big blue book of tears, where you essentially, you both write your directives for how you would like things to happen if you're no longer capable of making these decisions for yourself. And that was, it was actually really hard to go through, but we're very open with each other and we're very cognizant of each other's feelings and (he's) a really nice man and very kind. And you know, he is there for me, Yeah. It hasn't been bad. It's been sad. I think our biggest thing is that we, you know, get along so wonderfully and it's sad that we won't have as much time as we would like to have to be together. But that's part of the problem with meeting somebody late in life as well.

While describing his relationship quality, one participant revealed feeling there was no longer a connection with his partner. Bernard elaborated, “It’s gone from a 100 down to a minus 100. There is no relationship anymore. Unfortunately, there’s times I’d say (she) don’t even know I’m around. Noticed it about a year and half ago.”

Quality Time

All participants discussed how the progression of dementia disrupted their partner's cognition and functional abilities to perform ADLs and IADLs. Changes in their partner due to symptoms of dementia also affected how couples once enjoyed activities both independently and together. Most spouses described how prioritizing quality time with their partner was important to their daily routine. Many spousal caregivers discussed focusing on activities that their partners were still able to do despite the progression of dementia. For example, several people discussed enjoying shared activities such as walking or spending time in the kitchen together. June explained:

> We love going for walks on the beach. We do a lot of New York Times crossword puzzles every Saturday morning as we call it, dumb as dirt day. Because we get the newspaper, and we sit and that's what we do on Saturday morning. So that's kind of sad but true. But that's the highlight of our week, that's something we get, we enjoy doing. That and just kind of hanging around, we're pretty quiet people. He likes when I make cookies and he likes to eat.

Rose described similar shared interests with her partner, "Yeah, we're avid walkers, we love to walk and fortunately, it's something we can still share together too. And I found too, when we're out walking, we have nice conversations. But that's kind of nice." Annie also described walking as a shared activity with her partner:

> His biggest delight is going for a walk. So, we go for a walk. Usually, as long as the weather is good. We go, like I say, for 45 minutes to an hour-long walk. Usually, when the weather gets better, we'll go to different trails. But for now, it's in the winter, it's just been around the neighborhood because the trails haven't been walkable. And sometimes

> we do that in the morning, quite often or early in the afternoon, and maybe later in the afternoon. He'll say, "Well, do you want to go for another walk?" because that's all he has to do. He can't read anymore, he can't concentrate on television.

Raymond emphasized the significance of spending quality social time with his partner, as well as the importance of his partner maintaining social connections:

> Yeah, and we go to a number of performances locally, we love going to hear other people perform. And we eat out. Most days we are out at some point for breakfast or lunch or dinner. And he really enjoys going out cuz' that's his social time. I mean that's important to him.

Betty also mentioned enjoying quality time with her partner including displaying physical affection like cuddling. Despite the challenging process of leaving the house, she attempted to plan outings with her partner. She explained:

> But we still enjoy a good meal together. We do still enjoy theater, especially theater and concerts and things like that. I have to do that tonight. Something I don't enjoy is the process of getting there and getting back home much anymore. But still, that's still a shared enjoyment. We'll still enjoy watching the movie together. We'll still enjoy, especially in the morning, is a cuddle in bed.

One spouse, however, felt he no longer had quality time with his partner. Bernard stated, "There's no such thing as quality time. It's bad. Yeah."

Several participants discussed that before their partner's diagnosis of dementia, a normal aspect of their marriage was to spend time apart exploring individual interests. However, after the disease progressed, they found themselves spending more time with their partners than before. Raymond stated:

> We would have our own private time and down time, always had separate offices and we've always done things on our own. But now we do everything together. I never, like this was, this is a very odd thought, but I'm driving over here, I thought, this is the first time I've been alone for weeks, driving in the car coming over here.

Rose explained how her partner's lack of independence changed the amount of time they spent together as a couple:

> Well, it's more, he is able to take care of himself on a day-to-day basis but, if he were to go out for a walk without me, he's inclined to get lost. And even in the neighbourhood here. It's changed our lifestyle in as much as I need to take on a lot more responsibility like, everything. Like driving, he hasn't driven now for 2 years. So, if we go out anywhere or if he has a dentist appointment or a doctor appointment or whatever, I have to drive him. So, it's taking up my time, whereas before I was going to my thing, you know, during the day and he'd be at his thing. But now it's much more togetherness.

Communication

Caregivers had varying experiences with how dementia affected communication with their partners. For some, communication became more challenging, while others made efforts to maintain open communication with their partners. For instance, Annie offered insight into how the loss of meaningful conversation influenced her perception of their relationship:

> But for me, I feel like I've lost my life partner, because we have virtually no conversation. I shouldn't say we don't have any conversation. We don't have any meaningful conversation. He was always somebody that had a large vocabulary. He was always interested in current affairs, politics in particular. He's had very strong, I was gonna say strong opinions, I don't mean that in a negative way, he always was very assertive about

> what he felt was right and wrong and what was going on. He could express his opinions. Well, and now, he doesn't know anything that's going on in the world. It took him, he still has no grasp of what COVID is. And, you know, after having to tell him frequently over the last three years, what COVID was, and he had it himself. And, you know, he just has no grasp of anything like that's going on. So, I feel a loss of that partnership, for sure.

Rose also discussed the decline of communication in her relationship with her partner, which she felt resulted in a loss of companionship. She explained:

> The conversation between us sometimes. I think it's such a struggle. Sometimes I think it's not worth it. So you lose a lot of that. You lose a lot of camaraderie. You lose a lot of that conversation where you talk about events, some things or people, friends, you know, "Remember I told you about?" You know, whatever. No, he doesn't remember a thing. He says to me, "That's the first time I've heard about that." When you say, "I told you" because I think that doesn't do anything. It just makes him feel badly. So, I either don't tell him again or I start telling him again. And I try not to say, "Remember, when I told you about something?" Making that enforcement. I'm learning to be more patient. And more understanding. Because I think, oh my god, what if this were me, how would I feel. If you turn the tables around, you think, yeah this is not good.

June, who was in a new later-life marriage, acknowledged that change is part of relationship growth. She discussed adapting to changes with her partner's dementia and attempting to maintain open communication:

> I guess it's, you know, but, again, what relationship doesn't change as you know. It's not like we have been together for, like, years and years and years, right? So, we were essentially in the honeymoon phase of our relationship, when we sort of started to figure

> all of this out. And so from every honeymoon relationship, things sort of quiet down, and you sort of settle into life, right? I mean, I think, the biggest thing is that we are both very conscious to tell each other when we're frustrated, and to tell each other that we love one another on a regular basis. And that's a pretty wonderful thing to have every day.

Raymond provided insight into how he maintains open communication with his partner, “Yup, oh yeah, no we have no secrets whatsoever. Nope, we discuss everything. Sometimes whether he wants to or not (laughs).”

Roles Shifted

Spousal caregivers discussed how roles within their relationship had changed. Some spouses tried to support their partners in maintaining their responsibilities within the relationship, while others felt the need to take on more responsibilities. Raymond provided insight into the roles within his relationship with his partner by trying to allow him to continue with household responsibilities:

> Believe it or not, he’s still doing the bills. Yeah, he’s managed to hold onto that. And I’m desperately trying to watch and make sure they’re getting paid but I don’t want to interfere if he can keep going. Yeah, because he’s always looked after the household finances and contributed to the household.

He further added that his responsibilities at home had increased and that his partner required more encouragement to complete tasks:

> Anything he helps with I have to prompt. He wouldn’t just come up and say, “Oh the house is needing vacuuming or is needing dusting.” I always have to say “Could you”, and then he’d make an effort to do his best.

Two spousal caregivers discussed how they worked as a team with their partner before the diagnosis but had to take on more responsibilities as the disease progressed. Rose explained that her need to start monitoring the finances caused friction with her husband:

> We were just a team through our marriage and he would take care of the finances and I would take care of the home and the family, and more of a social… all our travel if we went on vacation and everything. I would take care of all of that and he did the finances but I noticed in the last few years, that because of his decline, he wasn't able to take care of the finances and he was starting to make mistakes which was very worrying. So, I suggested that our investments, this was one of the big things we did, he loved doing investments and because of his decline, I said no you can't be doing that anymore, we should give them to a professional to take care of it for us so neither one of us are worrying about it. That was a huge thing for him, to relinquish to somebody else. It caused a lot of friction between us because he didn't want to make that change, he didn't want to admit he couldn't do it anymore. And didn't want somebody else controlling his money. So, he agreed to give a certain amount to them. And then he was still taking care of the rest of it, but I could see that wasn't working because I was worried about him making mistakes. I could see him making mistakes and it was stressful for him as well.

Bernard shared his perspectives on how teamwork in marriage should look, reflecting on his relationship before the dementia diagnosis:

> For me, and for a lot of people, and I've seen, the way they look at marriage is, what yours is yours and what's mine is mine. Your paycheck is yours, that's not the way we were. Right from day one, we were a team. If one person was out of work, the other person was working, all bills were paid. That's the way a lot of people work, to me that's

> not a relationship. Both of us took part in the shopping, the cleaning or whatever. Like (name) worked and I worked and whoever got home that person started supper.

One participant discussed the experience of role reversal in her marriage. She described how taking on additional responsibilities led to feeling more empowered in the relationship. Annie explained:

> I guess I could say the roles in our relationship have reversed, almost switched significantly, because he was always the more domineering partner, I would say. And now the roles are quite reversed. So, I've had to take on the decision-making and everything else. For me, I feel more empowered, which has its pros and cons. I also feel the weight of the responsibility. But I also feel like I can do what I think is the right thing for him. Whereas before he wouldn't let me do that sort of thing.

Lack of Informal & Formal Supports

Access to formal and informal support differed amongst caregivers who participated in this study. Most caregivers sought support from formal services such as family physicians, geriatricians, home and community support organizations, and not-for-profits. Some caregivers mentioned that their family members lived far away in other communities, provinces, or countries, which made it challenging to rely on them for support. Raymond provided insight into his family situation, “He’s an only child and my sister is in (town). So, yeah. And the rest of my family is in (country). So, we’re basically on our own for family.” Rose explained that despite having family members living nearby, she felt they were too preoccupied with their own families to provide support. She described feeling isolated in their situation:

> Our children live away. Yeah. So, we have my sisters-in-law, my husband's brothers, two brothers live in (city). And we do get together with brothers and the sisters-in-laws.

> Maybe once a month, we get together and meet for lunch somewhere. And we do email back and forth. But they have their families, they have their kids and they have their grandkids. They've got their lives, you know, to deal with. You can't be expecting them to be keeping an eye on us all the time and what's happening in our lives. I do feel sometimes that we’re very much on our own. Trying to keep our head above water.

Betty provided a similar description of her children, who were also busy with their own lives:

> My daughter calls regularly, my son not quite as often, but they're both supportive. And I know they're both concerned. But in terms of, you know, the practical help, they're not able to release themselves, for getting busy and chaotic and all of that stuff. I don't expect more, more than the love that I know they give me.

June shared that she moved back to her home community after being away for 30 years with her ex-husband. She explained that her current spouse was not from the community and, having been away for many years, she felt a lack of support in her community. In addition, June was assisting her elderly mother without help from her other siblings, which she found overwhelming. She explained:

> So (he’s) not from here. I moved back here to (town), seven years ago, after living away for 30 years. I moved back here to retire with my husband and I retired from him instead (laughs). And, yeah, you know that you don't really have a way of meeting people. When I lived in (city), and I had a very large circle of friends, because you meet people through, you know, activities that you do in your neighborhood, your children's activities, your children's school. You know, you meet people a lot of different ways. And a lot of it is with, as your children grow up, you kind of clicked with different parents of other kids or what have you. So, I kind of left all of that behind. So here we really don't have anyone

> and I also have a 95-year-old mother that lives about a kilometer away. And out of seven children, I'm the only one in town. So, it's a little overwhelming.

Bernard shared that despite living close to his children, he felt unsupported by them:

> I mean, I know everybody got their own life, they've got things to do. And the hard part is with the two kids, I know they're busy but it's only a phone call to see how your mother is doing, that's all it takes. Everyday you don't hear from them, it hurts.

One participant reported having family in the same community and feeling supported by her children. Annie said, "We have two sons, who are both married and have children of their own and live in (city) where we reside. So it's very nice to have family support."

Although caregivers were open to receiving support, education, and information regarding what to expect on the dementia journey, many spoke of difficulty accessing services and support. Participants expressed frustration related to the inability to access services in the community due to wait times and high costs of home support. Some caregivers felt unsupported by primary healthcare professionals who did not provide resources or education when their partner was initially diagnosed. Rose provided insight on issues related to wait times to be seen by the geriatric assessment team in her area, "As I said, there's a 12 or 18 month waiting list before you get your foot in the door at the hospital. So meanwhile, you're out there trying to live your life with no help." Rose expanded:

> There are Alzheimer's cases on the increase. I keep reading and reading different articles about different areas and how it's on the increase and yet, they're not reaching out and giving us help. What hope is there for us? We're very much on our own. Trying to find our way in the dark.

Raymond expressed his frustrations about the lack of support from his general practitioner:

> Our GP has been awful. The day she, (name) and I were in her office and she gave us confirmation that it was Alzheimer’s, she looked at us and said, “get your affairs in order and pick a home you can live with.” And I said, “And..is there anything else, anything you can suggest, anything, anyone you can refer us to?” She said “No, just deal with it.” Interview over. And we were out in the hallway standing.

One caregiver described needing to advocate for her husband to receive a diagnosis from the geriatric healthcare team. June stated:

> I'm like, okay, so give us a geriatric appointment. And that was, that probably took about seven months. And the only reason I think we got it is because after six and a half months of me trying all the right avenues I finally wrote to the MLA who happened to be Minister of Health at the time. And I just lambasted him saying, you know, he doesn't have a GP, he has no access to health care, we need a diagnosis, we, you know, like, we needed something. So, within a week of that letter going off, and my tirade via email, he then got an appointment to be assessed three months later, at which point I wrote another email saying that that wasn't acceptable. And so, he got one a week later. But it's been a struggle trying to find any resources.

Bernard also expressed frustration with the lack of information or resources provided by medical professionals:

> Interviewer: What kind of information did your doctor give you, like the psychiatrist?
>
> Bernard: Not a lot other than this was, what they diagnosed her with, some information on it and here’s some information on it go and read more. And that’s basically the help I’ve been getting everywhere. For every so-called organization out there, all they do is send you a link, I can do that all myself.

Some caregivers mentioned that they were able to access home care services through private providers. While these services allowed them to have more independence outside the home, caregivers spoke to services being expensive. Annie provided insight on this issue:

> Fortunately, I found a caregiver who comes one afternoon a week, and she has started coming a little bit more frequently when I need her. But I haven't needed her. Up until now, we've managed by ourselves. Because I don't have too many places I have to go anyway. So that hasn't been a problem. But I can call on her to give us some extra hours when needed. But that is becoming quite costly. Since I haven't gone through an agency. I found her privately. And her prices are very reasonable. But it's still costly, and I've gone for even a few hours.

Betty expressed concerns about the cost of home support. She had difficulty convincing her husband to accept the support but ultimately found it helpful. The support enabled her to stay connected with friends and family. She explained:

> But anyway, to get him to agree to have someone come in, he's an economist, he's always been very money conscious, and to pay $250 a day to have someone babysit him when he doesn't need it, you can stay by yourself. That was an issue that I couldn't get around. And so, we started doing that. And that didn't, that was fine. Until life gets busy. And you know, my family, my grandchildren are in (city). And so that gave me a chance to go in and see, not to mention my friends but at least my family.

June also spoke to concerns related to the cost of home support. She expressed confusion about being ineligible for respite services through the government:

> I asked about caregivers. Like I asked, even as I asked about respite, and I was told that I was, that we're not eligible for any respite. Which I don't quite understand. You know, I

> have to work. I make approximately $20 an hour, I can't then afford to pay somebody $20 an hour to come and help. So yeah, I'm gonna have to take some time off next week to try and figure out what exactly is going to be available in the future.

Several spouses made comments about how healthcare workers could support other caregivers in the future. For example, Raymond suggested that it would have been helpful if his doctor had listened and been more supportive. He explained, “Just listen and be supportive and give referrals to services that are available. But basically our doctor said, “You’re on your own baby” like she didn’t even give me the number for the Alzheimer’s association.” June also felt that healthcare workers should offer more support during the early stages of diagnosis. She provided advice for healthcare workers:

> A message for health care workers, well don't diagnose and dismiss. You know, that doesn't do anybody any favors. That's like telling somebody they have cancer and then going, right. I mean, ultimately, this is you know, that ultimately it is a death sentence. It's a terminal illness and we're left to really spin and especially with early-onset Alzheimer's.

Bernard added that homecare providers should receive more education and training related to dementia to better serve older adults in the community. He advised:

> I think there should be more done or training for people who are looking after people with mental issues. I can understand someone with a physical disability or mobility issue looking after themselves sure, if you got CPR, first aid, sure. That’s all that’s required here, that’s it. More education about dementia.

Some caregivers sought community resources and found education and support through their own research. Two caregivers received support from the Alzheimer Society of Canada, which they found to be a helpful resource. Rose explained:

> So I, myself got in touch with the Nova Scotia Alzheimer's Society and got information from them. We've done a couple of online webinars with them, you know where they give you information and it was helpful, one in particular was very helpful and it was there for the caregiver.

Raymond also spoke to receiving support from the Alzheimer Society and was considering accessing their support group programming:

> Raymond: I did hear from the woman from the Alzheimer Society today, so I had a good long chat with her.
>
> Interviewer: I'm sure they gave you a list of supports?
>
> Raymond: Yeah, she's sending me a package and she had told me there's a number of support groups locally both online and in-person.

In addition, Raymond shared a positive experience with two medical professionals, including a locum doctor who was covering for his regular family physician during her maternity leave. This caregiver provided insight that earlier conversations may have reduced his frustration and anxiety related to his partner's diagnosis. Raymond added:

> The locum was very supportive and the last time we went in, she spent an hour and half with us. And she said if you ever need to talk, you know how to get a hold of me, just ask for a long appointment and you can take as long as you like. And she's been wonderful. And (name) who came to do the assessment was absolutely wonderful and she answered basic questions I've been asking for a year and half. And it's like, why did no one tell me

> that? Especially related to the COVID and how it affects patients with dementia and it's like, if I'd known that, I would have been less frustrated and anxious, yeah.

One caregiver acknowledged that at times, it can be difficult to ask for help. Betty shared, "I think we think we can take on things ourselves and it's hard to ask for help you know."

Conclusion

In summary, the data indicated that providing care to a partner with dementia had an impact on the caregivers' well-being and led to changes in the relationship. Key themes included the challenges of coping with the demands of caregiving, as well as the recognition that the dynamic of the relationship had shifted due to the onset of dementia. This shift in the relationship was attributed to changes in how couples spent quality time together and communication difficulties arising from the symptoms of dementia. Caregivers experienced increased responsibilities stemming from role changes within the relationship. The final theme addressed the varied experiences of caregivers in accessing support systems, encompassing friends, family, healthcare providers, and community resources. These findings will be further explored in the subsequent chapter.

Chapter 6 – Discussion

This research project examined how caring for a partner with dementia affects relationship quality. The findings suggest that caregivers perceived their relationship quality to change after the onset of dementia. Research has indicated that providing care for partners with dementia has complex impacts on both the well-being of the caregiver and PWD. Caregivers in this study expressed similar experiences and described struggling to cope and adapt to changes in their partner. As such, all participants in this study reported negative changes in their relationship due to the disease process. This was supported by research that has shown that caregivers perceive their relationship quality to decline during the progression of dementia (Fee, 2021; Harris et al., 2011).

In this study, caregivers discussed changes in their relationships, particularly in the quality of time spent with their partners. Some caregivers mentioned a decrease in shared activities they once enjoyed with their partners, while others tried to continue these activities despite the challenges posed by dementia. Similar experiences were noted in the literature, with some caregivers expressing a sense of loss due to no longer being able to share common interests, while others were able to maintain an enjoyable time together (Davies et al., 2010; Merrick et al., 2016; Molyneaux et al., 2012; O'Shaughnessy et al., 2010; Robinson et al., 2005). Both my findings and the research indicated that as dementia symptoms advanced, caregivers reported a decline in companionship, which had negative consequences on their overall relationship quality (Bruinsma et al., 2020; Evans & Lee, 2014; Harris et al., 2011; Youell et al., 2016). Findings showed that quality time was further impacted by the PWD's inability to have meaningful conversations with their partner, which resulted in loss of companionship. In the literature, loss of communication was also found to influence how couples could spend quality time together (Baikie, 2002; Evans & Lee, 2014; Youell et al., 2016).

Studies have shown that spouses who provide care take on additional responsibilities in the relationship due to their partners' increasing need for support (Evans & Lee, 2014). Findings from this study indicated that caregivers have taken on more responsibilities in their relationship since the onset of their partners' dementia. Increased responsibilities affected how caregivers spent time with their partners. One caregiver described more "togetherness" related to increased supervision and dependency from their partner. The findings also supported evidence of role reversal, as three female caregivers reported taking on additional responsibilities related to finances and decision-making in the relationship. While previous studies suggested that men may cope better with caregiver responsibilities than women (Baikie, 2002; Bolystein & Hayes, 2012; Braun et al., 2009; Simonelli et al., 2008), both men and women in this study reported difficulties with increased responsibilities and changes in their relationships. Participants described struggling to cope with the loss of independence in their partners. Research has shown that the increased stress from added responsibilities can negatively impact caregivers' health and quality of life (Braun et al., 2009). Caregivers who took part in this study further expressed a sense of mourning for the person their partner was before the dementia diagnosis, a sentiment supported by the research (Robinson et al., 2005). In addition, caregivers felt responsible for upholding their marriage vows and continuing to care for their partner, as found in similar studies reviewed by Evans & Lee (2014).

Participants from this study provided limited information about their experience of physical intimacy with their partners. As a result, it was difficult to determine whether providing care since the onset of dementia had affected this aspect of relationships. Only one participant was open to discussing how intimacy had changed with her partner. One other female caregiver commented that she shows affection to her partner by cuddling in the morning. Research has shown that spousal caregivers are hesitant to discuss physical intimacy, given uncertainty about whether it is appropriate to provide information about this aspect of their relationship (Benbow et al., 2019; Fee et al., 2021; Youell et al., 2016).

The study findings illustrated that most caregivers experienced a lack of support from their friends, family, and medical professionals. Spousal caregivers expressed frustration over the lack of helpful resources in their community to aid in understanding what to expect from the disease process and how to plan for the future. Some caregivers felt dismissed by medical professionals who they felt made no effort to provide support in the community. In addition, the findings showed that participants did not receive early interventions, despite previous research highlighting the importance of early support for couples and their partners (Bauer et al., 2001; Davies et al., 2010; Knop et al., 1998). Studies have shown that providing early interventions for couples can help prevent caregiver burnout, improve the well-being of both caregivers and PWD, and strengthen relationships (Bauer et al., 2001; Davies et al., 2010; Knop et al., 1998). Early interventions have been recommended to help couples manage realistic expectations of the disease process (Bauer et al., 2001; Davies et al., 2010; Robinson et al., 2005).

The studies reviewed for this research project did not discuss the financial demands associated with caregiving responsibilities in the community. Some caregivers in this study, however, spoke to concerns related to the cost of home care support and services. Others found it difficult to access support and resources without the proper education or tools. One participant spoke about the time commitment required to secure homecare services while already having a busy work schedule. This emphasizes the importance of understanding the financial strains caregivers and PWD may face in the community to support them effectively.

In this study the availability of social support for caregivers, including support from family, friends, and community resources, varied among participants. The studies reviewed for this research show that some caregivers felt supported by friends and family, while others experienced increasing isolation as the disease progressed (Benbow et al., 2019; Colquhoun et al., 2019; Robinson et al., 2005). The findings of this research project indicated that caregivers who lacked support from family and friends felt it was related to the distance of loved ones or busy schedules including childcare. Some caregivers, however, believed they had sufficient social support. For instance, a caregiver in a same-sex relationship expressed gratitude for receiving support from friends in the community. It is important to note that there is limited research on the experiences of caregivers in same-sex relationships, making it challenging to determine if this is a common experience.

Research has shown that caregivers in new later-life relationships may have limited social support due to challenging family dynamics, such as negative relationships with stepfamily members (Sherman et al., 2013). Caregivers in the literature reported both positive and negative interactions with stepfamily members and were found to rely on broader social networks for support outside of the family unit, including friends and community resources (Sherman et al., 2013). In this study, one caregiver in a new later-life relationship felt supported by their family while the other participant in a similar relationship struggled with support.

The existing literature shows that gender plays a role in impacting caregiver well-being, support, and ability to cope with the challenges of caring for a spouse with dementia (Baikie, 2002; Bolystein & Hayes 2012; Braun et al., 2009; Johnston & Terp, 2015). It is difficult to make definitive comments on how gender affected the caregivers in this study. One male caregiver, for example, did not conform to traditional gender roles and viewed his relationship as a team effort with shared responsibilities. Nonetheless, three female caregivers described experiencing role reversals that aligned with traditional gender roles, such as taking over financial responsibilities in the relationship. Johnston & Terp (2015) discussed similar findings, highlighting that gender role reversals in caregiving relationships are possible in a population that grew up with pressures from stereotypical gender expectations. In this study, one female caregiver reported feeling empowered by taking on more responsibilities, as her husband made most decisions before being diagnosed with dementia. Similar experiences were highlighted in a study by Bauer et al. (2001), which discussed how caregiving can positively affect the self-esteem of caregivers.

Having additional participants involved in this study and equal representation of men and women may have allowed for further conclusions to be drawn regarding the impact of gender. The inclusion of only one same-sex couple in this study provides limited insight into how heteronormative gender roles might influence caregiving experiences in non-heterosexual relationships. Additionally, specific roles within new later-life partnerships were not discussed by caregivers. Conducting more studies involving diverse types of relationships would be beneficial in understanding the influence of shifting roles and responsibilities in relationships, including those in gender-diverse partnerships.

Chapter 7 – Conclusion

In this final chapter, I will summarize the key points discussed in the literature review and findings, acknowledge the study's limitations, and propose avenues for future research. This section will conclude with personal reflections on this research experience. In addition, I will discuss the project's implications for social work practice.

The literature outlined various losses related to dementia, including the loss of previous identities for both the PWD and the caregiver, as their roles in the relationship changed with the onset of the disease. In previous studies, some caregivers experienced emotional strain due to their evolving roles, while others found purpose and emotional closeness through caregiving (Bauer et al., 2001; Colquhoun et al., 2019; Robinson et al., 2005). Consistent with the literature, this study found that caregivers often struggled to adjust to their caregiving responsibilities and the changing dynamics in their relationships. For these caregivers, more responsibilities in the household, including increased supervision of the PWD, often compromised the quality of time spent together. In addition, participants discussed the impact of dementia on their partners' daily activities. Many caregivers stressed the importance of dedicating meaningful time to their loved ones and focusing on activities they could still enjoy together. However, the progression of dementia often hindered effective communication, further affecting the quality of time spent together.

Studies have shown that gender may influence how caregiving impacts relationships when one partner has dementia (Evans & Lee, 2014). Some research explored instances of gender role reversal within these relationships, uncovering situations where women take on traditionally male responsibilities (Johnson & Terp, 2015). Additionally, some women were found to experience heightened stress and less satisfaction from caregiving compared to men.

Women who participated in this study had similar experiences and were found to take on additional responsibilities within the household. However, with a small sample size, it was difficult to determine whether men adjust more effectively to caregiving duties and experience lower stress levels, as suggested in the literature (Braun et al., 2009).

The research showed that dementia can affect physical and emotional intimacy between caregivers and their partners. Some caregivers in previous studies were found to experience a decrease in physical intimacy, while others reported an increase in emotional intimacy (Evans & Lee, 2014). The changes in intimacy were associated with factors such as cognitive decline and increased responsibilities within the relationship for the caregiver (Evans & Lee, 2014). Studies have emphasized that caregivers often felt hesitant to address issues related to sexual intimacy with medical professionals (Benbow et al., 2019; Fee et al., 2021; Youell et al., 2016). The majority of caregivers in this study did not openly discuss physical intimacy with their partners. Instead, they talked about the changes in their relationship quality related to a loss of companionship. This was connected to how quality time and communication were affected. Similar to previous research findings, caregivers also discussed setting aside their needs to prioritize their partners, resulting in mixed emotions of stress and frustration.

Caregivers in previous studies had different levels of access to both formal and informal support. The literature suggested that a lack of connection to family and friends led to a sense of loss for caregivers. Spousal caregivers who participated in this study had different experiences when accessing formal and informal support. The study's findings showed that caregivers actively sought assistance from formal services such as healthcare professionals but felt disappointed by primary care workers who did not provide resources or education when their partner was diagnosed with dementia. Some caregivers mentioned the challenge of having family members in distant communities or different countries, while others felt supported by local family members.

The studies highlighted the importance of support services for couples and recommended early intervention and social support to help reduce feelings of isolation, hopelessness, depression, and caregiver burnout (Bauer et al., 2001; Davies et al., 2019; Robinson et al., 2005; Knop et al., 1998). In this study, caregivers described their inability to access support early in their journey due to the lack of community resources and information about their partner's dementia diagnosis. As a result, caregivers had limited access to homecare services, with some receiving support and others handling responsibilities alone. Participants expressed frustration with long wait times and the costs of home care support in their area. Notably, the literature did not address the financial concerns associated with caring for a partner at home.

Although access to community resources was recommended in the literature as a possible intervention, research also provided more specific interventions for couples on the dementia journey. For instance, studies suggested that caregivers and PWD should recognize the challenges they face while also focusing on the strengths of their relationship. The idea of learning about dementia together was proposed as a way to deepen the bond between couples, ultimately helping them create practical plans for the future (Harris et al., 2011). Studies further illustrated the need to support caregivers and PWD as a couple rather than as separate individuals (Hellstrom et al., 2007; Wadham et al., 2016). Spousal caregivers who participated in this study did not discuss receiving these recommendations from medical professionals.

It is essential to prioritize inclusion and engage participants from a wide range of backgrounds in this field of research. It is worth noting that none of the studies analyzed involved individuals from the 2SLGBTQI+ community. Incorporating a more diverse participant pool, including individuals from different ethnicities, sexual orientations, and those in new later-life partnerships, would contribute to a more comprehensive understanding of the diversity of the dementia experience. Given that Canada is becoming an increasingly diverse nation, gaining insight into varied experiences will enhance support for all individuals navigating the challenges of dementia.

Reflections on Findings

The healthcare system in Atlantic Canada has been struggling with a shortage of primary care providers, particularly family physicians, leading to increased caseloads for those doctors. There have also been staffing issues related to homecare services, especially in rural communities. As a result, couples who have felt dismissed by healthcare providers in this study may be negatively impacted by a struggling healthcare system unable to provide appropriate resources. I was, therefore, not shocked to learn that participants were frustrated with the lack of support and access to community resources.

Surprisingly, the literature lacked reporting on the financial burdens associated with caring for a person at home. In Canada, however, it has been reported that caregivers supporting PWD in the community face significant financial implications (Alzheimer Society of Canada, 2022). I wondered whether previous studies failed to explore this topic due to how questions were framed for participants, or if it simply had not been considered related to relationship quality. The findings of this study have revealed that participants were concerned about the financial burdens associated with accessing community support. As such, I believe my findings regarding financial concerns help to enhance additional knowledge on this research topic.

Finally, it was not surprising that there were no discussions on sexuality and intimacy with the participants. This lack of conversation on physical intimacy may be influenced by societal norms and expectations that regard sexuality and intimacy as private matters. This issue aligns with the theoretical foundations of critical gerontology theory, which suggests that older adults are often made to feel uncomfortable or invalidated when discussing intimacy and sexuality.

Limitations

In this study, there were limitations that were difficult to avoid and had an impact on the findings. Despite efforts to reach out to various organizations, I was unsuccessful in recruiting a diverse sample of participants. It is possible that individuals may have been hesitant to participate due to my identity as a heterosexual, cis-gendered, Caucasian, able-bodied, and young researcher. During my analysis of the data, I also came to the realization that I missed the opportunity to collect information on the ethnicity and education level of participants in this study. Furthermore, by focusing solely on older adults, I excluded spousal caregivers under the age of 55 who are facing similar issues. Early-onset dementia, for example, can affect adults under the age of 55.

Despite the rich and thick descriptions within this study, having more participants would have been beneficial in gaining a better understanding of the influence of gender on roles in the relationship. Additionally, it is important to note that there are limitations when only focusing on the caregiver’s perspective rather than considering both partners. By including only the caregiver’s perspective, it is difficult to fully assess whether relationship quality is perceived the same by caregivers and the PWD.

I had a desire to delve deeper into physical intimacy, but I felt that there was not enough time to establish rapport with the participants. From my experience as a social worker, I know that building rapport is crucial for developing therapeutic relationships with clients. In research settings, however, there is limited time and space to achieve this successfully. As Garrels et al. (2022) emphasize: “While the purpose of the research interview is entirely different from the purpose of a therapeutic conversation, some of the conditions may be relatively similar.” (p.2). The opportunity to establish rapport with research participants may have facilitated deeper conversations about physical intimacy in the context of caring for a partner with dementia

Another challenge related to the recruitment process. Several people who were interested in the study chose not to participate due to time constraints. One person initially agreed to participate but later withdrew because of the stress related to caregiving responsibilities. It was, therefore, difficult for people to dedicate time to meeting and participating in the research. In addition, it was noted in the literature that participants from previous studies were recruited from settings such as dementia support groups, memory cafes, and clinical environments like geriatric assessment clinics, family physician offices, and hospitals. These were some of the settings from which I chose to recruit participants. Not all individuals in the community coping with dementia, however, may have access to these types of settings and services. Family physicians play a crucial role in referring individuals to specialized care services, like geriatric assessment teams. As such, due to the increasing difficulty in accessing primary healthcare providers, caregivers, and PWD may miss out on important education regarding how to recognize the early stages of dementia.

Without a diagnosis, individuals could encounter obstacles in accessing additional early intervention and support. Consequently, both caregivers and PWD may have lost opportunities to participate in previous studies and this project given the clinical nature of recruitment settings and criteria, such as a diagnosis of dementia required to partake in research. Research may then be limited to certain perspectives and overlook crucial insights from caregivers and PWD who have inadequate access to these opportunities. This includes those facing additional hurdles accessing healthcare services, such as historically marginalized groups and communities of diverse ethnicities, socioeconomic backgrounds, abilities, ages, genders, and members of the 2SLGBTQI+ community. These perspectives are vital as they can provide further understanding of caregiving experiences.

Although I offered to conduct interviews on Zoom for Healthcare and over the phone, taking notes on observations of body language and non-verbal cues was challenging. I could not see two participants as interviews were conducted over the phone. Being able to observe body language would have helped determine when it was appropriate to ask certain questions and gauge whether participants appeared comfortable when discussing more sensitive topics.

Justification for Further Study

After analyzing multiple articles for this research project, it is clear that more investigation is necessary to comprehend how caring for a partner with dementia could impact intimate relationships. Research on this topic is essential to enhance care and services for caregivers and PWD. Baikie (2002) highlighted that previous research on spousal caregiving has largely focused on caregiver burden. I observed similar findings when conducting research on this topic, as there were limited studies concentrating specifically on understanding the impact of dementia on relationship quality. Furthermore, many studies did not include the perspective of the PWD and concluded that additional research is needed to provide a better picture of relationship quality from both perspectives (Braun et al., 2009; Clare et al., 2012; Daniels et al., 2007; Holdsworth & McCabe, 2018; Merrick et al., 2016; Molyneaux et al., 2012; Rippon et al., 2020; Robinson et al., 2005).

I initially had concerns about recruiting participants due to the sensitive nature of this research subject. With that, some studies have shown that participants are willing to discuss intimacy when given the opportunity (Benbow et al., 2019; Youell et al., 2016). Holdsworth & McCabe (2018) suggested that future research is needed to understand how sexuality is affected in couples dealing with dementia, including how individuals cope with unmet sexual needs. Additionally, Davies et al. (2010) reported that limited studies on caregiving have examined the impacts of sexuality and intimacy in relationships where one partner has dementia. Research could, therefore, help provide evidence-based education for healthcare providers regarding harmful aging stereotypes to prevent stigmatizing spousal caregivers and PWD who may want to discuss intimacy and relationship quality.

Research has shown that the quality of a relationship supports psychological well-being, while dissatisfaction in a relationship can lead to negative mental health outcomes for partners (Rippon et al., 2020). Clare et al. (2012) have highlighted that the quality of relationships for older adults can be affected by the onset of health issues, such as dementia and taking on caregiving responsibilities. Further research in this area would not only contribute to understanding how to provide appropriate support to caregivers in the community but has the potential to significantly improve the well-being and relationship quality of the caregiver and PWD (Wadham et al., 2016). This includes identifying what motivates some caregivers to have an accepting attitude toward support (Bolystein & Hayes, 2012). Understanding why some caregivers hesitate to seek support can help service providers build more effective relationships with older adults. Additionally, future research is needed to determine the strategies that couples use to cope with the impact of dementia on their relationship. These strategies could then be used to help other couples develop similar skills (Hayes et al., 2009; Johnson & Terp, 2015). Finally, it is crucial to prioritize the perspectives of diverse populations, including individuals in new later-life partnerships and those from different ethnic groups, sexualities, and genders, in future research. Historically, these groups have been left out of the narrative, and it is important to address this issue.

One aspect of participant narratives that could be explored, but was not discussed in this study, is the evidence of enduring love shared between spousal caregivers and their partners with dementia. Although it was clear that relationships changed due to the progression of dementia, some caregivers discussed the love still shared with their partners. Future research into the significance of enduring love may be useful to help better understand the needs of caregivers and PWD including establishing appropriate support to foster relationship quality throughout the dementia journey.

The significance of this study lies in its contribution to existing literature on the impact of caring for a partner with dementia on the quality of the relationship. The participants shared their first-hand experiences, which provided valuable insights into this crucial topic. Through their unique narratives, the participants have enabled readers to gain a deeper understanding of how this disease affects everyday life and relationship quality. This study helps in comprehending the real-life experiences of those affected by dementia and prompts a reflection on the stereotypes around aging and dementia, raising awareness and increasing knowledge to better support partners on the dementia journey.

Final Reflections & Conclusion

In the concluding chapter, I summarized the key points from the literature and the study's findings. I acknowledged the study's limitations and argued for the need for further research in this area. Because this research relates to my professional role as a social worker, I believed it was essential to include a personal reflection on its connection to social work practice.

The field of geriatrics and this area of research are significant for social workers to address because we have the knowledge and skills to look beyond the dominant medical model of practice and individual pathologies. We can understand larger systematic issues that impact service users. Social workers can connect individual, micro-level struggles to larger, macro-level social problems often influenced by prominent economic and political systems. I feel this skill set can be used to better understand the gaps in our healthcare system that directly impact spousal caregivers and their partners with dementia.

Social workers play a key role in promoting social justice and educating the public on critical social problems. They understand the importance of intersectionality, including how age, gender, sexuality, and ethnicity can create stigma directed toward older adults and PWD. Social workers can aid in creating awareness for the inclusion of diverse populations in research, policy, and practice considerations. This could include promoting further study on what barriers may hinder individuals of diverse backgrounds from participating in research endeavors. With their experience in various settings such as community organizations, healthcare, government, and non for profits, social workers are well-positioned to support and amplify the voices of service users who have been historically marginalized. They can extend these efforts in the workplace by highlighting and challenging policies and practices that may cause further harm to service users, including older adults with dementia from diverse backgrounds and social experiences. In dementia care, social workers should aim to deepen their comprehension of the challenges encountered by diverse individuals with intersecting identities, to develop personalized methods of support instead of one-size-fits-all solutions.

The healthcare system will need social workers to act as navigators, to assist caregivers to appropriate resources to lessen the burdens of care, creating more space for quality time with their partners. By better understanding the impact of dementia on intimate relationships, social workers can find ways to support partners to age in place, maintain healthy relationships, and improve the overall quality of life for older adults.

My research has deepened my understanding of social work practice with older adults on the dementia journey. By delving into the literature and analyzing my findings, I have uncovered crucial insights that can help me build the capacity to understand how structural and social determinants including age, background, education, sexuality, and ethics, may impact older adults and their dementia experience. This allows me to use the knowledge gained from this project to collaborate and advocate for PWD and their families, promoting independence, autonomy, and dignity. By applying research and theory to my work, I can empower older adults in dementia care rather than limiting them to stereotypes or reinforcing prevailing views on aging. As the population of older adults and dementia cases rises, it is crucial to continue supporting research and educating myself on this important topic.

This project was an emotional journey, and there were many moments when I had to pause and collect my thoughts and feelings. As a social worker in an LTC home, I work with individuals and families dealing with dementia daily. I witness the difficult decisions that couples must make when choosing to move a spouse into institutionalized care, often accompanied by feelings of guilt. I have also experienced the dementia journey with my own family members and have felt the pain and heartache associated with these diseases.

I hope that healthcare workers consider what happens beyond the diagnosis and behind the closed doors of family homes, where individuals are struggling to cope and understand a new reality. A person is not their disease, and a caregiver is more than a caretaker; they are partners and individuals with their own needs and feelings. This project has illustrated that both individuals should be considered separately and as a couple to allow a full spectrum of support. To conclude, I want to echo the words of a study participant who said, “Don’t diagnose and dismiss,” stressing that individuals will continue to need support as dementia cases rise in Canada.

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Appendices

Appendix A – Consent Form

MEMORIAL
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Informed Consent Form

Title:	Understanding Relationship Quality Between Informal Caregivers and their Partners with Dementia
Researcher:	Carrie Frazier, School of Social Work, Memorial University, cefrazier@mun.ca (902) 514-6000
Supervisor:	Dr. Gail Wideman, School of Social Work, Memorial University, gwideman@mun.ca (709) 864-8161

You are invited to take part in a research project entitled **Understanding Relationship Quality Between Informal Caregivers and their Partners with Dementia**. This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study. To decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Carrie Frazier, if you have any questions about the study or would like more information before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the data collection process once it has started, there will be no negative consequences for you, now or in the future.

Introduction:

My name is Carrie Frazier, and I am a registered social worker and student at the School of Social Work at Memorial University of Newfoundland. I am conducting this research project for my Master of Social Work degree under the supervision of Dr. Gail Wideman.

Purpose of Study:

The purpose of this study is to examine how informal caregiving for a partner with dementia affects relationship quality. The objective of this project is to better understand whether relationship quality changes in partnerships in relation to providing informal care, the progression of dementia or both. I hope this study will contribute to existing research that aims to improve the quality of life for caregivers and their partners with dementia.

What you will do in this Study:

You will be asked to participate in an interview where I will ask you questions about your relationship with your partner who has been diagnosed with dementia. Questions will be related to your partner's dementia journey and your experience providing informal care during this time. I will also ask you about your perceptions of a good relationship and to describe your relationship quality since providing care to your partner. You will be interviewed by me either on the telephone, through virtual meeting via Zoom for Healthcare or at my workplace that has a private conference room that can be rented for community use. The name of this organization is Harbour View Haven located at 25 Blockhouse Hill Road, Lunenburg, Nova Scotia.

Length of Time:

To participate in this study, you will be asked to commit to a single interview which will be roughly 1 hour and 30 minutes.

Withdraw from the Study:

If you wish to end your participation in this study at any time, including partway through the interview, please indicate your desire to withdraw from the study. On your withdraw, any data collected prior to or during the interview process will not be used and will be destroyed. Participants will be able to withdraw from the study up until June 30th, 2023, which has been designated as the data collection cut-off date. You may contact me by email, telephone or indicate in person if you would like to withdraw from this study before the deadline. Data will remain anonymized and confidential during and after your participation in the study.

Possible Benefits:

By participating in this study, you will contribute to research that aims to improve the quality of life for informal caregivers and their partners with dementia. There are no known personal benefits for participating in this research.

Possible Risks:

It is not possible to know all the risks that could occur by participating in this study. There is a possibility you may find some questions in the interview difficult to answer or emotionally upsetting. If you wish to pause or stop the interview at any time, please inform me. I will debrief with you after the interview and provide the 24-Hour Provincial Mental Health Crisis Line: 1-888-429-8167 and the Alzheimer Society's Support Group network number: 1-800-611-6345. Both numbers are toll free within Nova Scotia.

Confidentiality:

The ethical duty of confidentiality includes safeguarding your identity, personal information, and data from unauthorized access, use, or disclosure. Your audio or video recorded responses from this interview will be kept private on my personal, password protected hard drive. I will attempt to avoid the use of any personal identifying information (descriptions of your personal appearance, names, locations) by using unique codes to identify data collected from you.

There are limits to keeping your information confidential. Disclosure of confidential information may be required if there are reasonable grounds to believe you may be in danger of harming yourself or another person.

The privacy statement and policies used by Zoom for Healthcare can found at:

https://explore.zoom.us/en/trust/privacy/

Anonymity:

Anonymity refers to protecting participants' identifying characteristics, such as name or description of physical appearance. Participation in this project is not anonymous, but the data collected will be anonymized. You will not be identified in publications without your explicit permission.

Recording of Data:

Consenting to being audio-recorded is a requirement to participate in this project. You will be asked to be audio recorded on an audio device or via Zoom for Healthcare. Videorecording is optional for participants who decide to partake in interviews via Zoom for Healthcare. Participants will be asked to ensure their cameras are turned off in these circumstances.

Use, Access, Ownership, and Storage of data:

All data collected for this research project will be stored on my personal hard drive which is password protected. The informed consent form will also be kept separate as a printed document for those conducting interviews in person and stored in a locked cabinet. For participants conducting interviews virtually or over the telephone, I will request signed informed consent forms be emailed to the MUN account cefrazier@mun.ca which will then be stored on my password-protected hard drive. The data collected will not be shared with anyone other than my supervisor, Dr. Gail Wideman

Data will be kept for a minimum of five years, as required by Memorial University's policy on Integrity in Scholarly Research. Data will then be destroyed by deleting files and shredding/disposing of signed consent forms.

Reporting of Results:

Upon completion, my thesis will be available at Memorial University's Queen Elizabeth II library and can be accessed online at: http://collections.mun.ca/cdm/search/collection/theses. Direct quotations may be used in the report however they will remain anonymized.

Questions:

You are welcome to ask questions before, during, or after your participation in this research. If you would like more information about this study, please contact: Carrie Frazier at cefrazier@mun.ca or (902) 514-6000. You may also contact the supervisor of this project, Dr. Gail Wideman at gwideman@mun.ca

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as the way you have been treated or your rights as a participant, you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

- You have read the information about the research.
- You have been able to ask questions about this study.
- You are satisfied with the answers to all your questions.
- You understand what the study is about and what you will be doing.
- You understand that you are free to withdraw participation in the study without having to give a reason, and that doing so will not affect you now or in the future.
- You understand that if you choose to end participation **during** data collection, any data collected from you up to that **point will be destroyed**.
- You understand that your data is being collected anonymously and therefore cannot be removed once data collection has ended.
- You understand that participation in this project is not anonymous, but the data collected will be anonymized and cannot be removed once data collection has ended.
- You understand that you can withdraw from this study up until June 30th, 2023, which has been designated as the data collection cut-off date.

I agree to be audio-recorded	☐ Yes	☐ No
I agree to be video-recorded	☐ Yes	☐ No
I agree to the use of direct quotations	☐ Yes	☐ No

- Note, you may also provide consent verbally, or in an email message.

By signing this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

Your Signature Confirms:

☐ I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

☐ I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.

☐ A copy of this Informed Consent Form has been given to me for my records.

______________________________ ______________________________

Signature of Participant Date

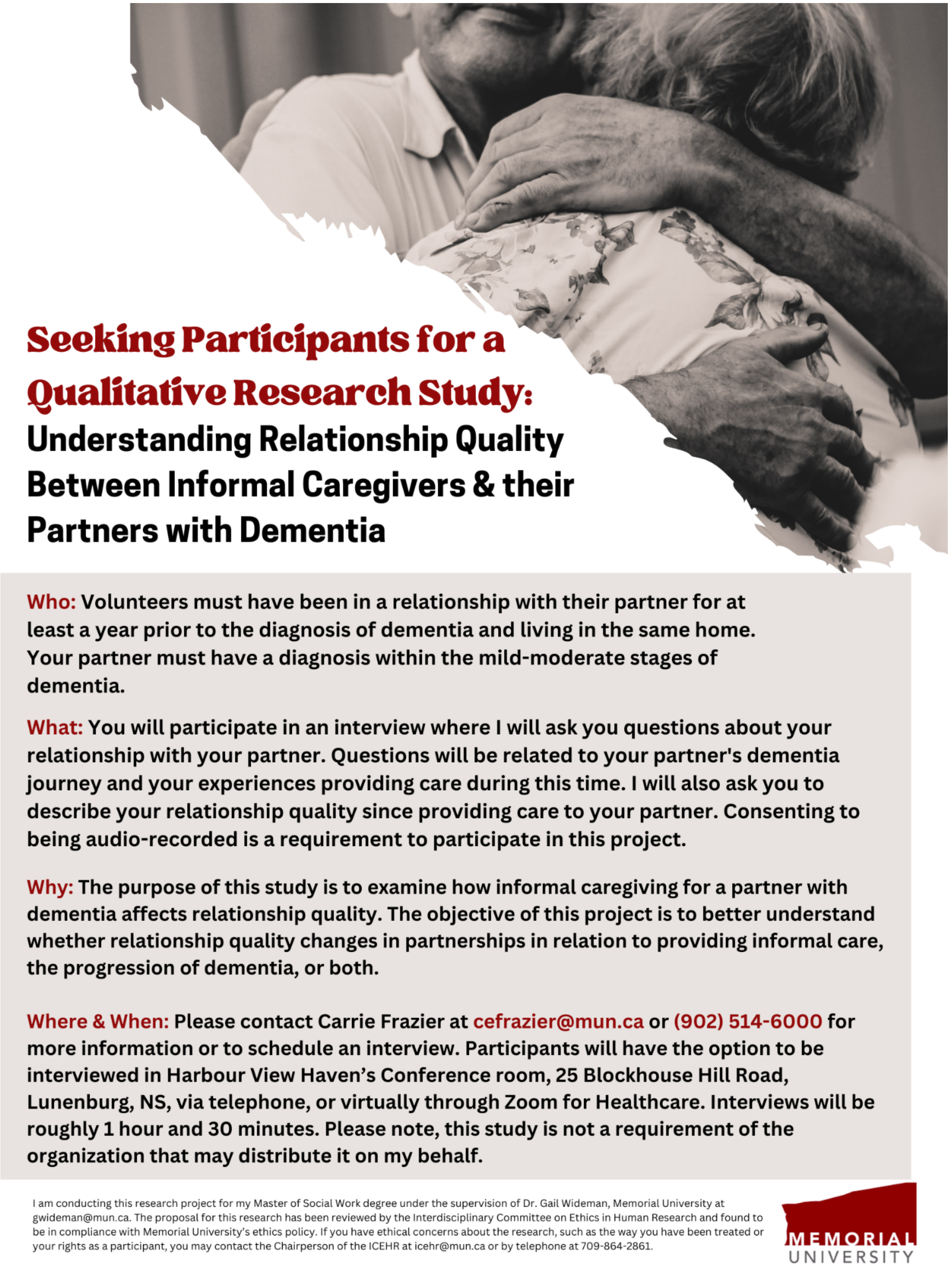
Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

______________________________ ______________________________

Signature of Principal Investigator Date

Appendix B - Recruitment Poster



Seeking Participants for a Qualitative Research Study:

Understanding Relationship Quality Between Informal Caregivers & their Partners with Dementia

Who: Volunteers must have been in a relationship with their partner for at least a year prior to the diagnosis of dementia and living in the same home. Your partner must have a diagnosis within the mild-moderate stages of dementia.

What: You will participate in an interview where I will ask you questions about your relationship with your partner. Questions will be related to your partner's dementia journey and your experiences providing care during this time. I will also ask you to describe your relationship quality since providing care to your partner. Consenting to being audio-recorded is a requirement to participate in this project.

Why: The purpose of this study is to examine how informal caregiving for a partner with dementia affects relationship quality. The objective of this project is to better understand whether relationship quality changes in partnerships in relation to providing informal care, the progression of dementia, or both.

Where & When: Please contact Carrie Frazier at cefrazier@mun.ca or (902) 514-6000 for more information or to schedule an interview. Participants will have the option to be interviewed in Harbour View Haven's Conference room, 25 Blockhouse Hill Road, Lunenburg, NS, via telephone, or virtually through Zoom for Healthcare. Interviews will be roughly 1 hour and 30 minutes. Please note, this study is not a requirement of the organization that may distribute it on my behalf.

I am conducting this research project for my Master of Social Work degree under the supervision of Dr. Gail Wideman, Memorial University at gwideman@mun.ca. The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as the way you have been treated or your rights as a participant, you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

MEMORIAL
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Appendix C - Recruitment Letter

My name is Carrie Frazier, and I am a registered social worker and student at the School of Social Work at Memorial University of Newfoundland. I am conducting a research project called **Understanding Relationship Quality Between Informal Caregivers and their Partners with Dementia** for my Master of Social Work degree under the supervision of Dr. Gail Wideman. The purpose of this study is to examine how informal caregiving for a partner with dementia affects relationship quality.

I am contacting you to invite you to participate in an interview in which you will be asked questions related to your relationship quality before and after your partner's diagnosis of dementia. Participation will require roughly 1 hour and 30 minutes of your time. You will have the option to be interviewed in Harbour View Haven's Conference room, 25 Blockhouse Hill Road, Lunenburg, NS, via telephone, or virtually through Zoom for Healthcare. If you provide consent to participate in this project, you will agree to being audio-recorded.

To volunteer for this study, participants must have been in a relationship with their partner for at least a year prior to the diagnosis of dementia and currently living in the same home. The partner of the participant must also have a diagnosis that fits within the mild to moderate stages of dementia.

If you are interested in participating in this study or have questions about my project, please contact me to arrange a meeting by email at cefrazier@mun.ca or phone at (902) 514-6000. If you know anyone who may be interested in participating in this study, please give them a copy of this information. Please note, this study is not a requirement of the organization that may distribute it on my behalf.

Thank you in advance for considering my request,

Carrie Frazier, RSW.

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as your rights as a participant, you may contact the Chairperson of the ICEHR at icehr.chair@mun.ca or by telephone at 709-864-2861.

Appendix D - Interview Questions

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Interview Questions:

1. Please tell me about yourself and your relationship with your partner.
2. What does a good relationship between partners look like to you?
3. How would you describe your relationship quality with your partner?
4. Please tell me about your partner’s dementia journey.
5. Please tell me about your experience providing care to your partner through this journey.
6. Please tell me about the type of care you have provided to your partner through this journey
7. How would you describe your relationship quality since your partner’s diagnosis of dementia?
8. How would you describe your relationship quality since providing informal care to your partner?
9. Is there anything you would like to add regarding the topics discussed in this interview?

Probing Questions:

-How did you come to that conclusion?
-Why do you think that is?
-Can you tell me more about that?
-How do you think that impacts your relationship?

Appendix E – Interdisciplinary Committee on Ethics in Human Research (ICEHR)

Approval Letter

MEMORIAL
UNIVERSITY

**Interdisciplinary
Committee on
Ethics in Human
Research (ICEHR)**

St.
John's,
NL
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A1C
5S7
Tel: 709
864-
2561
icehr@
mun.ca

www.mun.ca/research/ethics/humans/icehr

ICEHR Number:	**20231019-SW**
Approval Period:	December 13, 2022 – December 31, 2023
Funding Source:	
Responsible Faculty:	Dr. Gail Wideman School of Social Work
Title of Project:	*Understanding Relationship Quality between Informal Caregivers and their Partners with Dementia*

December 13, 2022

Ms. Carrie
Emma
Frazier
School of
Social
Work
Memorial
University

Dear Ms. Frazier:

Thank you for your correspondence addressing the issues raised by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) for the above-named research project. ICEHR has re-examined the proposal with the clarifications and revisions submitted, and is satisfied that the concerns raised by the Committee have been adequately addressed. In accordance with the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2)*, the project has been granted *full ethics clearance* for **one year**. ICEHR approval applies to the ethical acceptability of the research, as per Article 6.3 of the *TCPS2*. Researchers are responsible for adherence to any other relevant University policies and/or funded or non-funded agreements that may be associated with the project.

If funding is obtained subsequent to ethics approval, you must submit a Funding and/or Partner Change Request to ICEHR so that this ethics clearance can be linked to your award.

The *TCPS2* **requires** that you **strictly adhere to the protocol and documents as last reviewed** by ICEHR. If you need to make additions and/or modifications, you must submit an Amendment Request with a description of these changes, for the Committee's review of potential ethical concerns, before they may be implemented. Submit a Personnel Change Form to add or remove project team members and/or research staff. Also, to inform ICEHR of any unanticipated occurrences, an Adverse Event Report must be submitted with an indication of how the unexpected event may affect the continuation of the project.

The *TCPS2* **requires** that you submit an Annual Update to ICEHR before **December 31, 2023**. If you plan to continue the project, you need to request renewal of your ethics clearance and include a brief summary on the progress of your research. When the project no longer involves contact with human participants, is completed and/or terminated, you are required to provide an annual update with a brief final summary and your file will be closed. All post-approval ICEHR event forms noted above must be submitted by selecting the ***Applications: Post-Review*** link on your Researcher Portal homepage. We wish you success with your research.

Yours sincerely,

James Drover, Ph.D.
Vice-Chair, Interdisciplinary
Committee on Ethics in
Human Research

JD/bc

cc: Supervisor – Dr. Gail Wideman, School of Social Work

Appendix F – Interdisciplinary Committee on Ethics in Human Research (ICEHR)

Renewal

Interdisciplinary Committee on
Ethics in Human Research (ICEHR)

ICEHR Approval #:	20231019-SW
Researcher Portal File #:	20231019
Project Title:	*Understanding Relationship Quality Between Informal Caregivers and their Partners with Dementia*
Associated Funding:	Not Funded
Supervisor:	Dr. Gail Wideman
Clearance expiry date:	**December 31, 2024**

Dear Ms. Carrie Emma Frazier:

Thank you for your response to our request for an annual update advising that your project will continue without any changes that would affect ethical relations with human participants.

On behalf of the Chair of ICEHR, I wish to advise that the ethics clearance for this project has been extended to **December 31, 2024**. The *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* (TCPS2) requires that you submit another annual update to ICEHR on your project prior to this date.

We wish you well with the continuation of your research.

Sincerely,

DEBBY GULLIVER
Interdisciplinary Committee on Ethics in Human Research (ICEHR)
Memorial University of Newfoundland
St. John's, NL | A1C 5S7
Bruneau Centre for Research and Innovation | Room IIC 2010C
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